A Canary in the Coal Mine: Exploring African-American Women's Lived Experience of Childbirth

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Abstract

This purpose of this study was to better understand what contributes to high infant mortality rates (IMR) for African Americans living in Charlottesville, VA, a place with one of the highest IMR prevalence. The specific aim of this study was to examine the lived experience of the African American women living in neighborhoods with high infant mortality, looking for nursing implications that can inform targeted interventions for promoting maternal/child health. This study was a secondary analysis of data derived from a series of focus groups involving 60 women, with a subset of 42 African-American women. The thematic analysis approach was used to identify, analyze, and report patterns within data. A critical feminist lens, intersectionality and an ecological framework were used to underpin the analysis. In group interviews, women shared numerous and repeating experiences of the dissonance between what they sought for their care over the course of their pregnancy and what they actually experienced. Findings centered on a core experience, labeled *seeking a health care home and finding an institution*. Illustrations of this experience were found at every contextual point of contact for pregnant women, including family and community, health care providers of prenatal care in the clinic, the University of Virginia Medical Center, and local, State, and federal institutions and policies. Issues of trust and respect were thematic threads at every level of interaction. Women were using a new narrative to discuss a process not represented in the current literature, *negotiating a perceived threat,* to mitigate stressful encounters at each point of contact and ensure the best possible outcomes for themselves and their infants. These findings are understood in the context of important historical moments that continue to impact women's perceptions of their care today. This study takes seriously the historical, social, and political figurations through which threats, occurring on multiple levels at multiple points in time, must be negotiated by African-American women. Implications for nursing include short term strategies to improve levels of trust and respect in provider-patient relationships and communication and long term structural changes to influence medical and nursing education and culturally tailored models of prenatal care that are meaningful to women.

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CHAPTER ONE

Introduction

The amount spent on healthcare in the U.S. is greater than in any country in the world (Organization for Economic Co-operation and Development [OECD] Health Data 2014). Hospitalization related to pregnancy and childbirth costs $86 billion a year, the highest in any area of healthcare, yet maternal mortality ratios are higher in the U.S. than in 24 other industrialized countries (Andrews, 2008). African-American women are at especially high risk of mortality; nearly four times more likely to die of pregnancy related complications than White women (Heron et al., 2006).

Called the “canary in the coal mine” of public health, the infant mortality rate (IMR) is an indicator of the overall health in a community (March of Dimes, 2005 annual report). Infant mortality among African-Americans living in neighborhoods surrounding the University of Virginia Medical Center occurs at a rate of 20.2 deaths per thousand live births (Virginia Department of Health [VDH], 2012). This is four times higher than the 4.9 deaths per thousand for infants who die before their first birthday and are not African-Americans (VDH, 2012). The Center for Disease Control (CDC) has a goal of a 50% reduction in the African-American IMR by 2020 (CDC Healthy People 2020, 2014).

The overarching goal of this study was to interrogate this disappointing reality, and over the trajectory of their pregnancy and birth experience, listen to and analyze what African-American women voiced as contributing to this disproportionate rate of IMR in their community. It is crucial to know the deep history that refracts how the African-American experience is told and understood, how knowledge is produced within the community, and how that knowledge is disseminated to members of the community. Truly understanding health disparities requires a deep exploration of the situations and events through history that shaped our current social worlds with racism, discrimination and marginalization, as well as current, persistent systematic inequalities that privilege one group of people over another.

Problem Statement

As early as 1901, it was observed that knowledge about the causes and conditions contributing to fetal death was hampered by the absence of scientific information gathered in a systematic fashion (Ballantyne, 1901). The content of prenatal care (PNC) had not changed significantly during the previous 200 years from 1700 to 1900, and consisted of just one exam close to delivery (Ballantyne, 1901; Williams, 1915). Eclampsia was noted to contribute to maternal and infant mortality (Ballantyne, 1901; Williams, 1915) and shaped the content of PNC, playing an important role in establishing the timing and frequency of visits (Alexander, 2001).

Although prenatal care (PNC) programs have been studied, PNC has not been rigorously examined in randomized trials due to ethical concerns (Barash & Weinstein, 2002). A systematic review of observational studies concluded there was not sufficient evidence to support the hypothesis that routine prenatal care improved birth outcomes (Fiscella, 1995). Randomized trials comparing routine prenatal care verses enhanced prenatal care for women with high risk pregnancies found that home visits, extra office visits, and additional health education did not significantly improve prenatal outcomes (Klerman, 2001; Villar, 1992). A randomized trial comparing routine prenatal care with a reduced prenatal care model for low risk women found a reduction in clinic visits had no effect on birth outcome (Villar, 2001).

Summary of Prenatal Care Models

National organizations, such as the World Health Organization (WHO) and The American College of Obstetricians and Gynecologists (ACOG) have established guidelines for routine prenatal care clinic visits. Some of the major differences among published guidelines are whether they take a risk-factor-based approach to screening for specific disorders versus universal screening (Lockwood, 2016). Prenatal care is not a single intervention, but a series of assessments and interventions over time that are applied by multiple healthcare practitioners in a variety of settings and access to resources vary. It is possible to measure the *quantity* of prenatal visits, but the *quality* of prenatal care and the effect of multiple individual components on maternal, fetal, and neonatal outcome are more elusive to measure (Kotelcheck, 1994; Lockwood, 2016).

Office visits. The frequency of visits are determined by the patients' individual needs and assessed risk factors, but the current universal screening guidelines (www.acog.org accessed on December 16, 2016) advise an initial office visit at 8-10 weeks of pregnancy; followed by visits every 4 weeks for first 28 weeks; then every 2 – 3 weeks until 36 weeks gestation; and finally a visit every week after 36 weeks gestation until birth. The content of the visits varies widely (Haertsch, 1999), but usually consists of an assessment to identify maternal and fetal risk factors, estimation of the gestational age, ongoing surveillance of the mother and the fetus, and patient education.

Confounding socioeconomic factors. In the United States, according to the National Vital Statistic Report (Hamilton, 2010), approximately 71% of pregnant women received PNC in their first trimester and the number of pregnant women who received no prenatal care or care in their third trimester was 7%. Observational studies to measure the outcomes in women who did not receive PNC compared to women who followed the national guidelines have been confounded by socioeconomic factors that may influence maternal, fetal, and perinatal outcomes (Lockwood, 2016). A landmark document that laid the groundwork for investigating these confounding factors in health care research, *The Report of the Secretary's Task Force on Black and Minority Health* (1985), was commissioned by Secretary of Health and Human Services Margaret Heckler to investigate the "sad and significant fact: there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation's population as a whole" (1985, letter introducing the report). This led to the Institute of Medicine (IOM) report that recommended a national policy of enrolling all pregnant women into a system of PNC as a strategy to reduce their risks. The US Congress enacted a series of legislative initiatives that expanded Medicaid eligibility to low income pregnant women and children (IOM, 1985). Two observations are notable: During the last 25 years policy makers have been expanding a one-size-fits-all model of PNC for all patients (Krans & Davis, 2012). While one would expect this access to care would improve outcomes, as rates of PNC enrollment increased, the rates of low birth weight and preterm births have also increased (Fiscella, 1995).

Is the standard model of PNC appropriate for all women? Although the proportion of women receiving PNC is higher than ever before (Hamilton, Hoyert, & Martin, 2013), adverse pregnancy outcomes (e.g., preterm birth and low birth weight which are the leading causes of infant mortality) are still of utmost concern (Lau, Ambalavanan, Chakraborty, et al. 2013; Macdorman & Mathews, 2008; National Center for Health Statistics, 2011). Prenatal care continues to be touted as an effective approach to reducing low birth weight and preterm delivery, but growing concerns have been raised regarding the validity of the evidence used to support these claims (Fiscella, 1995). Legal scholars have begun to question if PNC as currently practiced would pass the Supreme Court’s strict scrutiny test that ensures that a policy is race neutral (Forde-Mazrui, 2013). There are researchers suggesting that current policy, as well as the timing of visits and diagnostic tests offered in the routine standard prenatal care models, may actually disadvantage African-Americans (Forde-Mazrui, 2013. Statistics illustrate that PNC has not eliminated rates of preterm birth and low birth weight babies (Fiscella, 1995), but these poor outcomes have not discouraged policy makers who continue to craft a one-size-fits-all PNC policy. The number of prenatal visits and the timing of the visits (Chiswick, 2008; Hack & Fanaroff, 1999) could be designed to more accurately screen for adverse pregnancy outcomes. Researchers also found that women were not adequately prepared for possible poor birth outcomes (Kotelchuck, 1994), and there was a lack of screening for diseases disproportionately affecting African-American women during routine PNC appointments (Fiscella, 1996).

As stated earlier in this paper, Kotelchuck (1994) reminds us that there is no way to assess the quality of PNC, only if it was utilized. We must avoid over-generalizing the effect of PNC on the IMR and arrive at conclusions that exceed evidence based findings. The standard model of PNC may not offer interventions for African-American women that prevent low birth weight and preterm birth (Alexander, 2001).

Statement of Purpose

As differences in birth outcomes continue to widen among ethnic and racial groups there is a need for a knowledge base that informs a different model of care that can be tailored to specific risks in population groups (Krans & Davis, 2012).

The Thomas Jefferson Health District

The Thomas Jefferson Health District (TJHD) is one of thirty-five health districts under the Virginia Department of Health. It is comprised of six health departments that serve the counties of Albemarle, Fluvanna, Greene, Louisa, and Nelson, along with the city of Charlottesville, and provides services to approximately 244,000 citizens. A steering committee of leaders from a wide array of organizations in 2007 engaged with the TJHD in a review, analysis and discussion of health data, and five goals were recommended: (1) Reduce the prevalence of tobacco use and obesity, (2) Improve mental health and ensure access to appropriate quality mental health services, (3) Reduce substance abuse to protect health, safety and quality of life for all, (4) Reduce the IMR, and (5) Reduce the disparity between white and black infant mortality.

Parent Study

Between May and June 2009, concern over high IMRs prompted the TJHD to conduct focus groups to better understand the factors contributing to high IMR for African-Americans living in neighborhoods identified with high IMRs (N=30).

Second Wave of the Study

Continued high IMRs prompted the TJHD and key community organizations in 2013 to fund a second study that investigated factors contributing to infant deaths. Between April and May, 2013, women who were pregnant or had delivered a child were recruited from lower-income areas within the TJHD and participated in a series of focus groups (N=30).

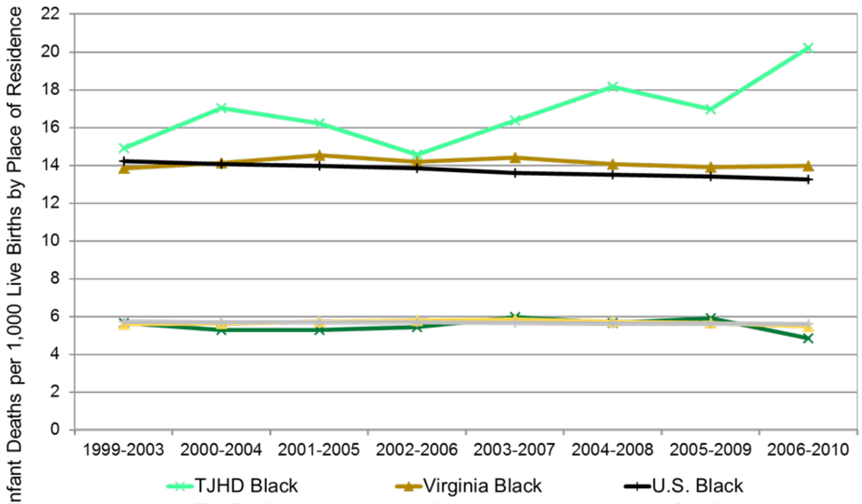
Specific Aim

The specific aim of this study was to examine the perspectives of African-American women on factors that contribute to high IMR in their neighborhoods. A long term goal of the study is to derive evidence that can inform targeted interventions for promoting maternal/child health.

Rationale and Significance

In 2006-2010 in TJHD, the IMR for white infants was 4.9 infant deaths per 1,000 live births and the IMR for African-American infants was 20.2. In 2008-2010 in TJHD, 12.5% of African-American infants were born at a low birthweight compared to 6.4% of white infants. During this time period, Charlottesville's IMR was 43% higher than the state average (Virginia Department of Health, 2009). A statistical breakdown of the data reveals the deaths are located in three predominantly African-American neighborhoods, and paradoxically from the Labor and Delivery unit of the University of Virginia Medical center, all three neighborhoods are visible. The recruitment and setting for this study included the communities in the TJHD identified with high IMRs. Concerns over the high IMRs (refer to Figure 1) led to a qualitative-interpretive design to explore the childbirth experiences of African-American women living in these neighborhoods in order to arrive at a better understanding of the multiple etiologies of infant mortality.

Figure 1. Infant Mortality by Race for the Thomas Jefferson Health District.



(Virginia Department of Health, Division of Health Statistics, 2012)

At the heart of infant mortality is situated a pregnant woman and her understanding of the healthcare provider’s role and response during a health care appointment. The woman and her healthcare provider may be of different races, classes, and genders. They may have varying educational levels and vocabularies. Maternity care has been characterized as a source of anxiety and frustration for women in the TJHD, and they voiced their desire for autonomy and independence in collision with a healthcare system that they viewed as a vertical hierarchical organization that was not responsive to their needs. The fact of being black in American was voiced by the women as if there was a tension on both sides of the hyphen connecting the term *African-American*. By studying these relationship and interactions we begin to untangle properties of this system to understand the constituent parts that contribute to its complexity (Martinez-Garcia, 2013). Communication failures and how the processes are viewed have tremendous impact on how a woman responds to her anxiety and constructs defensive strategies to negotiate risks to herself and her developing pregnancy. There is the potential for unintended actions by the actors within the healthcare system to be amplified by political, psychological and existential contexts grounded by her own identity and person history of oppression (Appiah, 2015). Actions with potential for resistance come from multiple points of contact with the healthcare system: clinics, hospitals, medical school curricula, and federal policies (Bronfenbrenner, 1986).

The best understanding of a complex system can be obtained by observing it (Paley, 2010), but the existing research on the subject of structural and personal barriers to access to care for low-income or marginalized mothers is in wide agreement that there is little qualitative data available, especially in regards to identifying behaviors and attitudes that facilitate access to maternal/child healthcare. Only two of the qualitative studies reviewed (Daniels, 2006; Milligan, 2002) utilized facilitated interactions with groups of study participants. The open-discussion format of the groups led to conversations about motivators that encouraged low socioeconomic status (SES) women to seek care for themselves and their infants. A factor that has been identified as a risk for infant mortality is maternal race (Muglia, 2010). African-American mothers who reported that they had experienced racial discrimination had an increased risk of poor outcomes when compared to African-American mothers who had not reported discrimination (Muglia, 2010). An understanding of factors that contribute to poor outcomes and barriers to access to care will help us answer the question at the heart of this study: How does Charlottesville become a safe and healthy place for African-American women and babies to live and thrive?

Overview of Methodology

This study was a secondary analysis of data derived from a series of focus groups conducted in the TJHD in Charlottesville, Virginia, consisting of facilitated focus groups. Permission to conduct this study was granted by the University of Virginia and Virginia Department of Health Institutional Review Boards.

Using this data set, including both waves of focus groups (N=60), a qualitative-interpretive design was used to describe the conceptual factors of the childbirth experiences for women living in the neighborhoods with high IMR. Community focus groups were the main source of data and the interview guide was informed by 1) the Bronfenbrenner Ecological model, which suggested a holistic way to arrive at a better understanding of the multiple individual, social, and contextual factors that may contribute to infant mortality (Bronfenbrenner, 1977; Cohen, Janicki-Deverts, Chen, & Matthews, 2010; Wuest, Merritt-Gray, Berman, & Ford-Gilboe, 2002.); and 2) intersectionality theory, which acknowledged that many of the experiences African-American women face are not subsumed within the traditional boundaries of race or gender as these boundaries are currently understood (Crenshaw, 1991; Hill Collins, 2012).

Interviews focused on patient perceptions, attitudes, and experiences regarding their childbirth care providers, and identifying specific barriers to accessing care services. The thematic analysis approach was used to identify, analyze, and report patterns within data (Braun & Clark, 2006). Thematic analysis is an approach that lends itself to examining the complex and interrelated contextual factors that have shaped African-American women’s childbirth experiences. It allowed an examination of the links among ecological systems (Bronfenbrenner, 1977), and how their intersection in African-American women's lives (Crenshaw, 1991) may have contributed to infant mortality (Schwartz-Shea & Yanow, 2012; Strauss & Corbin, 1990).

Role of the Researcher

I was involved in two major phases of this research. First, I contacted the doctoral student in psychology, who conducted the 2009 Parent Study focus groups. I discovered that she had the original focus group responses on an SPSS file. After IRB approval was obtained for a secondary data analysis, I requested data from 5 focus groups, but I limited my analysis specifically to the focus groups that had been conducted in my neighborhoods of interest, African-American communities with high IMRs. I was the primary analyst for the secondary analysis of the 2009 Parent Study focus group data.

In the second phase, I conceptualized the Wave 2 component of the study. I created the interview guide, and collected, analyzed, and interpreted the focus group data, integrating it with the secondary analysis described above.

Researcher Assumptions

My 30 year career as a maternal child healthcare worker, my experiences as a teacher in a Harlem neighborhood of New York, and my Peace Corps Volunteer work in Africa have contributed to my interest in racial disparities and infant mortality. Disciplinary perspectives alert nurses to look for specific possibilities and processes in the data. Blumer (1969) suggests sensitizing concepts provide a place to start, by loosely framing the subject of interest. Having been on “both sides of the stethoscope” by working in a hospital setting as well as a working in low SES communities, I was aware that there are two distinct discourses—that of the women in the community and that held by their health care providers. My assumption was that both these perspectives have value and neither should be privileged. An attempt to capture and describe the indescribable nature of the reality of the lived experience, this work is constantly re-situated within the present moment, in conversation with the historical past of the University of Virginia Medical Center, and shaped daily by a national dialog about race.

With a research aim of examining contextualized factors that have shaped African-American women’s childbirth experiences, an ecological framework

(Bronfenbrenner; 1977, 1986) was used to explore African-American women's interpretation of their childbirth experiences in a way that opened the analysis wider by diving deeper to expose underlying structures that shaped that experience. My assumption was that the present situation could not be interpreted without visiting the past and the women's exploration of their lived experience of childbirth touched on perceived historical racism within the Charlottesville community, the role of the University of Virginia (UVA) Medical Center, and the care provided by the medical students nested within that system. This study acknowledged and examined each point of contact to understand how the community narrative that emerges from each care encounter was shaped by a larger historical narrative. An ecological perspective offered me a way to analyze how cultural concepts have changed over time, and how these concepts are now understood by those living in the present. For Bronfenbrenner (1986), an ecological methodological framework, examines rules governing the past, and attempts to understand how, in a continuous narrative, the past has become the foundation and boundary of the present. Not history for history's sake, the past provides a context to diagnose and analyze the present moment. The history of three key places helped me to locate and make specific the context of describing the lived experience of African-American women: The University of Virginia, the University of Virginia Hospital, and the Vinegar Hill neighborhood in Charlottesville, VA.

The University of Virginia offered a context to guide the interrogation of the women's narratives of the underlying social systems and political structures of Charlottesville, Virginia; the University of Virginia Medical Center provided a context that is destabilizing to the central role that medical and nursing students play in women's perceptions of healthcare available to the African-American community; and the Vinegar Hill neighborhood demolition provided context for an analysis of several concepts voiced by African-American women in their transcripts.

Definition of Key Terminology

African-American An American who has black African ancestors.

Discrimination Making a distinction in favor or against a person based on the group to which they belong, rather than on their individual merit.

Race A social construct that categorizes groups of people based on self-identification, ancestry, and arbitrary physical characteristics.

Racism False biological attributions of race to justify or rationalize injustice.

Healthcare Provider Person who is licensed to conduct assessments and interventions that can be applied in a variety of settings.

Prenatal Care A series of assessments and interventions applied over the 42 weeks of gestation by multiple healthcare practitioners in a variety of settings.

Infant Mortality Rate Calculated as the number of infant deaths that occur for every 1,000 live births.

Feminist critical lens Seeking to account for the long-lasting political, economic, and cultural effects of the oppression of women by promoting a wider viewpoint of the complex layers of oppression that exist within any given society and the interactions of these multiple systems of discrimination.

Intersectionality Forms of oppression within a society do not act independently of one another; instead, these forms of oppression interrelate, creating a system of oppression and multiple forms of discrimination that cannot be captured by looking at race, class, or gender separately.

Ecological Framework An inquiry that includes the interaction of genetics, human biology, and environment in family processes; links between the family and hospitals, day care, peer groups, school, social networks, the world of work, and neighborhoods and communities; and public policies affecting families and children.

Microsystem Within an ecological framework, the level where one constructs their environment through their interaction with family members, friends, and peers.

Mesosystem Within an ecological framework, the level where one constructs their environment through interaction with schools, teachers, clinics, or healthcare providers.

Exosystem Within an ecological framework, the level where one constructs their environment through their interaction with hospitals, medical and nursing students, or providers of social services.

Macrosystem Within an ecological framework, the level where one constructs a cultural context framing their environment through their interaction with values, norms, or national policy.

Organization of the Dissertation

Following is a roadmap that briefly outlines the next chapters of my dissertation. Chapter 2 begins with a brief introduction to the literature review. A contextual background of infant mortality is presented to frame the state of the science review. Prenatal care concepts are discussed, followed by a synthesis of the validity of the evidence to support these concepts. A review of the literature related to explaining health disparities is examined along 5 themes: a racial-genetic model; a health-behavior model; a socioeconomic status model; a psychosocial stress model; and a structural-constructivist model. My critical feminist stance for research is described, and the theoretical underpinnings of intersectionality and an ecological model that frame this study are discussed.

Chapter 3 begins with the research design, and then describes details of the parent study as well as its extension in the current study, including the setting, participants, and method of data collection. Thematic analysis is defined, and the data analysis procedures are described. Validity and interpretive rigor are discussed, as well as the limitations of the study. The chapter concludes with tables that describe the sample demographics, setting for the study, and focus group prompts.

Chapter 4 begins with the overarching theme of the study. The sociological framework and a priori codes are described. Microsystem, Mesosystem, Exosystem, and Macrosystem points of contact are discussed and examples of each level are offered from the transcripts. Findings of the study are organized in the following way: First, the bi-polar theme of seeking a health care home, but instead finding an institution was experienced across points of contact during a woman's pregnancy and delivery. Points of contact are the times and places that a woman interacts with important others in her community and in the health care system over the trajectory of her pregnancy and birth experience. Examining each of these points of contact allowed a deeper investigation of the women's experiences, and these points of contact were embedded within an ecological system that included: the woman's family; the prenatal clinic; the hospital; and the intersection between the University of Virginia health system and the deeper historical context, including a medical school that historically provides health care for women and at the same time is training medical students by providing that health care.

Chapter 5 provides interpretation of the findings using a new narrative to discuss a process not represented in the current literature and which was broadly reflected and embedded throughout each ecological system while also reflecting the intersectionality of African-American women’s experience of childbirth. I will describe this process of negotiating threat that women used to mitigate stressful encounters across the points of contact to ensure the best possible outcomes for themselves and their infants. Finally, I make links between these findings and women’s perspectives on infant mortality.

CHAPTER TWO

State of the Science for Disparities in Infant Mortality

Epidemiology of Infant Mortality

The Center for Disease Control (CDC) defines the infant mortality rate (IMR) as “the rate at which babies less than one year of age die,” and the rate has steadily declined in the United States from 26.0 deaths per 1000 live births in 1960 to 6.1 deaths per live births in 2014, the latest statistics reported (CDC.gov, accessed 2-5-2017). In 2011 the United States, ranked 27th in world infant mortality statistics when compared with European countries (National Vital Statistics Report, 2014). This is due mainly to the disparities that continue to exist among racial groups, particularly African Americans. National figures for Infant mortality among African Americans occurred at a rate of 13.3 deaths per 1000 live births (National Center for Health Statistics, 2011). Infant mortality among African-Americans living in neighborhoods surrounding the University of Virginia Medical Center occurs at a rate of 20.2 deaths per thousand live births (Virginia Department of Health [VDH], 2012). This is four times higher than the 4.9 deaths per thousand for infants who die before their first birthday and are not African-Americans (VDH, 2012). Medical centers in the United States with the largest African American populations had the highest proportion of infants born at 22 and 23 weeks, and the rate of preterm birth among African American women is twice as high, and the rate of recurrent preterm birth four times as high, as the rate among White women. (Huynh, 2014; MacDorman, 2016; Muglia, 2010; Tyson et al., 2008).

Etiology of Infant Mortality

One of the leading causes of infant mortality is preterm birth. Ethical dilemmas exist across the entire spectrum of health care, and the birth of a preterm neonate stands out as one of the most dramatic illustrations; the burden of treatment must be balanced against the potential quality of life. Although we may be guided by data, we have no reliable markers for outcomes of individual infants at the time when these decisions have to be made (Chiswick, 2008; Hack & Fanaroff, 1999; Walther, 2005).

The most recent data available from the CDC National Center for Health Statistics are the statistics for 2014; the number of live births totaled 3,988,076 and the number of infant deaths were 23,215. One of the leading causes of infant deaths were disorders related to short gestational age and low birthweight. The percent of low birthweight infants (less than 5.5 lbs.) was 8.0%, and the percent of preterm births (less than 37 weeks gestation) was 9.6% (CDC National Center for Health Statistics, accessed 2-5-2017).

In a scientifically valid study due to its large sample size (n = 1,253,564), researchers from Harvard and MIT examined Norwegian birth records from 1967-1981 (Black, Devereux, & Salvanes, 2007). They discovered both short-run and long-run consequences related to birth weight and concluded that a 10%

increase in birthweight would reduce the IMR by 28 deaths per 1,000 live births. Birthweight was also found to have a significant effect on longer-run outcomes such as height, IQ at age 18, earnings, and educational attainment. A multivariate analysis of a cohort of infants followed from premature birth (< 37 weeks) to 22 months of age, recruited from 19 medical centers throughout the U.S. (n = 4,446), reported higher birth weights were associated with reductions in the risk of death, but also reduced profound neuro-developmental impairment (Tyson, et al, 2008).

Other than prematurity, contributing factors to the IMR are birth defects (congenital malformations, deformations and chromosomal abnormalities) affecting 1 in every 33 babies, maternal complications of pregnancy (anemia, urinary tract infections, mental health conditions, hypertension, gestational diabetes, or obesity), sudden infant death syndrome (SIDS), and injuries (e.g., suffocation) (CDC.gov, accessed 3-8-2017). Eclampsia was noted as contributing to maternal and infant mortality (Ballantyne, 1901). In their article reviewing the controversies and challenges facing investigators who seek to establish the value of prenatal care, Alexander and Kotelchuck (2001) point out that concerns regarding eclampsia continue to shape the content of prenatal care as well as the timing and frequency of clinic visits.

Infant Survival

Prior to the mid-1800s, the IMR was accepted as the natural order where the strong outlived the weak (Malthus, 1817). The Industrial Revolution valued children as an economic resource, and as a result, infant mortality became less acceptable (Brosco, 1999). Prenatal care had remained unchanged for the previous 200 years, consisting of one exam close to delivery, and care during active labor (Ballantyne, 1901). Scottish physician J.W. Ballantyne observed that the investigation of the causes contributing to fetal death was hampered by the absence of scientific information, gathered in a systematic fashion, and he advocated a prenatal care component that would provide prenatal diagnosis and treatments to prevent fetal death.

A synthesis of the current evidence establishes that advancing technology, rather than prenatal care, has improved rates of survival in all populations (although African-American outcomes still lag behind) from the level of 100 deaths per 1,000 births in 1900 to a rate of 5.82 deaths per 1,000 births in 2014 in the general population during the last century (CDC National Vital Statistics Report for 2014, retrieved 3-19-2017). New technologies and improved methods of care continue to drive down the age of survival for premature infants, and we have reached a biological barrier of the gestational age of viability considered to be 23 to 24 weeks gestation (Hack & Fanaroff, 1999). For infants born at 22 weeks or less, with a birth weight of less than 500 g, the Fetus and Newborn Committee of the Canadian Pediatrics Society suggests that only comfort care be given (Hack & Fanaroff, 1999). If the infant is determined to be 23 or 24 weeks gestation age, the guidelines suggest flexibility with regard to resuscitation, including consideration of the views of the family in addition to the condition of the infant at birth. Infants born at 25 to 26 weeks gestation receive full resuscitative interventions (Hack & Fanaroff, 1999).

Survival of extremely low birth weight and early gestational age infants increased in the early 1990's due to the combined effects of an increase in assisted ventilation at delivery, surfactant therapy and possibly increased use of antenatal steroid therapy (Hack & Fanaroff, 1999; MacDorman, 2016). Of major concern is the fact that the already high rates of neonatal morbidity including chronic lung disease, sepsis and poor growth have persisted or even increased, and the associated high rates of neurodevelopmental disability during early childhood have not changed, or possibly increased (Hack & Fanaroff, 1999). In multivariable analyses of infants born prematurely, better outcomes were observed in those babies who received antenatal corticosteroids, were female infants, singleton births, and higher birth weight (Hack & Fanaroff, 1999; Tyson et al., 2008). Progesterone supplementation for women with a previous preterm delivery has also shown promise in delaying preterm birth (Muglia, 2010).

A review of literature related to health disparities in birth outcomes reveals five relevant lines of research that have been employed to account for differences in birth outcomes for vulnerable women: the racial-genetic model; the health-behavior model; the socioeconomic statues model; the psychosocial stress model, and the structural-constructivist mode. Each of these areas attempts to explain health disparities by emphasizing different variables, with the models that emphasize sociocultural and psychosocial stress appearing in the literature as the most promising in eliminating health disparities (Braveman & Gottleib, 2014; Dressler et al., 2005). My dissertation research troubles that notion by suggesting a structural-constructivist model to understand the root causes of inequities and guide future nursing research strategies required to mitigate their effects as suggested as far back as the Heckler Report (1985), but as yet are still not realized.

A review of literature in these five areas is followed by a discussion of the theoretical underpinnings for this interpretive qualitative study, including critical feminism, intersectionality, and Bronfenbrenner's ecological framework. Finally, important historical underpinnings for health disparities, especially in Virginia and Charlottesville, will be acknowledged as laying the context for interpreting the findings of the study. History, not just for history's sake, is concerned with the past to inform our understanding of the present in a more powerful way.

The Racial-Genetic Model

Poverty, level of maternal education, age, marital status, and inadequate prenatal care have been associated in epidemiologic studies with an increased risk of preterm birth. (United States. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1998). Another consistent risk factor that has been identified as a risk for preterm birth is maternal race. (Muglia, 2010)

Despite the knowledge that race is a social construct masquerading as biology (Cooper, 1984; Montague, 1962) a racial-genetic model was suggested by researchers to explain poor birth outcomes (Boyle, 1970; Wilcox & Russell, 1990). This viewpoint shifted the focus of investigation from individual health behaviors to a racial-genetic model emphasizing population differences (Dressler et al., 2005), thus reinforcing racial and ethnic stereotypes. Who was generating this evidence? As early as the 1760s a new type of racialized medicine was using race as a defense of slavery, as a direct response to the abolitionist moral opposition to slavery, by attempting to provide “scientific” evidence to support White supremacy and African-American inferiority (Seth, 2017). Beginning in the Progressive Era, eugenics provided another way of “scientifically” legitimizing the South’s racist order (Dorr, 2000).

Technical advances in molecular biology have challenged conventional racial thinking and demonstrated that disparities, such as the differences in blood pressure between ethnic groups, could not be attributed to gene structure (Cooper, 1997) as researchers demonstrated blood pressure changes in response to environmental settings among groups of African descent. Gene-environmental interactions have been proposed to help explain IMR disparities, including: infection-mediated preterm delivery (PTD) with racial differences in amniochorionic membrane response to infectious stimuli; genes linked to vaginal microflora, pH levels, and cytokine activity; and differences between the African American and White populations in the frequency of immune modulating genes to help explain racial difference in PTD risk associated with infection (Fiscella, 2005).

A regional morbidity and mortality analysis of population-level incidence of trends in eclampsia, preeclampsia, and gestational hypertension contributing to poor maternal\child health outcomes reveals the risk of preeclampsia is significantly higher for women delivering in the South, while women delivering in the West are at the lowest risk. The authors of this study proposed that their findings were possibly because of the higher proportion of African American women living in southern regions (Wallis, Saftlas, Hsia, & Altrash, 2008). This is problematic as it reinforces a simplistic and flawed notion that African-American women are inherently predisposed to risk factors, thus reinforcing racial stereotypes.

Studies critical of the racial-genetic model demonstrated that Caribbean- and African-born mothers had birth outcomes similar to Whites (Dressler, 2005). In another study, records of 274,121 White births were compared to 279, 826 African-American births. While the overall IMR was 13.1 in Black births, compared to 4.8 in White births, the IMR was 10.0 in foreign-born Black women and 16.7 in African-American women (Fang, Madhavan, & Alderman, 1999). Especially significant is research data suggesting that her infant mortality risk increases with the length of time a women has been living in the U.S. (Fang et al., 1999) rather than her ethnic background. The research question appears to be less related to molecular biology, but more of a deeper question that poses "why is the experience of living in America detrimental to the health of women of color and their infants?"

Also critical of the racial-genetic mode was *The Report of the Secretary's Task Force on Black and Minority Health* (1985), more commonly known as the Heckler Report, that pointed out "Sensitivity to cultural factors is often lacking in health care of minorities" (1985, p. 10). The report suggested that it was not *the state of the science*, it was *the state of the system* that contributed to this disparity and required investigation:

> Research is needed into the factors that operate in medical care settings including: the dynamics of the patient-provider relationship; the behavior, beliefs and attitudes of minority patients and health care providers; and patterns of treatment/medical care provided to minorities (1985, p 44).

The Health-Behavior Model

Health-behavior research attempts to explain health disparities as differences between racial and ethnic groups related to individual health behaviors (Dressler et al., 2005). In many studies, substance use was self-reported thus opening the results to the critique of social desirability bias occurring when pregnant women underreport socially unacceptable behaviors.

Evidence obtained from one well-designed randomized control trial (RCT) was conducted from March 2006 to September 2008, studying prenatal use of alcohol, nicotine, and drug use, covering more than 90% of all deliveries in five geographically diverse regions and included 1.932 live births in addition to the 663 still birth deliveries (Apgar score 0 at 1 minutes and 5 minutes). Rather than self-reporting, umbilical cord samples from the infants and maternal serum were collected. Researchers calculated the increased risk of infant mortality for each of the substances they examined: Tobacco use had 1.8 to 2.8 times greater risk of infant mortality, with the highest risk found among the heaviest smokers; Marijuana use had 2.3 times greater risk of infant mortality; Evidence of any stimulant, marijuana or prescription painkiller use had a 2.2 times greater risk of infant mortality; Passive exposure to tobacco had a 2.1 times greater risk of infant mortality (Varner et al., 2014).

A study enrolled 211 postpartum women (35.5% African-American; 31.8% White; and 32.7% Native Americans), conducted face-to-face interviews in 4 Midwest hospitals in the U.S., and in addition to the interviews, demographic data and information on prenatal care visits was obtained from hospital records. Data were analyzed by Chi-square tests, followed by a series of one way analysis of variance across three care levels and the three racial groups. The researchers observed an increased incidence of smoking, hypertension, and other pregnancy risk factors in African-American women compared with White women in all maternal age groups (Lia-Hoagberg, Rode, Skovholt, Oberg, Mullett & Choi, 1990).

Arbour et al., performed a secondary analysis of the National Health and Nutrition Examination Survey 2001-2002 and 2003-2004 data sets. In a sample size of 1,497 women the researchers examined preconception risk factors that may have contributed to preterm births. African-American women had increased rates of preterm birth and in this analysis had an increased prevalence of bacterial vaginosis, trichomonas vaginalis, increased blood pressures, glycated hemoglobin >5%, BMI outside the normal range, and increased prevalence of iron-deficiency anemia when compared to White or Mexican American women.

An association between higher education levels and better health status has been reported in the literature, but as stated earlier, it is impossible to randomize people to receive different amounts of money or education. Evidence also suggests that raising the income levels of individuals leads to improvements in health outcomes. Quasi-experimental models looked at tax returns to create 725 low-income families and 632 control families, and compared them for 3 years (Elesh & Lefcowitz, 1977; Kawachi, Adler, & Dow, 2010). Researchers also observed lottery winners from 1968 to 1981 (Kawachi, 2010; Lindahl, 2002). In addition, the researchers observed the opening of a casino on an Indian Reservation that resulted in an increased income of $6,000 dollars per household (Costello et al, 2003; Kawachi, 2010). There is evidence suggesting that raising the incomes of the poor improves their health outcomes, and Kawachi's results (2010) suggested for each 10% gain in income, life expectancy was increased by between 5 and 8 weeks.

Widely cited natural experiments have exploited the fact that many women entered colleges in the 1960s and 1970s, the study also found that female college attendance demonstrated health effects including improved birth-weight and reduced smoking (Kawachi, 2010; Lleras-Muney, 2005). These findings were explained in three plausible hypotheses: 1.) Education makes one a better decision maker because one has wider access to health information (Grossman, 1972; Kenkel, 1991, Rosenzweig & Schultz, 1991); 2.) Poor health results in limited access to education (Perri, 1984; Currie & Hyson, 1999); and 3.) An unobservable third variable such as genetic characteristics or family background affects both health and education (Lleras-Muney, 2005.

In a study of 589 women, where 120 of the women were interviewed by a nurse researcher, women reported that they had experienced intimate partner violence (IPV). This finding suggests that significantly more low birth weight babies were born to women exposed to IPV than women who did not experience IPV (Bullock & McFarlane, 1998). Pregnancy reinforces the vulnerability of abused women and increases the risk of IPV, particularly among impoverished families (Kohrt and Worthman, 2009; O'Donnell, Agronick, Durna, Myint-U, & Stueve, 2010). Abused pregnant women especially encounter a lack of resources, including limited shelter space, inadequate time to secure affordable housing, and difficulties finding any job, let alone a well-paying one (Burnett, Ford-Gilboe, Berman, Ward-Griffin & Wathen, 2015). In some cases, abused women are dealing with legal issues such as divorce, custody and access to children in the midst of obtaining protection orders. These challenges occur within a complex system of policies and structures that often create barriers and obstacles, negatively affecting women's ability to rebuild their lives (Burnett, Ford-Gilboe, Berman, Wathen & Ward-Griffin, 2016). This violence impairs women's overall health, well-being and self-actualization, perhaps including prenatal health.

Research specific to maternal/child health supports the assertion that it has been improved public health measures such as pasteurization of milk and water sanitation (Braso, 1999) as well as anti-smoking and nutritional campaigns (Alexander & Kotelchuck, 2001) rather than prenatal care that have driven down the IMR. As a whole, studies tended to look at each risk factor independently, and a gap that I have identified exists in relationship to the concept of intersectionality (Crenshaw, 1989, 2012; Hill-Collins, 2012) where multiple etiologies and factors combine to contribute to poor maternal/child health outcomes.

Other limitations of research investigating the Health-Behavior Model are classified as an *omitted variable* bias or a *testing effect* bias (Pollit, 2012) because many of the topics of study are susceptible to confounding by an unobserved third variable that obscures the actual effect of an intervention.

The Socioeconomic Status Model

The socioeconomic status (SES) model posits the over-representation of some racial and ethnic groups within lower socioeconomic statuses (Dressler et al., 2005) as an attempt to explain health disparities. Cohen et al. (2010) examined two systematic reviews: Galobardes et al. (2004, 2008)) who reviewed 40 studies that examined the link between childhood SES and adult mortality, and Pollitt et al. (2005, 2007) who reviewed 49 studies examining childhood SES throughout the life course. Irrespective of their own SES or class, women living in deprived neighborhoods appear to have a higher risk of low birth weight and of preterm delivery. The reviews employed a variety of designs and methodologies, from a sample of 1,824,064, in Sweden down to a sample of 334 participants in Pittsburgh, and provided provocative evidence to support the hypothesis that that childhood SES contributes to adult health. [This article was based on a secondary analysis of data collected for other purposes, and consequently the study designs did not address African-American health disparities.]

Poor neighborhoods are characterized by a higher prevalence of hazards to healthy pregnancy, such as reduced availability of healthy foods (Cohen, Janicki-Deverts, Chen, & Matthews, 2010). They also have an increased prevalence of health-compromising behaviors, such as smoking during pregnancy (Vinikoor et al., 2008).

Lower family income and lower parental education have been associated with a higher burden of chronic infections in children (Cohen et al., 2010). There is also evidence that raising the incomes of the poor improves their health outcomes (Kawachi et al., 2010). There is consistent evidence linking more education with better health. More sophisticated techniques comparing racial and ethnic disparities with educational disparities find coronary artery disease, lung cancer, strokes, pneumonia, congestive heart failure, and lung disease contributed most to lost years of life in groups with less education (Wong, Shapiro, Boscardin & Ettner, 2002).

Transportation was a problem regardless of women's success in obtaining care and ranked as the top barrier by women who never tried to obtain care (Aved, Irwin, & Cummings, 1993). Sixty percent of White women had access to their own car or could borrow a car; African American women (42%) more often relied on someone to drive them to appointments (Lia-Hoagberg et al., 1990). As the highest incidence of IM occurs within the shadow of the University of Virginia Medical Center (TJHD, 2012), factors other than transportation are contributing to poor outcomes in these communities.

One study obtained birth certificates for all births in Durham and Wake Counties, North Carolina, between the years 1999 to 2001 and a total of 10,355 African-American births were included in the analysis (Messer, 2009). The study by a team of epidemiologists investigated confounding factors in studies where SES was a variable. Multilevel modeling was used, and many of the regression models demonstrated no actual data to support published findings. An example of their findings was maternal education data included on the birth certificate data, and census tract data was used to determine median household income. The pregnancy outcomes of interest were low birth weight and preterm deliveries. Researchers found that residence in a predominantly African-American community was associated with a decreased risk of low birth weight and preterm delivery among African-American women, and this association existed independently of a woman's own socioeconomic status Structural confounding limits the use of SES data for inference.

A critique of these studies must take into account the unreliability of linked birth certificate data to health outcomes. One study abstracted data from the prenatal clinic records of 2,032 women who attended a health department prenatal clinic in northeast Georgia from 1980 to 1988. Overall accuracy was poor. Only 14.3% *(n =* 291) of the records completely agreed on the total number of visits (Clark, 1997). Many studies question the accuracy of birth certificate data not only by the birth outcome but also by maternal characteristics that are associated with birth outcomes (Dobie, 1998; Reichman, 2001; and Schoendorf, 2006).

The Psychosocial Stress Model

The psychosocial stress model emphasizes the stress associated with minority group status, such as the experience of racism and discrimination, as an attempt to explain health disparities. The Whitehall I study was a landmark study in health disparities, with Whitehall II, a 20-year follow-up study (Marmot, et al., 1967; 1991). In 1967, Marmot began investigating the association between social class, as assessed by grade of employment, and mortality from a wide range of diseases. In the 20 years separating the two studies, there has been no diminution in social class difference in morbidity: there is an inverse association between employment grade and prevalence of angina, electrocardiogram evidence of ischemia, and symptoms of chronic bronchitis. Self-perceived health status and symptoms were worse in subjects in lower status jobs. There were clear employment-grade differences in health-risk behaviors including smoking, diet, and exercise, in economic circumstances, in possible effects of early-life environment as reflected by height, in social circumstances at work (e.g., monotonous work characterized by low control and low satisfaction), and in social supports. Healthy behaviors should be encouraged across the whole of society; more attention should be paid to the social environments, and the consequences of income inequality.

Most of the studies in the review of the current science are based on Marmot's work and they include the findings that lower SES children have greater difficulties with emotion regulation and poor emotion regulation during childhood may predispose individuals to higher anxiety, depression, and hostility in adulthood (Cohen et al., 2010). Lower SES school children have higher rates of victimization or threatened physical violence (Cohen et al., 2010). Studies have documented that stably employed adults experience better health and survival than those who are less stably or never employed and studies of perceived stress suggests prolonged fear of losing a job may be more damaging than job loss itself (Clougherty et al., 2010). It may be questioned whether social class factors influence disparities in infant morbidity and mortality.

Paradoxically, as cited in the previous Socioeconomic Status model section, pregnancy outcomes in African-American women may be better when they live in neighborhoods where they constitute the majority of the neighborhood population. (Vinikoor et al., 2008). Again, I take this opportunity to point to the Heckler report, "Sensitivity to cultural factors is often lacking in health care of minorities” (1985, p. 10). The report suggested that it was not *the state of the science*, it was *the state of the system* that contributed to this disparity and required investigation and research is needed into the factors that operate in medical care settings in neighborhoods where African-Americans constitute the majority population.

Do African American women trust the healthcare system? Braveman’s review of the literature (2014) posits that racial discrimination could be a causal factor by acting as a pervasive stressor in social interactions, even in the absence of an intent to discriminate. The psychosocial stress model has important nursing implications for promoting health, assessing risk, and targeting interventions to improve maternal and infant outcomes. Rather than concentrating on the 9 months while she is pregnant, primary prevention for women and infants needs to expand over the entire life span of the woman (Halfon, 2014; Lu, 2003; March of Dimes, 2002). Research evidence has suggested that African-Americans mistrust the medical system, do not seem confident that they would have an empowered voice in decision-making, and are suspicious of the motives of health care workers (Degenholz, Thomas & Miller, 2003) and this impacts care throughout the lifespan of the mother as well as impacts care seeking behavior for the lifespan of her child.

The Structural-Constructivist Model

Although numerous studies report that significant health disparities exist, only one research article measured the relationship between provider trust and perinatal outcomes (Peters, 2014). The study utilized the RaLES-brief (Harrel, 1997), a 9-item tool to evaluate if a patient has experienced racism within the healthcare setting, as well as a trust in physician scale (Anderson and Dedrick, 1990). Employing these tools, researchers in Detroit used a mixed methods approach based on Donabedian's framework (1980; 1995) to provide information about 187 African American women regarding *structure* variables and *process* variable to identify where gaps in care may occur that contribute to health disparity. The structural elements of care included type of health coverage, provider type, and an ability to see one provider consistently in the clinic setting. Process variables included the provider's technical skills and the medical aspects of care, as well as the interpersonal aspects of the provider relationship. The study found a conceptual distinction between *interpersonal* trust and *social* trust:

> Trust in the provider is interpersonal in nature, built through repeated interactions in which the patient can evaluate the trustworthiness of the provider over time. Social trust is placed in institutions, such as a health care system. Mistrust of social institutions is conceptually distinct from trust in provider but is also affected by previous health care experiences…(p. 151).

Structural-Constructivist models explore the potential that trust or mistrust has to add assumptions and meanings to observable experiences, thus leading to specific conclusions, actions, or outcomes based on those assumptions and meanings (Argyris, 1990). Due to the intersectionality of African-American women's lives, we see an intersection with the Stress Model and Structural-

Constructivist Models. Research data have suggested that African-Americans, who have a higher rate of preterm birth, “mistrust” the medical system, “did not seem confident” that they would have an empowered voice in decision-making, and “are suspicious” of the motives of advanced directives (Degenholtz et al., 2003). There is a need for qualitative research that explores these topics in a context of premature birth within the African-American community, and creates new knowledge-- built upon our existing body of science-- to design and test new interventions. Also, prenatal care was found to not adequately prepare women for possible poor birth outcomes (Kotelchuck, 1999).

An important article published in 2009 examined preterm births among African-American and Hispanic women who delivered at an inner city public hospital, Parkland Hospital in Dallas, in the context of contemporaneously increasing rates of IM in the United States (Leveno, 2009). Between 1995 and 2002, the rate of preterm birth in the United States increased from 9.4% to 10.1%. Between 1988 and 2006, the rate of preterm births at Parkland decreased from 10.4% to 4.9%. Moreover, the rates of preterm birth were significantly lower in Hispanic and African-American women who delivered at Parkland compared with the same ethnicity/race groups in the U.S. cohort. Prenatal care is considered one component of a comprehensive and orchestrated public health care system that is community-based. Putting this all together, the research team hypothesized that the decrease in preterm births experienced at this inner-city hospital was attributable to a geographically based public health care program specifically targeting minority populations of pregnant women.

I was a nursing student, later a nurse, and eventually a CNM, at Parkland Hospital at different times during this period and helped gathered research for this study. In the early 1990s, we began a concerted effort to improve access to and use of prenatal care with the intention of developing a program of seamless obstetrical care beginning with enrollment during the prenatal period and extending through delivery into the puerperium. Prenatal clinics were placed strategically throughout the county to provide convenient access for indigent women. In addition, these clinics had comprehensive medical and pediatric clinics that enhanced patient use. Because the entire clinic system, as well as the hospital, was operated by Parkland, administrative and medical oversight was seamless. For example, prenatal protocols were used by nurse practitioners (mostly TWU graduates) at all clinic sites to guarantee homogeneous care. The results of the Parkland care model that decreased the preterm birth rate by half were reported as surprising by the research team, but possible explanations offered by the authors were the co-location of medical clinics and pediatric clinics nested within the prenatal clinics providing a community centered life span approach to care.

Summary of State of the Science

The enrollment of all pregnant women into a system of prenatal care was promoted as a national policy in 1985 in an Institute of Medicine (IOM) report to reduce the risk of low birth weight. The U.S. Congress enacted a series of legislative initiatives that incrementally expanded Medicaid eligibility to low income pregnant women and children. This was motivated in part by the expectation that increases in early initiation and utilization of prenatal care would lower the risk of low birth weight and preterm birth and, as a result, lower IMRs (Alexander, 2001). Prenatal care continues to be touted as an effective approach to reducing low birth weight births and preterm delivery, but growing concerns have been raised regarding the validity of the evidence used to support these claims because rates of prenatal care have increased while rates of low birth weight and preterm births have risen (Alexander, 2001; Barash & Weinstein, 2002; CDC.gov, accessed 2-5-2017; Fiscella, 1999; Hack & Fanaroff, 1999).

Despite the Heckler report recommendations, and because of the difficulty in measuring qualitative differences in care for pregnant women, most of the current studies have focused exclusively on the number of prenatal care visits to evaluate perinatal outcomes. Grading the quality of the evidence in these studies produced methodological challenges on two levels: 1.) The quality of the care received is unable to be evaluated, and 2.) Assessing the efficacy of the care in achieving improved outcomes may be beyond the statistical power of quantitative studies. To evaluate any study of care, there must be an explicitly defined intervention that leads to an outcome (Fiscella, 1995; Pollit & Beck, 2012). Care for a pregnant woman is not easily measured because it does not consist of a single intervention. In prenatal care, we provide a series of assessments, health promotion education, psychosocial interventions and medical treatments that play out in a variety of community and medical settings over a 9-month term.

Polit and Beck (2012) offer several research design and intervention-related biases related to the validity of prenatal care claims. *Expectation bias* can occur in the absence of blind randomized controlled research trials. Randomized control trials are usually used to demonstrate efficacy, but “prenatal care” versus “no prenatal care” comparing infant mortality and morbidity would be considered unethical (Fiscella, 1995). Other biases offered by Polit and Beck (2012) include *reference bias* where researchers may cite more references to support their hypotheses than references to contradict them. *Publication bias* (also referred to as the *bias against the null hypothesis* or the *positive results bias*) reflecting the tendency of researchers, reviewers, and editors to not publish negative results (Polit and Beck, 2012). Rather than prenatal care, nutrition and antismoking interventions may have improved birth outcomes (Alexander, 2001).

There are several more validity threats that challenge our notions of the effectiveness of prenatal care for some women. First, there is little consistency within or among countries in the content of their prenatal care guidelines, suggesting a need for nurses to reexamine the content and the evidence on which prenatal education recommendations are based (Haertsch, Campbell, & Sanson-Fisher, 1999). Care for a pregnant woman is not easily measured because it does not consist of a single intervention. A survey of seven clinical practice guidelines from four countries (Australia, Canada, Germany, and the

U.S.) discovered 69 different recommendations given during prenatal education, and only 4 of the 69 recommendations were included in all seven documents' guidelines (Haertsch et al., 1999). Prenatal care, therefore, does not have consistent meaning or a consistent practice. Second, there are growing concerns regarding the validity of the evidence used to support the effectiveness of prenatal care when most researchers rely on linked birth and infant death certificates to study infant mortality, which is related to the ethical issues that surround the fact that direct randomized controlled trials of prenatal care versus no prenatal care would be considered unethical, as previously mentioned. (Barash & Weinstein, 2002; Kotelchuck, 1994; Martin et al., 2013). A National Vital Statistics Report (2013) review of 54 hospitals in four states revealed a disagreement between the birth certificate and medical records regarding the total number of prenatal care visits in 100% of the cases (Martin et al., 2013). Other methodological issues include underreporting of health conditions and missing data on the birth certificates (Martin et al., 2013).

Although the proportion of women receiving prenatal care is higher than ever before (Hamilton, 2013), adverse pregnancy outcomes (e.g., preterm birth and infant mortality are still of concern (Lau, 2013; MacDorman 2008; Martin, 2011). Experts suggest that the lack of improvements in adverse pregnancy outcomes may be because: 1.) Prenatal care is a one-size-fits-all approach (Fiscella, 1995), 2.) We have no reliable methodological standards for judging outcomes of current prenatal care nursing interventions, only methodological standards using flawed birth certificate and medical record data (Martin, 2013), and 3.) There is no consistency among prenatal care guidelines (Haertsch, 1999).

The Major Gaps in the State of the Science on Health Disparities

The sources of infant mortality disparities are complex, are rooted in historic and contemporary inequalities, and involve many participants at several layers, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and clients. A better understanding of the root causes of infant mortality disproportionately affecting African-Americans requires a deep exploration of the situations and events through history that shaped our current social worlds with racism, discrimination and marginalization, as well as current, persistent systematic inequalities that privilege one group of people over another (Alexander & Kotelchuck,2001; Block, 2011; Johnson, 2006). The complex processes for understanding of how pregnant African American women, who seek care at the University of Virginia Medical Center, construct the knowledge that informs their care choices cannot be subsumed within a general narrative, but must be analyzed in their specificity and unique context within a structural-constructivist model.

Appreciation of the social factors influencing the health behaviors of African-American pregnant women can help nurses develop more effective care plans. Nurses and care providers can refine and tailor routine procedures to assess and respond to their specific needs. Benefits of culturally competent care have the potential to carry over into the care of their infants, children, and their care across the life span.

Researcher Stance: A Feminist Critical Lens

In this study, I have taken a feminist critical lens to interrogate the persistent puzzle of what makes African-American women so prone to exorbitantly high IMRs despite living in a country of great wealth and resources. Feminist studies are designed, implemented and disseminated with the goal of providing explanations for women that they want and need about phenomena that affect their lives: (a) women's experiences are the major "object" of investigation, (b) the goal of inquiry is to see the world from the vantage point of a particular group of women, and (c) it is critical and activist in its effort to improve the health and living conditions of not only women, but all persons (Campbell & Bunting, 1991). Claims about gender made during the Second Wave of feminism were criticized in failing to recognize constituencies other than White privileged women who had access to resources and education (hooks, 1981). Postcolonial feminism seeks to account for the way that racism and the long-lasting political, economic, and cultural effects of colonialism affect non-White, non-Western women in the postcolonial world (Mohanty, 1988). This particular strain of feminism promotes a wider, more critical viewpoint of the complex layers of oppression that exist within any given society and the study of the interactions of multiple systems of oppression or discrimination.

Theoretical Underpinnings

Two bodies of theoretical literature were used to underpin this study of the lived experience of childbirth for African-American women. First, an intersectionality viewpoint (Crenshaw, 1991) shifts the focus of investigation from elements of race, gender, or class oppression to one whose goal is to determine what the links are among these systems. The intersection of racism and sexism factors into African-American women's lives in ways that cannot be captured by looking at race or gender separately (Hill Collins, 2012). Second, Bronfenbrenner's ecological framework accounts for the many levels of factors that contribute to birth outcomes such as IMR (Bronfenbrenner, 1977).

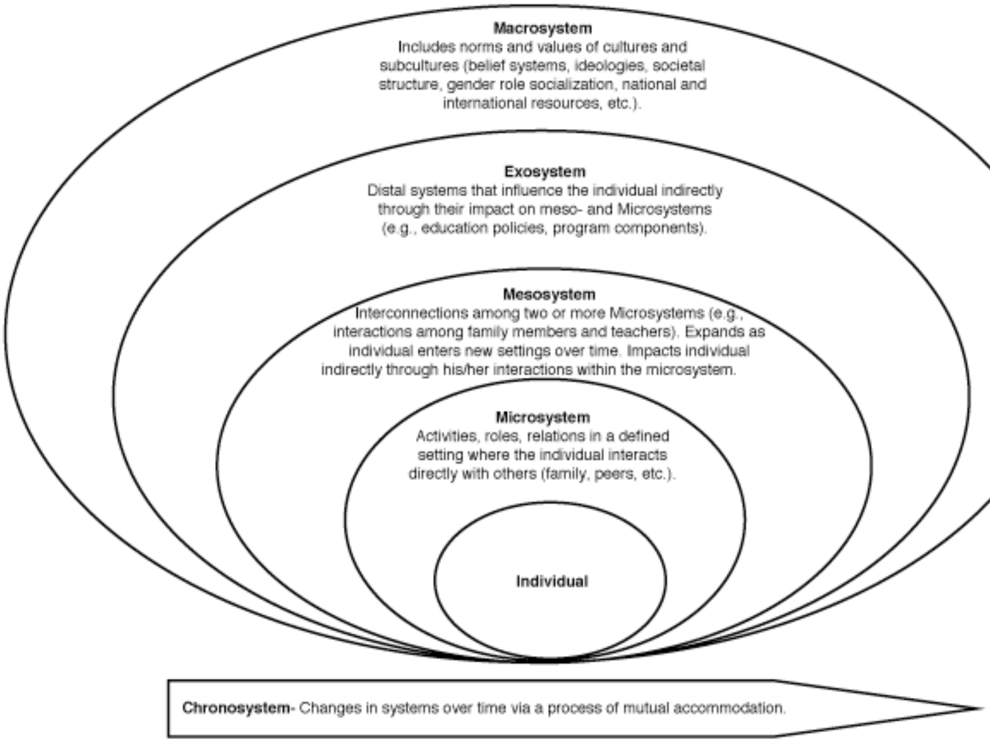
Intersectionality

For feminist theory and antiracist policy discourse to embrace the experiences and concerns of African-American women, the framework that has been used as a basis for translating *women's lived experience* has been *White* women's experiences (Crenshaw, 1989). Crenshaw (1989) also points out that the basis for examining the *African American experience* has traditionally used a framework and lens that emphasizes the exploration of African-American *men's* experiences. Making changes to practice and policy demands that nursing research be rethought and recast because many of the experiences African-American women face are not subsumed within the traditional boundaries of race, class, or gender as these boundaries are currently understood. They factor into African-American women's lives in ways that cannot be captured by looking at race, class, or gender separately. Forms of oppression within a society do not act independently of one another; instead, these forms of oppression interrelate, creating a system of oppression that reflects the *intersection* of multiple forms of discrimination (Crenshaw, 1991). Crenshaw's understanding of intersectionality was informed by African-American women's legal court cases regarding discrimination. African-American women were not able to sue successfully because companies that discriminated against African-American women could demonstrate that they employed African-American men in low-wage jobs, and White women were also employed. Crenshaw began to understand that African-American women's experiences of discrimination could not be subsumed under the African-American *male* experience or *White* women's experiences. Understanding intersectionality provided guidance for the construction of the focus group interview guide used in this study as well as a perspective from which to analyze and interpret the data. Intersectionality has the potential to understand intersecting etiologies, as well as multiple social factors, contributing to poor maternal/child outcomes.

An Ecological Framework

The ecology of human development is the scientific study of the progressive, mutual accommodation, throughout the life span, between a growing human organism and the changing immediate environments in which she lives, as this process is affected by relations within and between her immediate settings, as well as the larger social contexts, both formal and informal, in which the settings are embedded (Bronfenbrenner, 1977).

Figure 2.1. An Ecological Framework Overview



(Bronfenbrenner, 1986)

An ecological framework for inquiry includes the interaction of genetics, human biology, and environment in family processes; links between the family and hospitals, day care, peer groups, school, social networks, the world of work, and neighborhoods and communities; and public policies affecting families and children. A second major focus is on the patterning of environmental events and transitions over the life course.

Combined with an ecological framework (Bronfenbrenner, 1977), intersectionality provided a new and useful lens to understand how women's multiple identities collide and interact during their pregnancy and birth experiences. Because oppression occurs at the personal level, at the group or community level within the context of race, class, and gender, and at the systematic level of social institutions, analysis required clarification within each of these contexts. The blending of these two theoretical perspectives as well as that of critical feminism provide a better underpinning for investigating the root causes of infant mortality disproportionately affecting African Americans and has important nursing implications for promoting health, assessing risk, and target interventions to improve maternal and infant outcomes

Historical Underpinnings of Disparities in Infant Mortality

Critically reviewing the state of the science on disparities in IM and introducing the theoretical perspectives to guide a better understanding of this complex problem are incomplete without grounding in the historical events that have shaped and continue to impact African-American health. A lack of connection to historical context, both nation-wide and local, is a major gap in our understanding of IM in African-Americans. Truly understanding health disparities requires a deep exploration of the situations and events through history that shaped our current social worlds with racism, discrimination and marginalization, as well as current, persistent systematic inequalities that privilege one group of people over another. This study acknowledged that key historical moments are of potential relevance to a study on African-American women's birth experiences, including the practice of slavery, Jim Crow laws and segregation, dehumanization of black bodies, the Civil Rights Movement, integration at the University of Virginia Hospital and dismantling of African-American communities such as Vinegar Hill. An acknowledgement of the importance of this collective history aided in the interpretation of focus group findings and is integrated into the discussion of study findings presented in Chapter 4.

In conclusion, reviewing the literature that represents the state of our knowledge about disparities in infant mortality, it became clear that something larger is happening here that has not been underscored. The Hecker Report suggested that it was not *the state of the science*, it was *the state of the system* that contributed to the IMR disparity and required investigation. This viewpoint informed the focus of my investigation from elements of race, gender, or class oppression to one whose goal was to determine what the links are among these systems. Further, the historical context that has been silenced, yet remains influential today was imperative to use to interpret study findings.

CHAPTER THREE

Methodology

This purpose of this study was to better understand what contributes to high infant mortality rates (IMR) for African Americans living in Charlottesville, VA. The specific aim of this study was to examine the lived experience of the African-American women living in neighborhoods with high infant mortality looking for nursing implications that can inform targeted interventions for promoting maternal/child health.

Research Design

This study was a secondary analysis of data derived from a series of focus groups conducted in the Thomas Jefferson Health District (TJHD) in Charlottesville, Virginia. Concerns over high IMRs prompted the TJHD and key community organizations to investigate factors contributing to infant deaths (see Figure 3.1). Using this data set, a qualitative-interpretive design was used to describe the conceptual factors of the childbirth experiences for women living in the neighborhoods with high IMR in order to arrive at a better understanding of the multiple etiologies of infant mortality. This approach contributed to knowledge of the various pathways that may contribute to low birth weight and preterm birth and therefore, has the potential to inform nursing interventions that may lead to improving pregnancy outcomes in Charlottesville neighborhoods with high rates of infant mortality (Bronfenbrenner, 1977; Cohen, Janicki-Deverts, Chen, & Matthews, 2010; Wuest, Merritt-Gray, Berman, & Ford-Gilboe, 2002).

Parent Study

A focus group design was used to explore women's views of major sources of stress in high-risk women's lives and to determine whom they turn to for support in times of need; assess the women's knowledge, attitudes, and beliefs about causes of and factors contributing to infant mortality; and assess the women's perceptions of access to prenatal healthcare in Charlottesville and perceptions of the quality of care they receive.

Ethical Considerations

The original study participants included vulnerable populations, pregnant women and minors. The data were collected between 2009 and 2013 and de-identified for this secondary analysis dissertation study so there were no known risks to the participants. Permission to conduct the original studies that provide the data for this secondary analysis was granted by the University of Virginia and the Virginia Department of Health Institutional Review Boards.

The data in this secondary analysis consisted of de-identified transcripts, as well as results from a short demographic questionnaire assessing the level of education, relationship status, neighborhood locality, insurance status, healthcare service locality, and pregnancy experience. The data were in the form of verbatim transcripts and questionnaires and therefore were not sensitive data. However, every precaution was taken to protect the data from persons not associated with the research. The transcripts were only reviewed by me as the primary researcher and UVA faculty associated with the project. The data were stored in a locked cabinet when not being used for research purposes. A loss of confidentiality of any of the material would not put any participants at personal risk.

The data analysis did not provide any direct benefits to the participants of the original or secondary study, but the knowledge gleaned from the data may eventually benefit African-American women receiving health care in Charlottesville by informing targeted interventions and policy.

Participants and Setting – First Wave (Secondary Data Set)

In 2007, a steering committee of community leaders engaged with the TJHD to analyze health data and recommend goals. Two of the five goals recommended were: (1) a reduction in the IMR, and (2) a reduction in the disparity between White and African-American infant mortality. Recruitment posters offering a $25 incentive for participation in focus groups were printed and distributed throughout the health department, community partner organizations, prenatal clinics, and the Women Infants and Children (WIC) Nutrition Program office. Health educators from the TJHD began enrolling community members living in neighborhoods identified with high IMRs and between May and June 2009, three focus groups of community members were conducted (N=30). Participants completed a demographic questionnaire and consent form before each session began. Sample characteristics of these three focus groups are identified in Table 3.1. These two health department goals identified by community leaders framed the topics for focus group discussion (see Table 3.2**).**

Participants and Setting – Second Wave

Continued concerns over high IMRs again prompted the TJHD to fund additional focus groups, illustrated in Figure 3.1. Between April and May, 2013. Women who were pregnant or had delivered a child (n=30) were recruited from lower-income areas within the TJHD. Flyers advertising the focus groups were distributed to local health departments, community partner organizations, prenatal care clinics, WIC Nutrition Program clinics, and other interested parties. Additionally, a TJHD community outreach worker identified and invited women to participate in the study. Each study participant received a $25 gift card incentive to participate. Participants completed a demographic questionnaire and consent form before each session began. Permission to conduct this second wave of the study was granted by the University of Virginia and the Virginia Department of Health Institutional Review Boards. Sample characteristics of the second group of focus groups conducted in 2013 are identified in Table 3.3. Additional questions were used to focus discussions on expectations of care and attitudes regarding their care, and are listed in Table 3.4.

Setting for the Second Wave Study

Focus groups included community members living in TJHD neighborhoods identified with high infant mortality rates (see Figure 3.2)

Current Study - Sources of Data

Participants for this secondary analysis study were 60 women, including a subset of 42 African-American women, who participated in both waves of the parent study described above. The data set for this dissertation study is comprised of de-identified, verbatim transcripts from these eight focus groups of participants (n=60)

Thematic Analysis

The thematic analysis approach was used to identify, analyze, and report patterns within data (Braun & Clark, 2006). Thematic analysis is an approach that lends itself to use in any research paradigm, including the interpretive. It was particularly suited to examining the contextual factors that have shaped African-American women's childbirth experiences (Schwartz-Shea & Yanow, 2012; Strauss & Corbin, 1990). Interviews that are analyzed to thematically fit well into Crenshaw's intersectionality criteria (1991) as many of the experiences African-American women face are not subsumed within the traditional boundaries of race or gender as these boundaries are currently understood (Hill Collins, 2012). A thematic analysis of the community focus groups in the parent study (Braun & Clark, 2006) helped to determine what the links are among ecological systems that the women live within (Bronfenbrenner, 1977), and how their intersections in African-American women's lives (Crenshaw, 1991) may lead to a better understanding of specific underlying mechanisms that contribute to infant mortality.

A Thematic Analysis methods approach requires anchored material as a step in developing codes inductively (Boyatzis, 1998). Anchored material allowed two subsets of the raw data to serve as a comparison for developing the codes.

For example, a focus group subsample that contained exclusively African American women living in specific neighborhoods was compared to subsamples of women living outside those neighborhoods to help refine the codes and themes (see Table 3.1 and Table 3.3). The 3 neighborhoods with the highest IMR (Figure 3.2) were included in the sample and the 6 transcriptions of the exclusively African-American women's focus groups served to anchor the research (see Table 3.1 and Table 3.3). The data set was well suited for a thematic analysis approach because out of the 9 transcripts, it offered subsets that could be used in developing codes and themes specific to the research question (Boyatzis, 1998). The data set could also be compared as a subset to the city of Charlottesville population data. For an overview of Charlottesville Demographic Information please see Figure 3.3 through Figure 3.6.

Data Analysis Procedures

Braun and Clark (2006) outline six phases for thematic analysis that ensure a systematic, rigorous, and auditable process of data analysis and synthesis.

Familiarization with the data. First, I immersed myself in the data by reading all of the focus group transcripts in multiple iterations and taking notes on the overall nature of each group.

Generation of initial codes. Second, I open-coded each transcript, giving interesting features of the data a name or conceptual label. This was a data expansion phase of analysis in which no decisions of salience were made; the purpose of this open-coding was to examine the breadth of all that is involved in a particular phenomenon. Codes were inductively derived and interesting *in vivo* codes were used when a participant's verbatim language provided an evocative presentation of a concept or idea. I also created *a priori* codes based on the ecological framework that explored themes that were central to my research aims. *A priori* codes were given to quotes corresponding to each ecological level, such as: any quotes referring to the father of the baby were coded as Microsystem; quotes related to the prenatal clinic were coded as Mesosystem; and quotes related to the UVA medical center were coded as Exosystem. Women described actors and experiences that were unique to one system (a sonogram, was an example of an *a priori* Mesosystem level coded phenomenon), as well as those that intersected multiple systems (medical students were an example of *a priori* codes at both the Exosystem and Mesosystem levels).

Search for themes. Third, was categorizing the codes into themes, and gathering all data relevant to each potential theme. A theme is a common thread or pattern that is indicated by the data and moved to an abstract, conceptual level by the researcher in analysis (Morse & Field, 1995). Two initial themes that emerged from the transcripts were *searching for a connection* and *seeking a healthcare home but finding a healthcare institution*.

Reviewing themes. Fourth, I checked the themes within each coded transcript (Level 1) and checked the themes in relation to the entire data set (Level 2). This is an analytic strategy commonly referred to as constant comparison method (Glaser & Strauss, 1967). I then generated a thematic map of the analysis.

Defining and naming themes. Fifth, was the iterative process of refining themes to the highest level of abstraction and identifying the narratives that the analysis of the women's voices had revealed. ***Seeking a health care home*** and ***finding an institution*** represented the overarching bipolar theme that framed the salient thematic findings. Chapter 4 will unpack the multiple socioecological levels and various points of contact articulated by the women when describing this theme.

Producing the report. The last phase of thematic analysis consisted of writing the final report. Examples extracted from the data related the analysis back to the research question, specific aim, and extant literature.

In addition to the analytic procedures proposed by Braun and Clarke, I interrogated the findings and interpreted them within their historical context. The women's exploration of their lived experience of childbirth touched on perceived historical racism within the Charlottesville community, the role of the University of Virginia (UVA) Medical Center, and the care provided by the medical students nested within that system. This study acknowledged and examined each point of contact with the health care system to understand how the community narrative that emerges from each care encounter was shaped by a larger historical narrative. Chapters 4 and 5 will describe in detail how actors at all levels were perceived by the community, and without awareness of the historical context, their interactions may have unwittingly contributed to destabilizing the health care home that the women were seeking.

Validity

When do we know, and how do we know, if the data and the analysis have faithfully generated knowledge about the community so that we can act critically to change practice and policies? Borrowed from positivism, I maintained procedural rigor in the application of my research methods and applied interpretive rigor (Denzin & Lincoln, 2005) to ensure the validity or verification of the findings.

Rigor in application of the Thematic Analysis method. Monthly meetings were conducted with members of the TJHD Improving Pregnancy Outcomes committee to discuss the credibility and dependability (qualitative evaluative criteria that parallels reliability and consistency) of my judgments regarding emerging codes and themes.

Interpretive rigor. Guba and Lincoln (2005) suggest 7 points to consider for ensuring interpretive rigor, and this provided a framework for my study:

1. Positionality/standpoint. Combined with a feminist lens (Campbell & Bunting, 1991, hooks, 1981) and an ecological framework (Bronfenbrenner, 1977), intersectionality provided a new and useful lens to provide a richer, more nuanced lens to view how women's multiple identities collided during their pregnancy and birth experiences.

2. Specific discourse communities and research sites as arbiters of quality. A Thematic Analysis methods approach requires anchored material as a step in developing inductive codes (Boyatzis, 1998). The specific communities sampled in my study were neighborhoods with the highest IMR which anchored my research (Figure 3.7, Table 3.1, Table 3.3). Infant mortality among African-Americans living in neighborhoods surrounding the University of Virginia Medical Center occurs at a rate of 20.2 deaths per thousand live births (Virginia Department of Health, 2012). This is four times higher than the 4.9 deaths per thousand for infants that die before their first birthday who are not African-American (Virginia Department of Health, 2012).

3. Voice. The coding and analysis of the transcripts was an iterative process of refining themes and identifying the narratives that the women's voices revealed. Data from focus groups were transcribed verbatim to reflect women's subjective experiences. The analysis was verified with women from similar social contexts to ensure applicability (Lincoln & Guba, 1985). This included Holly Edwards, a prominent African-American nurse who originated the 2008 parent study. Dr. Edwards was a former member of the Charlottesville City Council, and served as the Service Coordinator for the Public Housing Association of Residents. Dr. Edward's participation and expertise, from her standpoint situated with the African-American community and city government, offered a particular degree of rigor to the interpretation of the findings. Further, staff members of the TJHD, and members of the key community organizations that made up the TJHD

Improving Pregnancy Outcomes committee reviewed products of the analysis with me throughout the course of the study.

4. Self-reflexivity/critical subjectivity. Historically the inclusion of African-Americans in research studies is framed by the ethical questions that arise from researchers in Tuskegee, Alabama, who withheld effective penicillin treatment from African-Americans for 27 years so that syphilis could be studied (Triola, 2004) or the more recent ethical questions surrounding *The Immortal Life of Henrietta Lacks* (Skloot, 2010). These general points explore the arc of a cautionary tale that has led to national research guidelines and Internal Review Board oversight. Considering the issues surrounding race, and ways that I personally, as a white male nurse researcher ensured sensitivity for the African-American women study participants, I reflected on the fact that I practice within a healthcare structure that favors members of my race, class, gender and educational level (hooks, 1992). Working with women who view healthcare providers with suspicion, I may have been viewed as a member of a group that has affected discriminatory policies and practices and who continue to benefit from maintaining power, and privilege (Morrison, 1992). Many populations are blamed for their poor health and their resistance to utilize a predominately white healthcare system (Fowler, 2010) and those other than white are often described as disadvantaged, and in need of attention by the dominant group who assumes that every person should aspire to achieve the white norms (Manglitz, 2003). I employed a systematic reflexive practice throughout the study and wrote reflexive notes following each analytic session and developed reflexive memos in order to be ever-mindful of how my own lens, as well as those lenses that might represent my identity memberships and my own intersectionality may have influenced my interpretations of the data.

5. Reciprocity rather than hierarchy. I actively collaborated with the original group of community partners with interest in the high IMR in these neighborhoods to continue to add to our understanding of IMR in this community. In addition to my dissertation committee, throughout the analysis I verified the analysis with community experts. I maintained a relationship with these stakeholders and they provided feedback throughout the analysis.

6. A regard for how science can contribute to human flourishing. An ecological method of inquiry includes the interaction of genetics and environment in family processes; links between the family and hospitals, day care, peer groups, school, social networks, the world of work, and neighborhoods and communities; and public policies affecting families and children. This holistic, contextualized framework for understanding not only identified areas of problem, disparity and systematic disadvantage, but created an opening for the identification of positive, strength-based internal and external assets that women may have that could be leveraged to promote flourishing.

7. Sharing the perquisites of privilege. The perquisites of privilege that accrued from my academic nursing research examining the lived experience of African American women provided a contextual for understanding conditions that contribute to health disparities and higher African-American IMRs in Charlottesville.

Limitations of the Study

A major limitation that has been identified in qualitative secondary analysis is the challenge of identifying, locating, and gaining access to an appropriate database. Additional challenges, once a suitable qualitative database has been identified, is the adequacy of the thick descriptive quality of the data sufficient to answer the research question (Polit, 2008). There can be technical limitations as a result of the specific software operating system that was used to code the primary data, as well as access to software compatible with the data storage method.

This study had several limitations. Study participants were all volunteers and a small incentive was offered for participation, which might have resulted in selection bias. Most of the recruitment took place where maternal-child health services are offered; participants therefore may have been more likely to access health care than other women in the community. The timeframe of the two waves of data collection (2009-2013) may not have taken into account more recent practices by the University of Virginia Health System to improve prenatal and obstetrical care for African-American women, however in the process of verifying my findings with community experts, these findings continue to resonate.

Despite these limitations, this study was the first to pay attention to the multiple dimensions of the everyday experience of women's lives in

Charlottesville, acknowledging that African-American women's voices in the neighborhoods with the highest IMRs are particular and uniquely situated to bring a nuanced understanding of nursing implications that can inform targeted interventions for promoting maternal/child health.

Table 3.1
Age and Race/Ethnicity Demographics of 2009 Study Participants

Sample	**# of Participants**	**Race/Ethnicity and Age Demographics**
Focus Group 1.	12	12 African American Age *Range* = 16 – 65, *Mean* = 28.42, *Median* = 23 years
Focus Group 2.	9	9 African American Age *Range* = 26 – 73, *Mean* = 48.44, *Median* = 42 years
Focus Group 3.	5	2 African American, 1 Native American, 1 Hispanic, 1 Caucasian Age *Range* = 15 – 19, *Mean* = 17.2, *Median* = 17 years
Focus Group 4.	4	2 African American, 2 White Age *Range* = 30 – 62, *Mean* = 51.5, *Median* = 57 years

Total	30	25 African American, 1 Native American 1 Hispanic, and 3 Caucasian Age *Range* = 15 – 73, *Mean* = 33.19, *Median* = 26.50 years

Characteristic:	**# of participants, Total *n* = 30**
Education:	4 Still in high school (1 in 9th, 2 in 11th, and 1 in 12th grade) 16 Graduated from high school or received GED 5 Received further education after high school
Relationship Status:	5 Married 8 Single and in a committed relationship 12 Single and not in a committed relationship
Neighborhood:	11 10th Street & Page Street 8 Prospect 2 Friendship Court 2 Downtown 3 Other
Insurance Status:	2 No insurance 24 Have some type of insurance

Type of insurance	18 Medicaid 2 Medicaid and Medicare 1 Medicare 1 Insurance through work 2 Don't know
Usually Seeks Healthcare Services From:	17 University of Virginia 3 University of Virginia and a private doctor 1 University of Virginia and the Free Clinic 1 University of Virginia and 'other' 2 Private doctor 2 'Other'
Pregnancy Experiences:	19 Pregnant in lifetime (includes 5 current pregnancies) 7 Never pregnant
# of pregnancies	*Range* = 0 -14 pregnancies, *Mean*= 2.54, *Median*=2.00 7 Never pregnant 4 One pregnancy 4 Two pregnancies 5 Three pregnancies 6 Four or more pregnancies

# of children	*Range* = 0 – 5 children, *Mean* = 1.76, *Median* = 1.00 2 pregnant participants 5 One child 1 Two children 6 Three children 1 Four children 3 Five children 7 No children
# who experienced a miscarriage	6 participants
# who experienced a stillbirth	2 participants
# who reported experiencing infant mortality in their family	10 participants

Table 3.2.

Focus Group Prompts for the 2009 Study

Targeted Objective	Discussion Questions & Prompts
Objective 1: To assess major sources of stress in high-risk women's lives and to determine whom they turn to for support in times of need.	• Who do you turn to for support/help? • How do they help you, i.e., what do they do for you? • How has the father of your baby helped you/other mothers you know? • What are you stressors in your lives?
Objective 2: To assess women's knowledge, attitudes, and beliefs about causes of and factors contributing to infant mortality.	• Where do you go / who do you go to for health information? • What do you think causes babies to die early? • What have you heard about the effects of smoking, drinking, or drugs on pregnancy?

Objective 3: To assess women's perceptions of access to healthcare in Charlottesville and perceptions of the quality of care they receive.	• Where do you usually go to see a doctor? When do you go? • Many women in Charlottesville don't start seeing a doctor for prenatal care until later in their pregnancy or they don't keep their appointments. Why do you think that is? • Is it difficult to get appointments? What are the barriers to making it to appointments? • What is your perception of the quality of care you receive from health providers in this community?

Table 3.3.

Demographic Characteristics of the 2013 Study Participants

Sample	# of Participants
Focus Group 5.	6 African Americans
Focus Group 6.	5 African Americans
Focus Group 7.	3 African Americans
Focus Group 8.	3 African Americans, 7 White
Focus Group 9.	2 White

Characteristics:	# of participants, Total *n*=30 (%)
Race	
African American	17 (57)
White	13 (43)
Age	
14-19	3 (10)
20-24	12 (40)
25-29	7 (23)
30-34	7 (23)
35 +	1 (4)
Marital Status	
Single	15 (50)
In Relationship	7 (23)
Married	5 (17)
Separated	3 (10)
Education	
Some High School	3(10)
High School Graduate	15 (50)

Some College	5 (17)
College Degree	6 (20)
No Response	1 (3)
Annual Income	
<$15,000	17 (57)
$15,000 - $29,999	8 (27)
$30,000 - $44,999	1 (3)
No Response	4 (13)
Medical Insurance	
None	2
Medicare	2
Medicaid	15
Private	1
Employer Provider	1
Other	1 (“Covered under my father’s plan”)
No Response	8

Table 3.4. Focus Group Prompts for the 2013 Study

1. What does “prenatal care” mean to you? What comes to mind when you think about prenatal care?
    a. **Probe:** Do you think it's important or helpful for a pregnant woman to get medical care before the baby is born? Why?
    b. **Probe:** What are the steps you think women should take when they find out they’re pregnant?
    c. **Probe:** Who did you talk with to get the most information or advice about your pregnancy?
    d. **Probe:** How did you choose where you received your care?

Expectations/attitudes towards prenatal care

1. When you go to a clinic for an appointment, what do you expect to happen?
    a. **Probe:** What are some unexpected things that have happened during your visits?
2. What do you think your doctor or nurse is supposed to do during your appointment?
    a. **Probe:** Would it be helpful to know what to expect before your first visit?

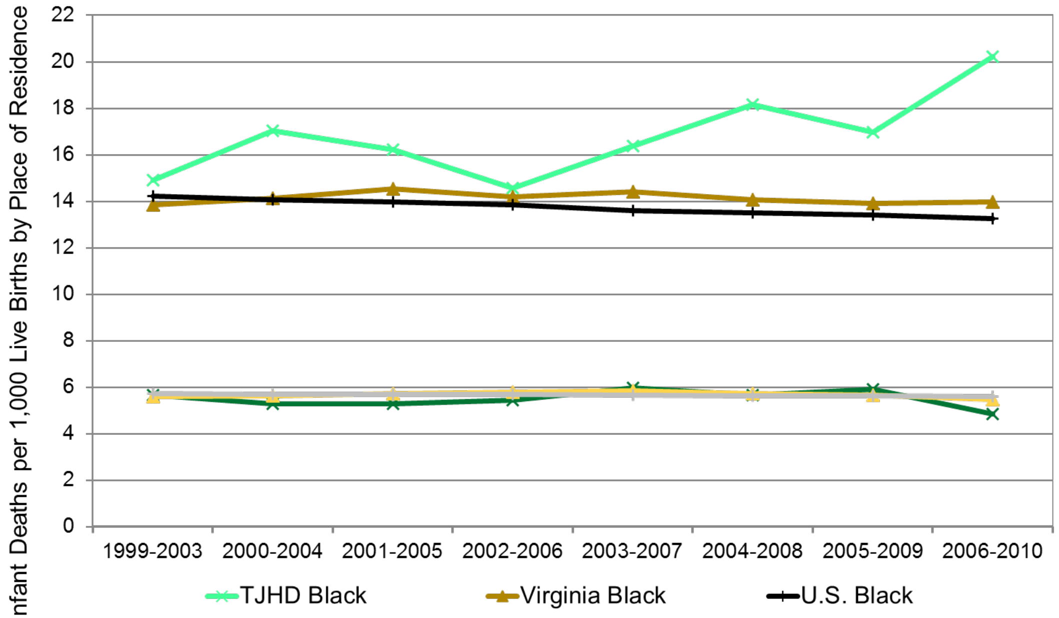
3. What was your experience like receiving care?
    a. **Probe:** Do you think your care providers understand you and where you’re coming from?
    b. **Probe:** How did you feel during your visits? Did you feel welcome or comfortable?
    c. **Probe:** What could doctors or nurses do better?
    1. Could you describe what happens during a visit? What feelings do you have during your visits?
        a. **Probe:** Could you describe a visit that was particularly worthwhile or meaningful for you? What did you like about this visit?
            i. What were some of the things the nurse or doctor did to make you feel good or comfortable about the appointment?
        b. **Probe:** Could you describe an appointment that was **not** meaningful or worthwhile for you? What did you dislike about this visit?
            i. What were some of the things the nurse or doctor did to make you feel bad or uncomfortable about the appointment?
    2. Do you feel like you had a good relationship or connection with the doctors or nurses you saw?

    a. **Probe (if negative):** Would you have liked to have a different relationship? How do you think it would have changed things?
    b. **Probe (if affirmative):** How did your relationship with your doctor or nurse affected your care? Was it important?
    c. **Probe:** What does it mean to have a good relationship to a doctor or a nurse? Could you describe what that would be like?

3. Did you see the same doctor or nurse several times during your pregnancy? How did you feel about that?
    a. **Probe (if affirmative):** How many times did you see the same doctor or nurse?
    b. **Probe:** Would you like to have had more visits with the same person? Why or why not?
4. Did students provide your care? How did you feel about that?
    a. Probe (if negative): Do you have any ideas for what might make patients feel more comfortable in those situations? What would have made you more comfortable?
5. What are some things that make it harder for you to go to or stop you from going to your appointments?
    a. **Probe:** What are some things the community could do to make going to your appointments easier?
    b. **Probe:** Does anything else keep you from going to your appointments?

Figure 3.1.

Infant Mortality by Race for the Thomas Jefferson Health District (TJHD).



(Virginia Department of Health, Division of Health Statistics, 2012)

Figure 3.2.

Setting for the Study

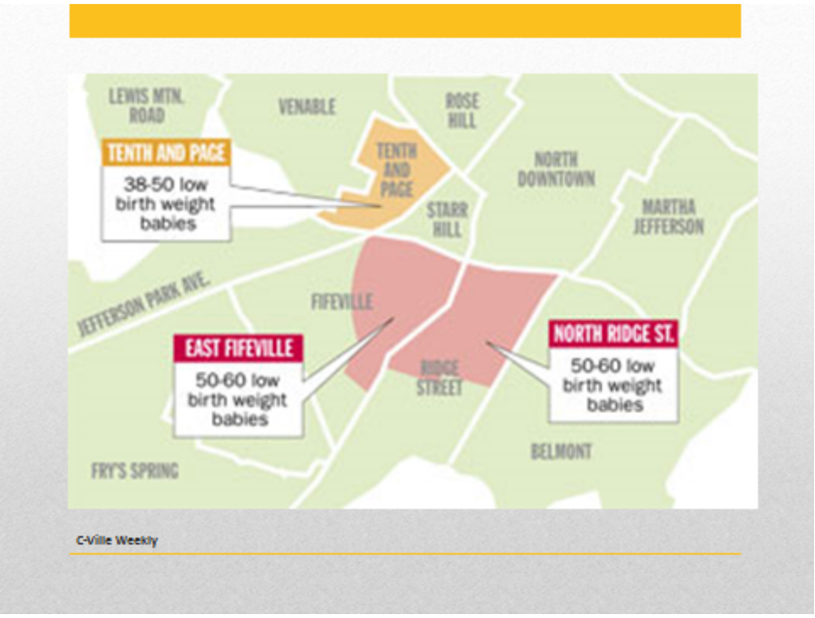
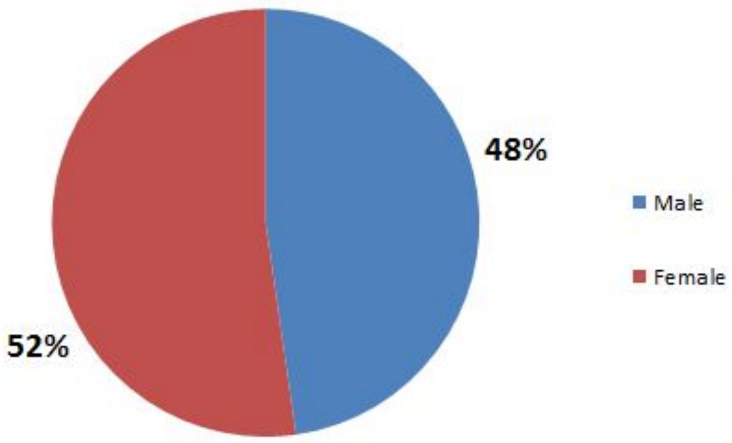
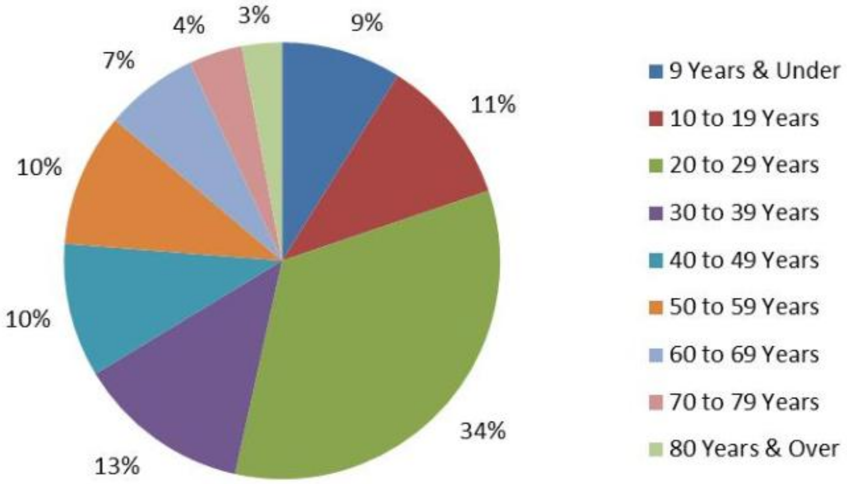


Figure 3.3. Charlottesville City Population by Gender



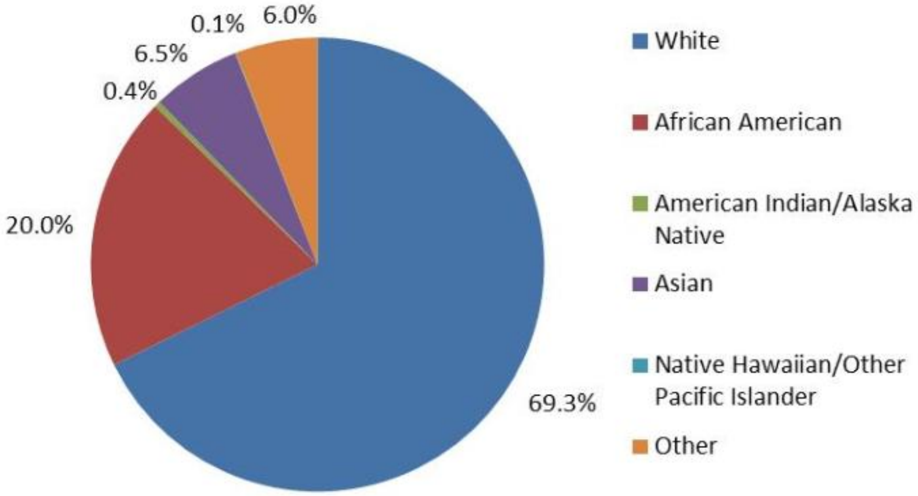
Source: American Community Survey, U.S. Department of Commerce, Census Bureau, 2013

Figure 3.4. Charlottesville City Population by Age



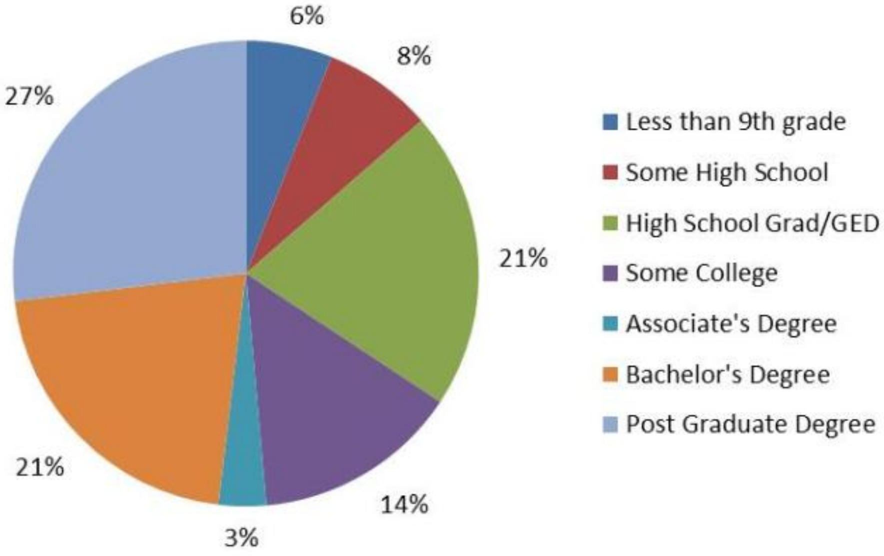
Source: American Community Survey, U.S. Department of Commerce, Census Bureau, 2013

Figure 3.5. Charlottesville City Population by Race



Source: American Community Survey, U.S. Department of Commerce, Census Bureau, 2013

Figure 3.6. Charlottesville City Population by Education



Source: American Community Survey, U.S. Department of Commerce, Census Bureau, 2013

CHAPTER FOUR

Findings

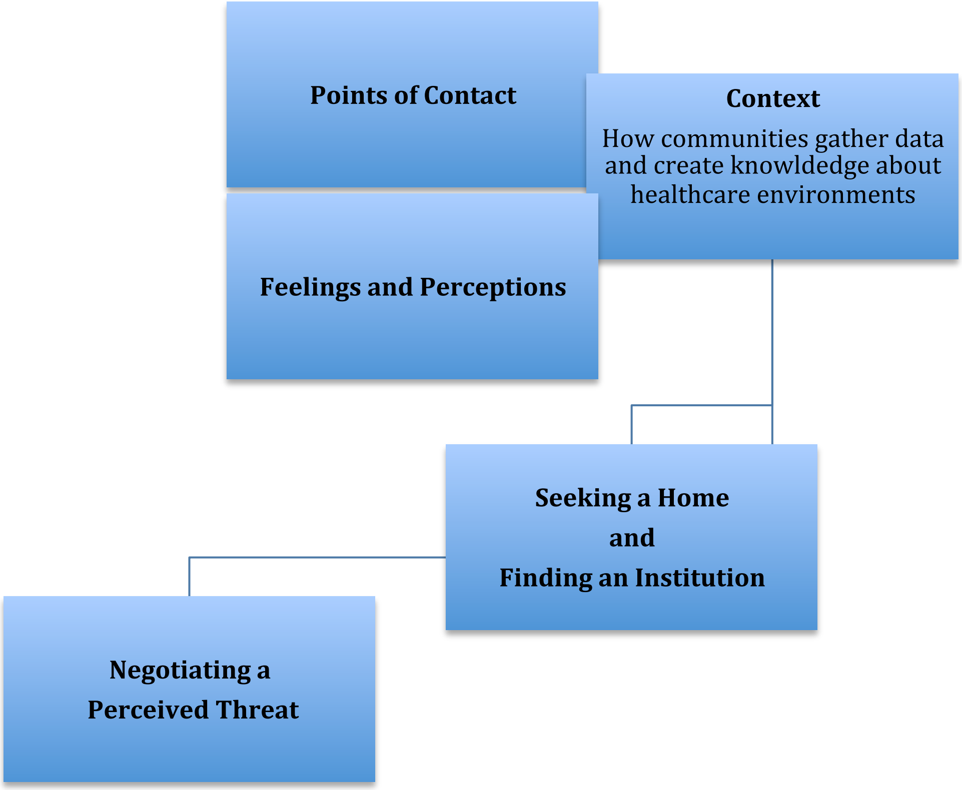
The overarching theme of this study was *seeking a health care home and finding an institution*. The women in the focus groups shared numerous and repeating experiences of the dissonance between what they sought for their care over the course of their pregnancy and what they actually experienced. **Seeking a health care home** became my metaphor for a community that is designed to support the health and safety of its inhabitants. It is an environment with long lasting supports that foster learning, competence, creativity, self-sufficiency and agency. This is a place offering privacy and intimacy shielded from the gaze, judgments, or moralizing of others. The labor required maintaining it, and the rituals and practices necessary to keep it going, are transparent and unambiguous. Based on the findings from the data of this study, the perceptions of a health care home are rooted in feelings of trusting and being respected.

Its antithesis, *finding an institution*, describes the disappointing reality of care that was often experienced by women as impersonal and meeting the needs of the institution versus the woman herself. **Finding an Institution** is my metaphor for a place that either intentionally or unintentionally (e.g. a hospital system) destabilizes the notion of home and homemaking. Because it is deaf to the contextual qualities that signify safety and security for the community, an institution appears to be an impersonal and threatening place that one must navigate strategically to ensure the safety and security of the mother and her infant. It is a hierarchical structure in an environment where one shuffles from local, State, and federal offices to obtain services that expose one to the gaze of program administrators and surveillance on multiple levels. The labor required maintaining it and rituals and practices necessary to keep it going are hidden and ambiguous. Based on the findings, the perceptions of seeking a health care home but instead finding an institution are rooted in the woman's feeling of mistrust and not feeling respected on multiple intersecting levels.

Findings of the study will be organized in the following way: First, this bi-polar theme of *seeking a health care home but instead finding an institution* was experienced across *points of contact* during a woman's pregnancy and delivery. Points of contact are the times and places that a woman interacts with important others in her community and in the health care system over the trajectory of her pregnancy and birth experience. Examining each of these points of contact allowed a deeper investigation of the women's experiences, and these points of contact were embedded within an ecological system that included: the woman's family; the prenatal clinic; the hospital; and the intersection between the University of Virginia health system and the deeper historical context, including a medical school that historically provides health care for women and at the same time is training medical students by providing that health care.

Second, during preliminary analysis of the data, it became apparent that respondents were using a new narrative to discuss a process not represented in the current literature and which was broadly reflected and embedded throughout each ecological system while also reflecting the intersectionality of African-American women's experience of childbirth. I will describe this process of *negotiating threat* that women used to mitigate stressful encounters across the points of contact to ensure the best possible outcomes for themselves and their infants. Finally, I will make links between these findings and women's perspectives on infant mortality.

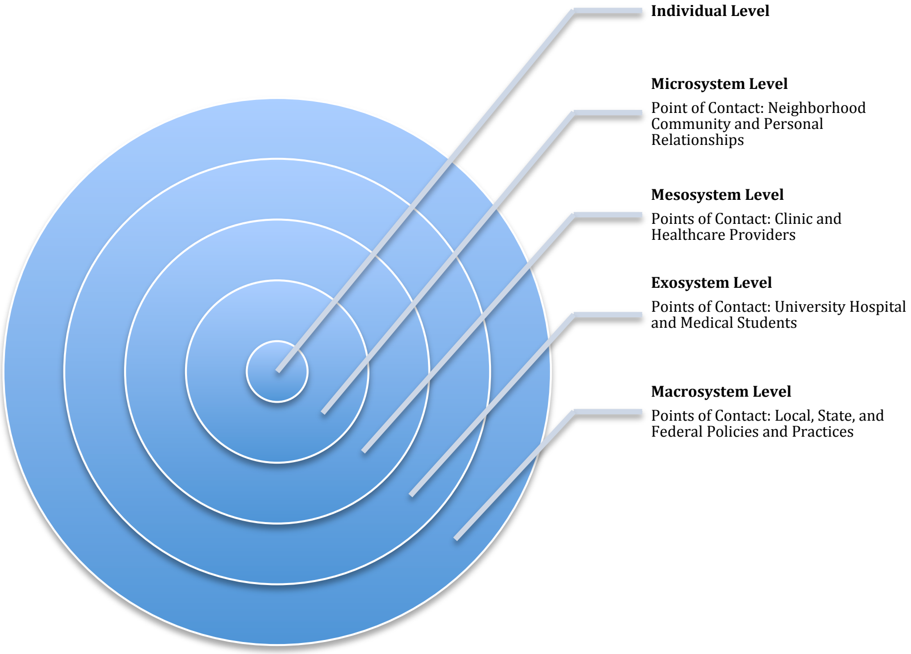
Figure 1.



The Socioecological Framework and Points of Contact

A priori codes, based on the ecological framework, that explored themes central to my research aims included Microsystem, Mesosystem, Exosystem, and Macrosystem level phenomena (see Figure 2). The ecological framework gave a lens from which to view the context of women's lives in order to excavate narratives that are absent from current nursing research. Points of contact that correspond to these nested systems are highlighted in Figure 2 below:

Figure 2.



Women described actors and experiences that were unique to one system (the sonogram is an example), as well as those that interesected multiple systems (medical students is an example).

Microsystem Points of Contact

Multiple perspectives and interactions within the local community culture that reflected seeking a health care home were explored at the Microsystem level. Coding at the Microsystem level explored to whom the focus group participants turned when they first considered that they might be pregnant. These Microsystem points of contact include cousins, friends, sisters, or partners. One participant reported that her niece came to her with health questions, and participants agreed that they would not initially go to their parents if they thought they were pregnant. They would go elsewhere for advice and information to help them navigate the emotional and ethical issues in which they suddenly found themselves immersed when they wondered if they may be pregnant. This was illustrated in this focus group excerpt:

> Participant 1: ***When I found out, I went to my older sister. (laughs). I didn't go to nobody else first. I called my older sister and then after her, I told the baby's father and that's when we discussed it or whatever and that's when we started telling everyone else.***
>
> Participant 2**: *I think at first—my first child, for me I asked my older cousins that already had kids. I asked them how was the experience, was it going to hurt, what's it going to feel like, what am I supposed to do? I did. I was so nervous I didn't know what to do.***
>
> Participant 3: ***I was crying for two weeks.***

Many women stated that they preferred to ask family and friends for information rather than seeking medical help, as illustrated by this exchange:

> Participiant A: ***I feel like you have to really be like—accept the help. If you're not willing and ready to accept that help, then you're just***

> ***going to be lost. You—the baby doesn't come with a guide. But older people--- that's why I try to listen to older females because they've been there and they've done that. ..whatever you have to say to me, you're going to say it but I'm not necessarily going to do it. But I'm going to listen to you. I'm not going to be like "This is my child?" and I'm not going to do that, I feel I like that's very rude and disrespectful where at the end of the day, you could use that guidance.***
>
> Participant B: ***Not only that, that person was trying to help you there.***
>
> Participant C: ***And your child.***
>
> Participant D: ***At the end of the day, you really need the help.***

In stark contrast to the women who sought the advice of more experienced women in her community because ***"the baby doesn't come with a guide,"*** this woman voiced the feeling that she did not perceive a caring home environment that supported her health and safety:

> ***My pregnancy, I did it by myself. I did everything by myself. Everything. Like my mom, she moved away and stuff like that and I have younger siblings. They weren't there for me—they basically wanted me to take care of their kids and stuff like that. I'm basically the person everybody goes to when they need something and stuff like that. So when it's my time, I didn't get that support, I didn't get that. I had to do everything for myself. And when I—when I had him, I***

> ***just felt like I don't know what I'm going to do, I don't know what I'm going to do—like "do I want to do this?" You know, it brought a strain on the relationship that I had with my son's father. And I do it, still, by myself. So, it just depends on who you are and how strong you are because sometimes you get that support and sometimes you don't.***

The Mother of the Pregnant Woman

When the pregnancy was confirmed, it was their mothers to whom the women turned when preparing themselves for their birthing experiences. Exploring the concept of ***seeking a health care home***, it was their mothers whom the pregnant women identified as fostering learning, competence, self-sufficiency and agency. A key task of the pregnant woman identified at the Microsystem level was nurturing cooperative relationships that facilitated benefical outcomes during her developing pregnancy. In additional to emotional support, financial support as well as knowledge deficits regarding her developing pregnancy were adressed by the woman's mother. Although the women mentioned other members of her family, her mother was seen as the central point of contact while she was pregnant:

> ***But, when I went to the doctor, my mom came with me. And I wasn't expecting that. Because she was like "I'll come" and I was like "Why do you have to come?" "Because I want to come." So I think she felt like I was pregnant, and I didn't know I was pregnant. So, she was a***

> ***big—she was there and her dad. But, it was mostly my mother and my sister that were there with me. But they was all… there. She was there when I was delivering my child. And she cried. She was there—she cut her cord, it was like an experience for her…it was like I know I have to take care of this little person. She was a big help, she was telling me what to do, my mother—so it was a lot of help.***

When asked if anyone gave her advice regarding prenatal care, another woman reflected her mother's instructions:

> ***My mom did. Go to your doctor, go to my OB/GYN that I was seeing anyway, and go to my doctor and set an appointment with her. And go to the WIC office.***

The Father of the Baby

In addition to the relationship with her mother, reconnecting with the father of the baby was the other key point of contact on the Microsystem level in nurturing cooperative relationships that facilitated benefical outcomes. After learning that she was pregnant, the next step was ***"And go and find your partner. Yeah (laughs)… go find your partner."*** During their developing pregnancies, particpants recalled how the father of the baby offered emotional as well as financial support. When asked by the facilitator to explore a possible support person to guide her through her pregnancy and birth process, one woman responded:

Facilitator: What about having like a buddy system? Like they may or may not be pregnant, but somebody else that can go through the process with you?

Participant*: **Baby daddy. You call that the baby daddy!***

Another woman described how the pregnancy initiated a home environment with long lasting supports:

> ***My first kid, I wasn't expecting. I was just out of high school. I mean I got lucky, found a great man. Same father, both children. I'm happy with that. Been with the same guy for almost 6 years, been married for 3. We have a great relationship together. I got extremely lucky with what I've got. And I don't mind telling people that.***

The women encouraged their partners' involvement in their clinic appontments:

Participant**: *And it's always good when they include the father in on the conversations and stuff. They care about how they feel and what they're going through—you know, that's important, too, the father's being in on the conversation, too.***

Facilitator: Having a relationship with the father?

Participant: ***To me, that's important. Because they're a part of what's going on inside of you, too …***

The father of her baby's particpation in her clinic visits also served as the intersection between Microsystem and mesosytem points of contact. According to one woman, her partner's participation fostered a connection to her health care provider:

> Participant: ***Um, I, at one of the visits I brought along the baby's father. And I want to say I was maybe 4 or 5 months pregnant at that time. And he met him, and that's when I fostered a relationship with my OB.***
>
> Facilitator: You said he met who?
>
> Participant: ***My OB met my boyfriend . . . That particular visit when we were all together kind of just bonded on a different patient-doctor-friend level. So that was a worthwhile visit for me.***

The father's involvement had two outcomes, either the potential to be a stressor or he could decrease stress levels during encounters with heath care providers. This woman explained a situation where the father attempted to down-regulate her stress:

> ***It was like this big muscular student doctor and he was ready to give me my Pap smear and he's like "Get comfortable" and I'm like, get comfortable? I don't want you down there! I don't want you nowhere near me! And like my baby's father's looking at me like "Are you really going off on these people like that" and I'm like "Yes!"***

The father of the baby could also contribute the woman's stress, as this participant relates announcing the news that she is pregnant:

> ***My fiancé was in the car, so I held it together. I mean we've been together 6 years, so it's been a long time, anyway. And I went outside and held it together and as soon as I got by the car door I was like "I'm pregnant!" He was like "Mhmm." And I was like "What do you mean, Mhmm? Do you not know how it happened?" He was like "Mhmm" And then he's like "Just calm down, everything's fine." So I was just like "Really?" and he's like "It's okay, but the first step is you need to take me to the liquor store when we're done.***

Another woman explained the anxiety she felt regarding the risk that her partner may expose her to sexually transmitted infections during her pregnancy:

> ***I was glad… every time I got a checkup, especially when I needed to get an STD one. I loved my partner, but at the same time, every time everything was negative—I was happy.***

When the father of the baby was not involved, there was the potential of delaying the women's entry into care, as demonstrated in this focus group response:

> ***People don't go because they don't want to go, or because they don't know who father is. It's embarrassing because they may ask about the father and the woman is a single mom or doesn't know who the father is. Or because the dad doesn't want to go, so the woman looks like a single mom.***

An ecological framework revealed the voices of women who are looking for connections with people they trust and respect. The pregnancy became an opportunty to strenghten ties to their mothers, partners, and extended families. These points of connections on the Microsystem level fostered learning, competence, and agency as the women sought the safety and security of a home for themselves and their children. Here is how one focus group described their pregnancy experiences:

> Participant A: ***God knows who He's going to have pregnant—there's females out there that try to get pregnant and can't get pregnant for nothing. It's when you stop trying all that, that's when God say's "Oh, there you go!" (laughs).***
>
> Participant B: ***And this is going to be a learning experience. I don't think anybody should be disappointed in life. It's a blessing. If people look down on you, you got the right to look down on them because they're judging you. And you're more, you're out of high school—you already started your career. That's a process you and your child can walk through together. You know? And by having your child, that will give you more determination to do what you got to do. To go to*** [medical school] ***be that doctor. So if those people want to look down on you, they're dumb then. They're dumb then. I'm saying a child is a blessing and it's up to you only. How you treat your child and how you structure your life after you have that child. Don't be one of those that has a kid—you still have goals and you continue making those goals for yourself. Don't give up because the***

> ***baby's here. That's not what it's about. There's a lot of people do give up because they think it's so hard. It's really not hard. It's as hard as you make it.***

In the lived experience of this woman, pregnancy became the catalyst for creating a community of trust and respect that supports not only the health and safety of mothers and infants, but also empowers her agency and self-sufficiency. She voices seeking a home-like environment with long lasting support throughout her life span.

This focus group exchange was an opportunity to view a point of contact when women felt their experience of safety was challenged. There was a perception that the women's wishes to have their trusted family members support them during birth were not respected by her health care providers, as these women described:

> Participant A: ***I actually had to say something—because they told us, you can't have more than 2 family members in there. And they have like a crew of students—the room is so crowded and the actual RN is sitting on the sink. …It's entirely too crowded. I felt that they*** [the medical students] ***needed to leave. And I let it be known that I feel like they need to leave. And someone more experienced, like the RN sitting and looking, should've came and did that. I don't like that.***
>
> Facilitator: So what did you think about that?

> Participant B: ***Like, if they have that many students in there, they can have that many family in there.***

Women described the rules for who could attend the birth to support them as inequitable with the open ended attendance of health care professionals:

> Facilitator: You did say you had your child at UVA. How many people did they allow?
>
> Participant A: ***It changes a lot-- I think it's only like two. But of course like—***
>
> Facilitator: Did that include the dad?
>
> Participant A: ***Yeah the dad is included— and another. So you can have like the baby's father and your mother.***
>
> Participant B: ***But I had my moms, sisters, brothers, cousins.***
>
> Participant C: ***That's really irritating to me because I really want—of course the dad. But I wanted my mom definitely and his mom to be in there.***

Family members, who provided comfort and a sense of safety and security to the women, were limited or restricted during the birth process. The home that the women were seeking to create was threatened by rules imposed by the institution. The visitation rules that were established to protect patients, actually had a paradoxical effect as the women voiced feeling less safe, and that their wishes were not respected.

Mesosystem Level Points of Contact

The Mesosystem level is nuanced by occupying the intersection of the concepts of *seeking a health care home* and its antithesis, *finding an institution*.

The Mesosystem level points of contact were coded at the points where the women accessed care from their providers, generally at a University of Virginia affiliated clinic. Participants had positive attitudes towards health care in general and felt that accessing care during pregnancy was important to ensure the health of both the mother and baby:

> ***I think it's important to find out how you, not only you, but how your child is doing while you're carrying the child. It's important to find out if—because they can come out with anything being wrong with them so it's important for you to go to all of your doctor's appointments. You could be sick and not know it. And when your child is born, your child has the same thing. And you didn't know you had*** [it]***. So it's very important to us all.***

Participants also reported that they knew people who attended appointments only three times during their pregnancy: to date the pregnancy and ascertain the estimated delivery date; to obtain a sonogram and learn the sex of the fetus; and for the delivery of the infant:

> ***My last child, I went to the doctor twice. Once to find out what I was having and the second time I was in labor. I was just stuck on "I'm not going to no doctor." I just didn't want to go.***

When the women perceived the staff as providing an environment of trust and respect, they reported they were more likely to utilize the health care resources available to them; conversely, judgmental or threatening staff attitudes discouraged repeat appointments. Here is how the women talked about their experience:

> Facilitator: Do you feel that relationship affects your prenatal care?
>
> Participant 1**: *For me, I'm all about vibes and how I feed off of people. And so if I don't feel like I have a good relationship with people or at least a cordial relationship with someone, I won't be as open or as honest if I don't feel safe sharing some information with you. Because I don't do that, if something happens, you know. So I try to be, you know, respectful so I can get their respect back because I didn't want anything to happen with him or any of my information to be shared. Like, "Let me tell you about this patient who you know did X, Y, or Z."***
>
> Participant 2*:* ***Like why go to UVA. Like they're messy at UVA. Know it or not, I've never had a personal issue, but I know people that have. And it's not even the doctors that are sharing your information. Of course they may talk about something small against their colleagues. I know people that check out people in*** [the waiting room]***, "You girl are seeing Miss X. (pseudonym) up here, she got so and so," you know, it's not cool at all. It's not even the doctors, it's the people that are around that…***
>
> Participant 3*:* ***So true.***

Health Care Provider Respect

Women who reported having a positive personal relationship with their health care provider described their clinic experience favorably. Participants highly valued warm, friendly interactions and a personal touch during their visits. One woman who had a particularly long-term relationship with her provider underscored this theme:

> ***…I can talk to her about anything and it goes all the way down to how's your family doing at my doctor's appointment. And we see each other now, yearly because of yearly checkups because I ain't carrying no more babies. So yeah, that's one of the main questions she'll ask me. Because we have this bond. Because I was 17 then and I'm 34 now, so I've been going to see her since then.***

Another woman emphasized the importance she placed on a personal relationship with her providers:

> ***I guess like some of them do act like they're concerned. You know, where they have the individuality relationship with the patient. And not like everybody—like sometimes you go in there like they don't remember your name, they can't remember the last time they've really seen you. Though I don't really want you for my doctor if you don't have a personal relationship with me. You just dealing with me and everybody else. So no, I will change my doctor. You got to have a personal relationship with me because I'm not going to have the same issues as the next patient. So you know, individuality, you***

> ***don't know who I am really. I'm just a medical record number to you, that's basically it.***

A consistent health care provider who knows their patient's name was seen as a significant mark of respect for the women in this focus group, as well:

> Participant A: ***Like when I come in, you should know me by my first name. No matter that you have 3,000 women that you're seeing. You should know me by my first name. When you look at my chart, you should have a general idea of what's going on with me and my pregnancy. You should know who I am before I walk in the room. I mean you don't have to know my favorite color (laughs), but you should know that this is my first child, you shouldn't ask me that when you come in the room and I'm 7 months pregnant. "Is this your first one?" Uh, you should know that.***
>
> Participant B: ***They ask you that like ten times.***
>
> Participant C: ***That happened to me often. Like, "Is this your first one?" and I felt like I was saying the same thing every visit, this is my first one, yes I don't know what to expect, yes I'm new to this.***
>
> Participant D: ***And that's what happens when you have a different person every time, I hate that. I hate that.***

Participant A: ***Yeah you should just know who I am, as your patient, I guess.***

How the community perceives their nursing care. The role that nurses played was most conspicuous in its absence, but focus group comments regarding nursing care were nuanced by geography. Not all encounters with nurses were perceived as negative, and women who received nursing care at a facility that was not affiliated with the University of Virginia Medical Center reported more positive interactions with their nurse. One focus group participant explained,

> "***With any nurse that I saw, …, that happened to check me, they were very polite, very courteous. If I had any questions or concerns, they could answer them. If not, they could direct them to someone who did. So my experience with that has been pretty positive.***"

How a community constructs their perceptions of disengaged care by a nurse. The nurses' care of the community is troubled by historical contextual factors that barred African-Americans, who served as herbal healers and nurses within their homes, from professional registered nurse education programs. This resulted in very few Registered Nurses of color working in the community and this under-representation persists to the present day in a health care system where women are seeking a health care home. It was the *absense* of nursing care that was salient in the focus group discussion. When the nurse was occasionaly mentioned as the point of contact at a Univeristy of Virginia affiliated clinic, some of the focus groups reported that their nurses were quick to offer advice before being fully present in listening to the women's assessment of her condition. One woman stated, ***"I felt that I was almost speaking on deaf ears, to put it lightly."*** Although focus group participants in Louisa and Nelson counties reported positive clinic visit encounters with their nurses, this negative perception was representative of Charlottesville focus group participants analyzed for this study. When asked to provide an example, this woman explained an encounter with her nurse that was articulated as a perception of *disengaged care*:

> Participant: ***Yeah it was pretty bad.***
>
> Facilitator: So when you were there, the nurse just—she didn't necessarily make you feel at ease or more comfortable?
>
> Participant: ***No, I don't feel that as a pregnant woman, I should have to walk into an establishment, and be told that what I'm feeling is possibly not there or is not correct or that maybe I'm crazy. I don't that I feel like I should have anyone tell me that. Yes, we are pregnant, we are at a very sensitive moment, not only because are we sensitive physically but also sensitive emotionally. We have enough problems, as it is, with changing bodies and cravings and random stuff that drives you insane. We have enough issues with all of this. God knows I loved being pregnant, both times, until I hit about 8 months, then I just felt like a whale and I was ready for it to be over with. And that's when you get to the point where you hate it. And I don't feel like when we go somewhere and we ask for help, we***

> ***should be told that we're wrong. I feel that someone should listen because you never know what the person's trying to tell you and you're not taking the time to listen for is—actually a serious problem. I had 2 more episodes that occurred before I was taken seriously on my blood sugar.***

This is how a woman described her converstion with her nurse regarding her challenge to quit smoking:

> ***There are some choices that we make, pregnant or not pregnant. Many of those things affect our well-being. Before getting pregnant with both of my children, I was a smoker. I don't smoke now, but quit. But that's another thing. Why? Why should I have to walk into a doctor's office and have someone look at me and give me this, "you're disgusting" look because you smoke? Look. It took me about till 3 months with both of my children to be able to quit smoking.***

Participants perceived nursing care that lacked compassion, and was not only disengaged but also re-traumatizing at each clinic visit:

> ***…I felt ashamed. And I know that may sound weird in a way, but some reason the way that people handle pregnancy with younger mothers and all of this stuff. I felt like I had made a choice in my life that made me look like, excuse my French on this one, a whore. I really did and I actually had people that made me feel that way. . . My***

> ***cousin had a baby at 15… She said that they always made her feel bad about herself and the choices she made in her life. And she didn't like it very much. I know that much.***

How a community constructs their perceptions of care provided by a medical student. As stated earlier in this paper, PNC is not a singel intervention, but a series of assessments and interventions over time that are applied in a variety of healtcare settings. Medical students emerged from the focus group data in two distinct settings, on both the Mesosytem and Exosystem levels. Medical students became a tinderbox for the women that ignited the historical context of a marginalized past to their present encounter with the health care system. The women's perception of the medical students intersected multiple system levels and points of contact. Care by a medical student was perceived as a trifecta in disengaged care performed by an actor at the nadir of their experience, confidence, and knowledge. In addition to a sign of respect demonstrated by a medical student acknowledging the women as individuals and knowing their names, respect for the women's time and effort in accessing the clinic visit was important to the women as demonstrated in this exchange:

> Participant 1: ***Sometimes, they have like students come in…And I just tell them quick, "I don't want you to touch me". Because I had a student doctor come in and she was "I can't hear a heartbeat!" And I'm like I carried my baby low, so I'm trying to tell her…I don't want them on me.***

> Participant 2*: **And yeah! I don't want, I don't care if y'all are in here, but I don't want y'all touching me. And that just takes the doctor longer to come in here. It's like I'm sitting there and I'm sitting there…***

In addition to the medical student's lack of experience, the majority of the women resported having to answer questions repeatedly for medical students, and then being asked the same questions by a physician, as these women explained:

> Participant 1: ***If my doctor is coming to see me, why do you send a student in? I understand, the student is getting, they need to do their job as well, but come in with the doctor, and you can even ask the questions my doctor asks me, but why do I have to go through it twice?***
>
> Participant 2: ***Yes. Then what is up with the notepads that they be having? Like I don't understand. They take my information and just like put it all in some notes or something then they go in and log into the computer.***
>
> Participant 3: ***I feel like they go and tell my doctor what's going on with me and then they come in and talk about the same thing—my doctor asks me the same exact questions over—and I feel like they just asked that question.***
>
> Participant 4: ***Yeah, like that's because that's how it is. They'll come in with their notepad and write everything down. Then they***

> ***leave back out. Then thedoctor comes in here with them, and like, they'll just be going over the notes that I just told the person what I was going through.***

When asked about prenatal visits, every focus group participant at every location voiced a universal complaint similar to this participant's comment:

> Facilitator: How about any experience you had in prenatal care with medical students? Did you ever have any medical students?
>
> Participant: ***I hate medical students. I'm not going to say I hate them, but they, me and medical students don't get along.***

A theme that fueled participants' universal dislike of medical students was the perception that care by students prolonged their clinic wait times. This theme is evident in this focus group exchange:

> Facilitator: So what kinds of other things do you think the doctors and the nurses could do better as far as pre-natal care?
>
> Participant 1***: The waiting. Um gosh. The waiting part actually gets you worked up. Frustrated. And that's the worst part of your doctor's appointment for me.***
>
> Participant 2: ***That's all doctor's appointments, not just the OB/GYN. In general, that's just all doctors' appointments.***
>
> Participant 3: ***Yeah that would be for me, the waiting.***
>
> Participant 2: ***It's starting to get a little quicker every time I go.***
>
> Participant 3: ***I went at 10 and I didn't get seen till like 11:30.***

Participant 1: ***But it's when they put you in the room. You sitting and you sitting and you sitting and you sitting. At least in the waiting room you can carry on a conversation but when you're sitting in the room, all you can do is watch the clock like dang…***

Participant 4: ***And those rooms have like no service.***

Participant 1: ***And they come in and then they go right back out for another 15-20 minutes.***

Participant 3: ***That's why I feel like some of the doctor's appointments are about—is sitting there waiting. Just sitting there.***

Facilitator: What about during your actual visit? So when the doctor finally comes, what kinds of things could they do better to make you feel more comfortable?

Participant 1: ***I feel like when they come in there, they should already have everything they need for you. If you're coming in there to like to see me, why do you have to leave and then come back in. I don't understand it. It's like irritating to me.***

Participant 3: ***Or if my doctor is coming to see me, why do you send a student in. I understand, the student is getting, they need to do their job as well, but come in with the doctor, and you can even ask the questions my doctor asks me, but why do I have to go through it twice?***

Participant 4: ***Yes. Then what is up with the notepads that they be having? Like I don't understand. They take my information and just like put it all in some notes or something then they go in and log into the computer.***

Participant 1: I feel like they go and tell my doctor what's going on with me and then they come in and talk about the same thing—my doctor asks me the same exact questions over—and I feel like they just asked that question.

Facilitator: Are there others of you that experienced that? Like asking the same question over and over?

Participant 5: ***Yeah, like that's because that's how it is. They'll come in with their notepad and write everything down. Then they leave back out. Then the doctor comes in here with them, and like, they'll just be going over the notes that I just told the person what I was going through. I'll be like, "If I walk out, how would y'all feel?" That's how I feel, if I just walk out, I need this appointment for next month. Because that's what they tell you anyway, come 3-4 weeks from here. So I can just go to the front desk and be like, "Can I get an appointment 3-4 weeks from here?" Like I'm done with them, I dismiss them. That's how I be feeling sometimes.***

When the focus group participant states, "***Like I'm done with them, I dismiss them,"*** this can result in women choosing to discontinue their prenatal care. This woman explains:

> ***I went to the hospital like twice. One time to find out what I was having and then as soon as I was in labor. I didn't have no pre-natal care with that one. It was number five, I was like I know what I'm doing by now. He was the biggest baby I had out of all five of them. Did something right.***

The most salient example at the Mesosystem level of the incongruence of a woman who is seeking a health care home and instead finds an instituion was revealed in the voice of this woman when she spoke about the trust she placed in an experienced care provided:

> ***I think the tactfulness in the medical field is gone out the window now. Not that every doctor has had that like good bedside manner. But some kind of consideration that this person is not like just a patient. Even just like regular going to the doctor if something's going on. It's very cold. Like some people that do have bedside manner—they're like 40*** *[years old]*. ***They're like way older because they've been doing it. And now they just like looking at you like "this is my science experiment, let me see what experience I can get out of it." I don't really like that, I like somebody else. But it's just out the***

window now. It's like okay, this is what's going on—we going through the motions.

The wholesale repudiation of medical students has been framed by the community's perceptions of institutional interventions performed by the least skillful actors that pose the threat of causing fatal consequences as the lens to view a tangled web of pathologies that have contributed to racial disparities in Charlottesville. Perceptions of inequalities were subsumed under the notion *medical students* by these women. The women voiced being fed-up with generations of marginalization that connected their past to the present as well as connecting the present to their past. This perception of the medical students as a perceived threat was voiced, and this theme was revisited by the women in all focus group locations during multiple points of contact within the health care system. This notion will be explored in more depth in Chapter 5.

Health Care Provider Trust

The experience level of the health care provider was an important element in gaining the women's trust, as these women explained what they considered important during a clinic visit:

Participant 1: ***Ask you a lot of questions. And ask a lot of questions. Don't want no teachers, no learners, no students, no—I want the oldest doctor here with the wrinkliest hands, you know?***

Participant 2: ***Old, or you want nobody's student.***

Participant 3: ***They can sit, but no hands on, no hands on please.***

Participant 2: ***Don't let them go inside you. That's what they tell me.***

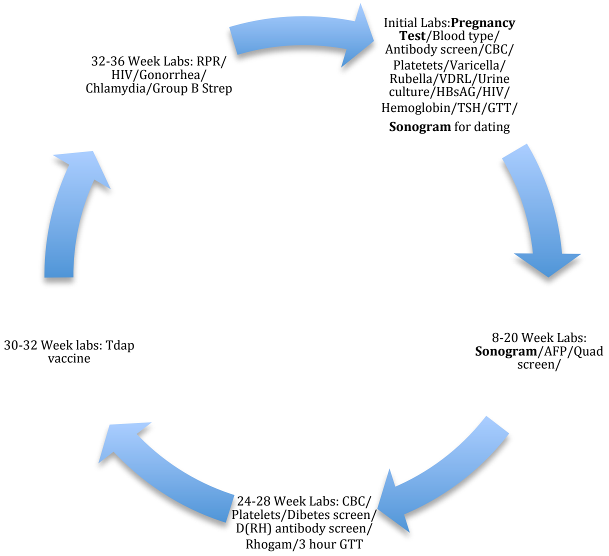
Participant 1: ***They just take vitals and all of that. But as far as you telling me about—you ain't telling me—you got a little white coat, you ain't got no long white coat.***

A physician's longer white lab coat was seen as a mark of trust, as compared to the shorter white coats worn by medical students.

Disparate Perceptions of Meaningful Prenatal Encounters

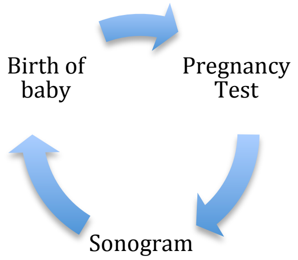
Maternity care is not a single intervention, but a series of assessments and interventions over time that are applied by multiple healthcare practitioners in a variety of settings, and access to resources, as well as the quality of those resources, may vary. During the course of her pregnancy, a woman has several standardized points in which she has contact with the health care system for routine procedures (see Figure 3).

Figure 3. Meaningful Encounter for Health Care Providers.



Women reported that they knew people who attended appointments only three times during their pregnancy: to find out how many months along they were; to obtain a sonogram; and for the delivery when labor began (see Figure 4).

Figure 4. Meaningful Prenatal Clinic Encounters Women in the Study



Despite ACOG standards (of an initial office visit at 8-10 weeks of pregnancy; followed by visits every 4 weeks for first 28 weeks; then every 2 – 3 weeks until 36 weeks gestation; and finally a visit every week after 36 weeks gestation until birth), many women endorsed that three encounters were the only valuable experiences during their pregnancy trajectory: an initial pregnancy test, a sonogram, and the birth of the baby. The sonogram, in particular was of high significance to the women. It determined the baby's sex and allowed women to concretely see and tract the size and health of their baby. Here is an example that underscores the significance of sonograms:

> ***The only thing I liked was the ultrasound. Because I was just like—I want to know what I'm having. And he's like hold on, you know, we're not checking for all that yet. Like everytime I went, I wanted to***

> ***see what I was having. And they'll be like you know, we can't find that yet, you got to wait. But I was like I want to know (laughs).***

The discussion continued with other women recalling their sonogram experiences:

> Participant A: ***I look forward to—not like the pre-natal appointments, but when I know I have an ultrasound. I know I'm there early, I'm ready to see my baby.***
>
> Participant B: ***I asked for an ultrasound.***
>
> Facilitator: So what kinds of other things make you excited to go, or what do you enjoy about pre-natal visits?
>
> Participant C: ***When they tell me what I'm having.***
>
> Participant D: ***They tell me about the baby's heartbeat.***
>
> Participant A: ***The heartbeat, yeah, yeah. To know around about how big my baby's going to be.***
>
> Participant D: ***I just like going when it has something to do with my baby. Like that's when I think I'm more up and more ready. But if I know it's just me having to go to the 3rd floor and seeing the OB/GYN, I'll be like man, I don't want to go up here. But when I have to go to that 1st floor, the pre-natal care*** [sonogram unit] ***or something like that, I have him up like we have to go, we have to go.***
>
> Participant B**: *Yeah like show up 30 minutes early, be like 45 minutes or an hour early.***

Participant A: ***I'll come an hour early I ain't going to lie.***

When the interview moved to suggested interventions to facilitate access, these women only saw value in a home visiting program if the visit included a sonogram:

Facilitator: What do you guys think about like home visits from the doctors or nurses?

Participant: ***They could come to my house and bring the ultrasound thing, that would be okay.***

Participant: ***They have to come with the machine.***

Participant: ***If they're not coming with the machine, why are they coming?***

Exosystem Points of Contact

The women's exploration of their lived experience of childbirth that touched on the role of the University of Virginia (UVA) Medical Center, or the medical students nested within the that system, were coded at the Exosytem level. This study acknowledged and examined each point of contact to understand how the community narrative that emerges from each health care encounter at the Exosystem level is being shaped. Actors at this level should pay attention to how they are perceived by the community because without this knowledge about their interactions on the Exosytem level they may unwittingly contribute to destabilizing the health care home that the women are seeking.

The dissonance between a home and an institution was articulated in these interactions:

> Participant: ***Because like women, are not saying we're here to do that, but we're here to procreate. So there are always going to be babies popping up. So why are you making it so expensive, $400 for a sonogram, $1000 to push the baby's head out? Like really? We're going to keep popping these babies out so why make us pay so much money?***
>
> Participant: ***Exactly! Like having a baby is free. You can do that at home, really. Like why are you making it so much more expensive just to go to an institution. Like I don't understand they got fees and this and that but… they pushed the baby out, cut the umbilical cord and you're good.***

In contrast to the women's perceptions of birth as simple and natural, every intervention was viewed as potentially threatening as this woman explains:

> ***I felt like sometimes, some of the things that the doctors say—they can scare you into not wanting your baby and stuff like that. Like my son had an extra heartbeat. And he could've come out with Down's Syndrome or something like that. So they wanted to all these tests and stuff, and he was not going to—I felt like if you get that one test that they always want you to have when they hear that extra heartbeat, they're going to kill your baby. And I didn't let them do it. I***

> ***said, "Well if he comes out, I'll just leave him at the hospital" because… I didn't want to have, I didn't want to have to deal with all of that. But then, you know, when I had him, he did have complications coming out, because the cord was wrapped around his neck. And lo and behold, he's 7 pounds and 9 ounces, but I didn't do all the things the doctors told me to do, because I felt like—they tell each person different things. Like, my friend and I got the same—she went and got the shot in her belly button and it killed her child. And I felt like they tell you that's the risk, but they don't tell you how much of a risk that is. So, I avoided all of that because I feel like sometimes these people do try to kill your baby. They don't tell you that, but I feel that that's what they're doing. Because there's a lot of people, who get all those extra exams done knowing that that's a risk, but doctors don't tell them how much of a risk it is. You know, they carry their babies that far along, and then you just—you killed my child, period. Point blank. So I don't feel like the doctors' support is always as good as they make it seem.***

When women entered the hospital to deliver a baby, the themes of trust and respect were revealed at a heightened level of vigilance. The hospital was seen an an environment that harbored many threats to the women's safety, as this woman explains:

> Participant**: *My doctor was the worst. Because you're only supposed to have one person check you to dilate, I had 2-3 different doctors check me. One doctor would say I'm all the way dilated, another would say I wasn't. One would say that you know, you're almost there… but at the same time I didn't have no medicine, tell me to rock it out… Oh no, oh no. The cord was around my baby's neck and so, you know they're telling me to push, because one person is saying I'm fully dilated and the more I push, the more his heart rate starts dropping… when I was in there, I felt like they was trying to kill me. That's what I told them. And I won't have another child. I won't. Mmm-mmm.***
>
> Facilitator: So you feel like they were giving you misinformation?
>
> Participant: ***Yeah they were! Because they, they already tell you for one, my stuff is wide open. You're not supposed to have different peoples' fingers up in there. That leaves infection and more stuff. Except it matters! Because it's open and all that blood and stuff. You're telling me to push. It doesn't matter, pushing that stuff back into me. The stuff that's coming out, you're pushing back in there. No. Mmm-mm, I don't ever want to do that again.***

As noted previously, PNC is a series of assessments and interventions over time that are applied in a variety of settings, and so theme of Medical Students emerged from the focus group data on both the Mesosytem level and Exosystem levels. These women once again adressed the students' lack of experience:

> Participant A: ***All of them doctors are in there for a reason. You're not going to have one doctor that's going to know how to do everything by themselves.***
>
> Participant B: ***Yeah but they were students! Students.***
>
> Participant A: ***Yeah but they know what they're doing, they've been in school for a reason.***
>
> Participant B: ***I asked them … and you know what she told me? She told me two months.***
>
> Participant C: ***I feel like I still know more than you.***
>
> Participant B: ***You've been going to school for two months! I've been pregnant for nine months. I need you to leave.***

Family members, who provided comfort and a sense of safety and security to the women were limited or restricted during the birth process. Medical students, who were seen as an annoyance and a threat due to their lack of experience, were given unrestricted access to their birthing process. Adding to the feeling that the woman's safety was subordinate to the students' education, was the feeling that the woman's profound knowledge about her own body was not respected. Again, the concept of disengaged care (first articulated in the clinic setting) is heard emerging at the hospital point of contact. Advice regarding frightening surgical and invasive proceedures was offered by health care providers that the women did not always trust with the added perceptions and feelings that the women were not fully listened to, as these women explain:

> Participant: ***They kept pushing for a C-section for mine because of my disability and they were expecting my daughter to be like 2 pounds when she was born. She was actually 8 pounds, 14 ounces. I was like 118 pounds when I delivered her and the comment that the doctor made after she made the delivery, she was like lying ... And the entire time she was pushing for a c-section and I was actually able to push her out. I think some doctors, they do know what they're talking about. But nobody knows their body better than the woman...***
>
> Participant: ***My doctor didn't listen. .... They gave me an epidural, it didn't work…some doctors think they know it but they don't know your body better than anyone else. No matter what degree you got, you know?***

An examination of the women's perceptions of care at all points of contact within the Exosytem level revealed that instead of the personal connections of a *health care home* that they were seeking, the women were *finding an institution*. Women described the disappointing reality of care that was often experienced by women at the UVA Medical Center as impersonal and meeting the needs of the institution, including the training of its students versus the physical, emotional, and social needs of the woman herself.

Macrosystem Level Points of Contact

The points of contact coded within the macrosystem level included interactions with local, State, and federal agencies as well as the policies that govern these agencies. An interrogation of the data at the macrosytem level informed the understanding of the extent that individual and institutional difficulties faced by the women are rooted in a larger historical, social, and political context.

Points of Contact at Local Agencies

Rather than seeking care from a clinic or hospital, some women reported turning to counselors, social workers, or pastors at local agencies because they have good relationships with them. Here is how one woman explained her pregnancy support network:

> ***I was told to go get Medicaid, and go check and sign up for WIC so I could get the proper nutrients or whatever. Then once I went through all that, they started telling me, the WIC people started telling me, the CHIP [Child Health Improvement Program] people, you know it was coming, it's coming, and you know they were just giving me like the heads-up on things.***

Some participants had a higher opinion of their home visitation health workers than they did their prenatal health care providers due to their friendly, ongoing relationships with their caseworkers as well as their offering of support that was tangible and meaningful to the women.

Points of Contact at Federal Agencies

The decision to seek care services is a complex intersection of many structural and psychosocial factors. For some women, improving pregnancy outcomes requires the removal of structural barriers to access to care, such as shuffling from office to office in order to obtain services that exposes the woman to lack of respect at multiple points of contact. The data illuminated that efforts to improve maternal and child health for under-resourced women cannot end once patients enter the examination room or the hospital. The dissonance between what the women sought for their care and what they actually experienced was shown in these women's comments:

> Participant: ***People say that "You have Medicaid," or "You have food stamps"—if I work and I pay taxes, no matter if it's little or big, we all pay taxes, we all take care of each other.***
>
> *Participant:* ***Whether you got Medicaid or not, you got poor people paying money. And I think they should make it a little easier for all patients whether it's here or across the world. Because it's bad enough that you have to pay to be honest.***

Another woman articulated a common theme that there are two tiers of health care, and Medicaid recipients are relegated to an inferior level of care. ***"I really didn't want to have a birth in a bed; I wanted a water birth,"*** one woman explained, ***"but Medicaid doesn't pay for that. And I know I don't***

have the money to pay for that." Here is how another woman described her perception of obtaining Medicaid during her pregnancy:

> ***And even dealing with Medicaid itself is a job ... So dealing with that department is like… they're doing you a favor, that's how they treat you. So you don't want to go there, you don't want to deal with them, but what other option do you have? So you're forced to deal with the attitude, the slow service, the whole horrible customer service, but you're not asking for this. This is something like, you know, I need this. And you, in hindsight it's like if I didn't have to deal with you, I would've tried to find a way to pay for this all out of pocket. Because trying to go through the health system … they're like, this is my job, and you're not a patient, you're just another number, here you go.***

Once Medicaid coverage was obtained, this woman described her experience in the emergency room:

> ***Because when I went to the doctor with my cousin, for her and myself—we both have Medicaid. And honestly, I do feel like because we have Medicaid, they're kind of poor with their service when they're dealing with people on Medicaid. Like you're sitting in the ER, waiting to be checked in, especially if it's a true emergency whether it's with your kid or yourself or whomever. Especially when they're sitting and looking at you like yeah, whatever, go on out of here. Because I was looking at my cousin, she was pregnant with twins.***

> ***And they were sitting here like, like literally rushed her out of there. And I told my cousin, I said they do the exact same damn thing to me sometimes. They like, I really feel like they don't care if you have Medicaid. Like, you know what I'm saying? They look at you like you're not really paying for it, such and such is paying for it. You know I'm saying? I don't feel like they really do care if you're paying through Medicaid.***

In summary, viewing data from a socioecological perspective allows us to clearly see the complexity of interrelated factors across systems and their points of contact that have influence on a woman's process of seeking a health care home within the context of her prenatal care.

Negotiating a Perceived Threat

Chapter 2 of this dissertation assembled and framed the resources attempting to address the crisis of racial disparity in healthcare. Despite these resources, the IMR rate in the African-American communities in Charlottesville continues to disappoint maternal/child health advocates. Are we learning what we need to learn from the time, effort, and money spent investigating this crisis? If the studies are not sound, we have nothing to base decisions regarding direct patient care as well as decisions guiding health care policy. As a maternal/child healthcare provider, it is my ethical obligation and duty to find a method that leads to interventions in the current systems that are more effective and successful in reducing the racial disparities and infant mortality. As a point of departure for an evolution out of this crisis, my research question asked African-American women living in neighborhoods with high infant mortality to voice “What was your lived experience of pregnancy?” A new narrative was embedded in the answer to this question, as the participants described a process not represented in the current literature and which was reflected throughout each ecological system level as the women voiced their reflections of their experience of childbirth. A bi-polar theme of *seeking a health care home but instead finding an institution* was experienced across *points of contact* during a woman’s pregnancy and delivery.

Microsystem Level Threats

There was a perception that the women’s desire for the safety and security, represented by her trusted family members, was not respected by the healthcare providers. Women described the rules for who could attend the birth to support them as inequitable with the open ended attendance of health care professionals:

> Facilitator: You did say you had your child at UVA. How many people did they allow?
>
> Participant A: ***It changes a lot-- I think it’s only like two. But of course like—***
>
> Facilitator: Did that include the dad?
>
> Participant A: ***Yeah the dad is included— and another. So you can have like the baby’s father and your mother.***
>
> Participant B: ***But I had my moms, sisters, brothers, cousins.***

> Participant C: ***That's really irritating to me because I really want—of course the dad. But I wanted my mom definitely and his mom to be in there.***

Mesosystem Level Threats

During the initial few minutes of each focus group session, the participants expressed positive attitudes towards health care in general, such as **"…*it's important for you to go to all your doctor's appointments. You could be sick and not know it*.**" As the participants told their stories, it emerged that either someone they knew, or they themselves reported a theme similar to this woman's experience: **"*My last child, I went to the doctor twice. Once to find out what I was having and the second time I was in labor. I was just stuck on 'I'm not going to no doctor. I just didn't want to go."***

When invited to elaborate on this theme, women identified clinic visits as not respectful of her time and effort, a perception of disrespect demonstrated by students-in-training providing her medical, and a threat of losing wages or employment due to extended waiting times in the clinic. This woman stated:

> ***If my doctor is coming to see me, why do you send a student in? I understand, the student is getting, they need to do their job as well, but come in with the doctor, and you can even ask the questions my doctor asks me, but why do I have to go through it twice? But I don't want y'all*** [medical students] ***touching me. And that just takes the doctor longer to come in here. It's like I'm sitting there and I'm sitting there…***

Exosystem Level Threats

Examining each of these points of contact allowed a deeper investigation of the women's experiences, and these points of contact were embedded within an ecological system at an intersection between the University of Virginia health system and the deeper historical context, including a medical school that historically provides health care for women and at the same time is training medical students by providing that health care. This woman's perception of childbirth was explained as "***Like having a baby is free. You can do that at home, really.***" In sharp contrast, every intervention was viewed as potentially threatening, as this women told us: ***I felt like if you get that one test that they always want you to have when they hear that extra heartbeat, they're going to kill your baby. … I didn't do all the things the doctors told me to do, because I felt like—they tell each person different things. … And I felt like they tell you that's the risk, but they don't tell you how much of a risk that is. So, I avoided all of that because I feel like sometimes these people do try to kill your baby. They don't tell you that, but I feel that that's what they're doing. Because there's a lot of people, who get all those extra exams done knowing that that's a risk, but doctors don't tell them how much of a risk it is. You know, they carry their babies that far along, and then you just—you killed my child, period.***

Women described their search for the safety and security of a *home* and instead, perceived a potentially threatening *institution*. Women voiced the hope of finding a bridge to improved health for themselves and their infants, and instead the women illustrated examples of a University Medical center that provided a draw-bridge only offering care as an opportunity to train students. This was summed-up by one focus group participant who characterized her childbirth experience in these words: "***And now they just like looking at you like "this is my science experiment, let me see what experience I can get out of it."***

Macrosystem Level Threats

The participants explained her perception of being relegated to an inferior level of care due to her Medicaid status:

> ***So you don't want to go there, you don't want to deal with them, but what other option do you have? So you're forced to deal with the attitude, the slow service, the whole horrible customer service, but you're not asking for this. This is something like, you know, I need this.***

An Epistemology of Threat

Mistrust of the medical system by African-Americans has multiple factors, from institutional racism looking back over 60 years up to the daily perceptions of a system of privilege that treats some people differently. Pregnant women are forced to engage in a health care system in ways that men and non-pregnant women are not, and one woman described her lack of agency: ***"So you don't want to go there, you don't want to deal with them, but what other option do you have?...I need this."***

Women are delivering a baby in an environment where they have an attitude of fear and mistrust regarding diagnostic screenings and procedures, as these women provided examples from their lived experiences:

> ***But like, as I got bigger, and bigger, you know you kept on going to doctors' appointments. I felt like sometimes, some of the things that the doctors say—they can scare you into not wanting your baby and stuff like that. Like my son had an extra heartbeat. And he could've come out with Down's syndrome or something like that. So they wanted to all these tests and stuff, and he was not going to—I felt like if you get that one test that they always want you to have when they hear that extra heartbeat, they're going to kill your baby. And I didn't let them do it.***

The women voiced a perceived threat of medical errors due to providers not knowing the patient's name: "***Like sometimes you go in there like they don't remember your name, they can't remember the last time they've really seen you. … I'm not going to have the same issues as the next patient…"*** Threat of infection by multiple vaginal exams by students was also voiced: "***You're not supposed to have different peoples' fingers up in there. That leaves infection and more stuff."*** The perceived threat was amplified by care delivered in a climate perceived as a 2-tiered system that does not value Medicare recipients: "*... **I really think they could really care less about people who are on Medicaid. Because their insurance isn't as good as anybody***

else…” Adding to the disrespect perceived by the inexperience, lack of knowledge, and disengagement of the actors providing their care, the women voiced their own lack of agency within the institution: “***You’re sitting there like “Oh God, I don’t want this person to check me because I don’t know if they know what they’re doing” but it’s always… well just go on with it.”***

The women described an environment where disengaged care at each ecological level and perceived potential harm occurring from neglecting her symptoms: “***I felt that I was almost speaking on deaf ears.*** The trust and security of the home that the women are seeking is subordinate and disrupted by the needs of the institution:

> ***I actually had to say something—because they told us, you can’t have more than 2 family members in there. And they have like a crew of students… Like, if they have that many students in there, they can have that many family in there.***

Women voiced feeling themselves at risk as well as their developing baby threatened, and responded to their interpretation of their experience of fear and mistrust by ***Negotiating a Perceived Threat*** at each ecological system level and point of contact in their care. Disparities and doubts raised by the women about their health care and their providers resulted in negotiations to mitigate the threats to their well-being as well as that of their unborn infant. Explaining this *Negotiation of a Perceived Threat* makes it possible to see where the health care system unintentionally erected barriers requiring navigation and negotiation by each woman.

Epistemic Disobedience as Resistance to a Perceived Institutional Threat.

The women voiced inhabiting an unpredictable world and are hyper vigilant of students at the nadir of their experience, confidence, and knowledge. The more perilous the perceived medical encounters, the greater the risk of being separated from their closest family members and surrounded by medical students. The dynamic tension of the search for a medical home by the women was complex and contradictory to the mission of the medical institution. What obligation do they owe their children in return for their medical care? The women described an epistemology of care that was almost an economic analysis model of benefit verses loss (see Figure 4) where they balanced the risk to themselves and their developing fetus and considered three visits worthwhile in spite of the perceived risks. This challenged their caregiver's alternative epistemology of safe care (see Figure 3). Concerns perceived as threatening included: the participation of medical students contributed to the perception that African-American women were used as science experiments for the medical school; a perceived threat of losing wages or employment due to extended waiting times in the clinic exacerbated by medical student's participation; potential for mistakes occurring due to care givers not knowing the patient's name; multiple vaginal exams by learners in direct tension to the increasing risk for infection with each exam; financial costs of medical care that is in direct opposition to the women's perceptions that "***having a baby is free***"; and a perception of a 2-tiered system that does not value Medicare recipients. The drift of the women's argument binds all these concerns together and brings them to conclude that they are negotiating threats at every health encounter. "Making a way out of no way" is a perspective heard from individuals, families, communities, and organizations—both local and national. From the women in the focus groups who explored these themes of their lived experience of child birth, they articulated that that they were able to negotiate "a way out of no way." When the focus group participant states, "***Like I'm done with them, I dismiss them,"*** this resulted in women choosing to discontinue their prenatal care. This woman explains her strategy of making a way out of no way:

> ***I went to the hospital like twice. One time to find out what I was having and then as soon as I was in labor. I didn't have no pre-natal care with that one. It was number five, I was like I know what I'm doing by now. He was the biggest baby I had out of all five of them. Did something right.***

A pattern happening over and over again will not change unless the system changes. The most effective way to look at a process systematically, an ecological framework allows us to examine the individual pieces that contribute to IMR, look at the effects of intersecting pieces, and provides a look at the fundamental processes as a whole.

CHAPTER FIVE

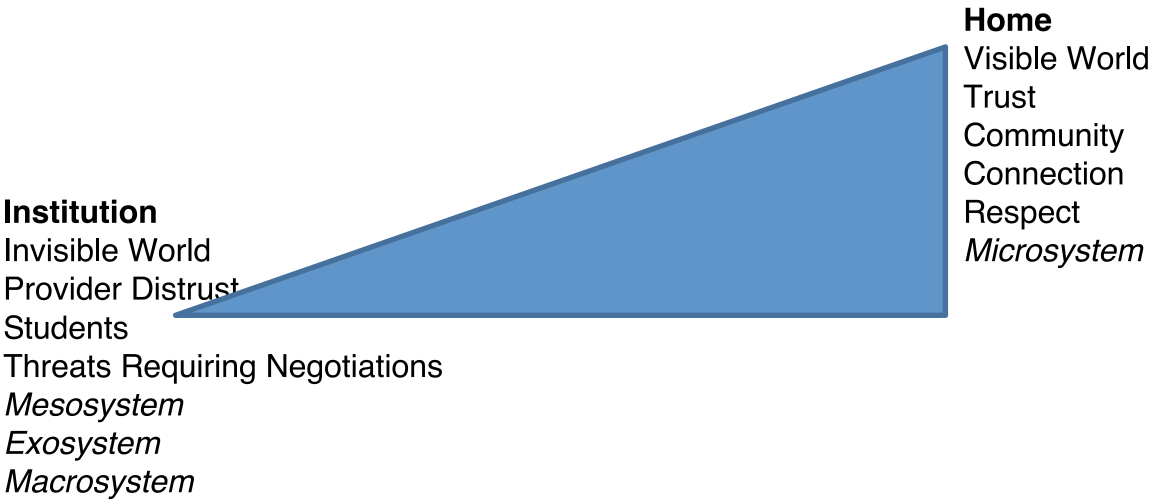
Discussion

Discussion of the findings of the study will be organized in the following ways: First, the bipolar theme of ***seeking a health care home but instead finding an institution*** will be explored using a deeper historical context of the University of Virginia health system, including a medical school that that has historically provided care for women to contextualize the women's lived experience of childbirth.

Second, I will discuss the new narrative reflecting the intersectionality of the women's experience of childbirth, described as the process of ***negotiating threat*** that women voiced to mitigate stressful encounters to ensure the best possible outcomes for themselves and their infants. Finally, I will make links between these findings and current literature.

This study takes seriously the historical, social, and political figurations through which threats, voiced as occurring on multiple levels at multiple points in time, must be negotiated by African-American women to insure her health and safety and the health and safety of her child. The premise that the lived experience perspective is an important one in the context of interrogating the causes and conditions contributing to IMRs. The metaphor of *seeking a health care home versus finding an institution* that framed the lived experience is useful to understanding the complex situations requiring negotiations for pregnant African-American women.

Figure 1. ***Seeking a Home/Finding an Institution*** **Theoretical Framework**



Historical Perspectives of Seeking a Home versus Finding an Institution

Microsystem Level

A key task of the pregnant woman was nurturing cooperative relationships that facilitated benefical outcomes during her developing pregnancy. In addition to emotional support, financial support as well as knowledge deficits regarding her developing pregnancy were adressed by the woman’s mother. Although the women mentioned other members of her family, her mother was seen as the central point of contact while she was pregnant. In addition to the relationship with her mother, reconnecting with the father of the baby was the other key point of contact on the

Microsystem level. The father's involvement was characterized in two ways: either the potential to be a stressor, or a nurturing cooperative relationship that facilitated benefical outcomes. The father of the baby could buffer stress levels during encounters with heath care providers. An ecological framework revealed the voices of women who are looking for connections with people they trust and respect. The pregnancy became an opportunty to strenghten ties to their mothers, partners, and extended families. These points of connections on the Microsystem level fostered learning, competence, and agency as the women sought the safety and security of a home for themselves and their children.

Women experienced *finding an institution* across many points of contact during a woman's pregnancy and delivery. *Finding an institution* is a theme voiced by the women for a place that either intentionally or unintentionally (e.g. a hospital system) destabilizes the notion of home and homemaking. Because it is deaf to the contextual qualities that signify safety and security for the community, an institution appears to be an impersonal and threatening place that one must navigate strategically to ensure the safety and security of the mother and her infant. Rituals and practices are ambiguous, as the history of the Vinegar Hill neighborhood illustrates.

Historical context of persisting distrust. The mothers of the pregnant women were seen as central for information and support, so the historical context of her mother's lived experience is present in the narrative that is shared with her pregnant daughter. To provide triangulation for analytic trustworthiness, I interviewed Holly Edwards, a Charlottesville community activist and parish nurse. She provided insight about the historical context as she explained: *"…**part of the lack of trust came from people who have not had good experiences and those stories being passed down from one generation to the next generation. And the best way to mitigate some of those stories is to create a new series of success stories. But where were those success stories…?**"*

One story that continues to be handed down from mother to daughter began in 1954 when the Charlottesville Redevelopment and Housing Authority wanted to create access between Interstate 64 and Route 250, and standing in the way of the most direct route between these major highways was the Vinegar Hill neighborhood. In the years following the Civil War, migration of both Whites and African-Americans from rural to urban areas had placed a strain on housing, and the diminished air quality adjacent to the Fourth Avenue Gas Works had provided inexpensive land that eventually became the center of the Charlottesville African-American community. As an example of the community services offered, ambulances refused to transport African-American patients to the University Hospital, and it was the African-American owned funeral homes that transported patients to the hospital in their hearses (Daily Progress, 2-3-2012). The kindness and safety net of living in a close-knit community had a buffering effect on the community and this was lost when the Vinegar Hill neighborhood was demolished.

The desire for connection of a community and a home, but instead finding its antithesis, appears to mimic other essential services in the intersecting ecology of their lives: police, justice, and housing. Holly Edwards described the destruction of homes in the Charlottesville African-American community of Vinegar Hill:

> ***Westhaven was created as the result of the Urban Renewal Policy that began in the 1940s, 1950s, and basically the downtown area, where you see the downtown mall and where you see the Omni—used to be a thriving African-American community. The community was designated as "blighted" and so it was an opportunity for the city to apply for federal funding with the idea of providing improved roads and improved businesses. And the poor people who lived there, who could not afford to buy a house on their own were all moved to public housing, which gave birth to Westhaven. Westhaven is the oldest, and the largest, public housing site, and is one of 7 public housing sites in this city. Vinegar Hill is a fascinating history because I've learned that there is a***

relationship between poverty, health, barriers, and the outcomes.

The focus group sample included Westhaven neighborhood residents, and it is noteworthy that this is the neighborhood that consistently has the highest IMR in the city (MAPP 2012

Mesosystem Level

At the Mesosystem level, women accessed care from a health care provider, generally at a University of Virginia affiliated clinic. They had positive attitudes towards health care in general and felt that accessing care during pregnancy was important to ensure the health of both the mother and baby. When the women perceived the staff as providing an environment of trust and respect, they were more likely to utilize the health care resources available to them; conversely, judgmental or threatening staff attitudes discouraged repeat appointments.

Women who reported having a positive personal relationship with their health care provider described their clinic experience favorably. Participants highly valued warm, friendly interactions and a personal touch during their visits. A consistent health care provider who knows their patient's name was seen as a significant mark of respect for the women.

Historical context of nursing care. The role that nurses played in prenatal care seemed minimal and nursing care was rarely mentioned. The nurses' care of the community is troubled by historical contextual factors that barred African-Americans, who served as herbal healers and nurses within their homes and communities, from professional registered nurse education programs. This resulted in very few Registered Nurses of color working in the community and this under-representation persists to the present day in a health care system where women are seeking a health care home. When the nurse was occasionaly mentioned as the point of contact at a Univeristy of Virginia affiliated clinic, nurses were seen as disengaged from what the woman needed. The women's perceptions of their disengaged nursing care confirmed a lack of respect for the women and the distrust of the clinic in general. A lack of visible African-American nurses reinforcing a Jim Crow past that they percieive continues to this day on the mesosystem level.

Historical context of persisting disrespect. A theme that emerged and became highly symbolic was the sign of respect demonstrated by medical practitioners acknowledging the women as an individuals and knowing her name. Holly Edwards' response to this finding was:

> ***I think that it's the small things over time make the big things an issue. And being able to maintain the importance of those appointments in the very beginning is just crucial, and getting up to the hospital and having to wait and making sure that people feel welcomed, and what is the customer service? Cause right now if you call the Hampton Inn someone will answer the phone "It is my***

> ***pleasure to serve you, this is the Hampton Inn." How is that same spirit of hospitality applied to a health care system to a person who really doesn't want to be bothered being there in the first place?***

Historical context of care provided by medical students. The most salient example of finding an institution was revealed in the voices of the women when they spoke about trust in an experienced care provider. The perceptions of *finding a health care institution* are rooted in feelings of mistrusting and being disrespected. Medical students unintentionally became a trigger for the women, re-traumatizing because it connected the historical context of a marginalized past to their present encounter with the health care system. Care by a medical student was perceived as disengaged care performed by one with the least experience, confidence, and knowledge. What women wanted was assurance of competent care and to be acknowledged as individuals, known by name and respected for the time and effort it took to attend the clinic visit. Given their novice experience, being cared for by medical students, inadvertently stimulated feelings of being devalued in the context of care.

Where did these strong feelings originate? Opening the field of vision, from the small sphere of personal experience to the larger contextual themes that echo these personal experiences, enables us to recognize an epistemology that is drawn from a larger life experience and informs the women's knowledge of their world. This was the way that

Elizabeth Dawson, an African-American nursing student, remembered a visit to her mother, who was a patient at the University of Virginia Medical Center in 1954:

> ***“There were vermin in the basement. Water pipes stretched all across the room, water would actually drip down on the black patients. The utility pipes and heat pipes were all exposed. The beds were placed in long, narrow wards with just enough room between them for a white enamel table. At the end was a desk with a nurse.”*** (Johnson & Swift, 1998)

It was not the medical factors that she remembers, it was the hospital architecture that mirrored what was happening all over the Southern United States from the post-Civil War Era until the Brown v. Board of Education decision in 1954, and well into the civil unrest of the 1960s. The voices captured in this study echo the architecture of segregation at the University of Virginia Hospital in the period from 1901, when the hospital opened, until the early 1960s when construction of a new hospital was completed at the university established by Thomas Jefferson—the third President of the United States and author the Declaration of Independence .

The cognitive dissonance between Thomas Jefferson’s actions and beliefs are noteworthy. In 1776, slaves comprised one-fifth of the general population, but the colonies still had not resolved the paradox of slavery. The penultimate devaluing and objectification of African American people has its deepest roots in the history of slavery in this country. Racial segregation did not begin in the basement wards at the University of Virginia hospital as in the story Ms. Dawson recounts; it was evident in the beloved home of Jefferson. When you first observe Monticello, the building that he spent a life-time designing and rebuilding, it appears to be a one-story building. Yet Monticello is as complex as the man himself; the architecture hides the world inhabited by his 200 slaves below the level of the main house (McCullough, 2001). There are limitations that argue against making a causal link between the relegation of enslaved African-American people to the basement of Monticello and the African-American wards in the basement of the University of Virginia Hospital.

This study marked an attempt at a fully-integrated interpretive explanation of the lived experience of childbirth for African-American women living in Charlottesville. Offering a coherent model, including contextual background, to show how *the search for a health care home and instead finding an institution* raised concerns by African-American pregnant women that resulted in a distinctive defense strategy to mitigate those concerns has the potential to explain to providers how health care is perceived by their patients. This knowledge has the potential to provide diagnosis and treatment in a timelier manner, leading to better health outcomes.

During the time of segregated care, the major functions of the University of Virginia Hospital were articulated as "…a laboratory for medical students in their clinical years; as a reference center for difficult cases from every section of the

State; and as a general hospital to provide care for the indigent in the local area" ((The University of Virginia Medical Alumni News Letter of October, 1953, pp 1-4). The "laboratory for medical students" persists today with African American women feeling objectified as specimens for study, without names or other forms of respect. Historical memories of unequal and substandard treatment are echoed in women's interpretation of how they are presently treated in their prenatal care by medical students.

In 1947 Congress passed the Hill-Burton Act, or the Hospital Survey and Construction Act, to create a modern healthcare infrastructure for the South with $3.7 billion in federal funding and $9.1 billion in matching funds from state and local governments. The legislation did however, preserve and perpetuate segregation within hospitals by allowing for "separate but equal facilities" (Thomas, 2006). After the Brown v. Board of Education decision of 1945, civil rights activism increased dramatically in most regions of the South, and the NAACP began to file lawsuits against hospitals asking courts to declare Hill-Burton's "separate but equal" clause unconstitutional. The importance of using one's name has historic context as well. "**I always treated everyone as if they were persons, but white people had to be called Missus so and so**," Ms. Dawson reported. "**If you called a black person Missus, you were corrected and told to call them by their first name** (Dawson, 1996). The minutes of the Administrative Policy Committee of the University hospital of December 11, 1951, recorded “considerable dissatisfaction on the part of the local negro (sic) community that complimentary titles are not routinely used when Negroes (sic) are addressed by personnel of the Hospital.” The committee decided that a formal policy to direct the staff when addressing African-American patients would not be issued due to the difficulty of enforcing such a directive (Minutes of the Administrative Policy Committee of the University of Virginia Hospital, 1951). As we see today, these early, poignant stories of disrespect reverberate in the lack of respectful address that African American women perceive by the medical students who don’t know their names.

Figure 1.

Exosystem Level

The women's exploration of their lived experience of childbirth that touched on the role of the University of Virginia (UVA) School of Medicine, or the medical students nested within the that system are repeated at the Exosystem level and help us understand how threads of history are woven into the current community narrative that emerges from each health care encounter–Clinicians at this level should pay attention to how they are perceived by the community because without this knowledge about their interactions on the Exosytem level they may unwittingly contribute to destabilizing the health care home that the women are seeking.

When women entered the hospital to deliver a baby, the themes of trust and respect were revealed at a heightened level of vigilance. The women's perceptions of birth as simple and natural, every intervention was viewed as potentially threatening, and the hospital was seen an an environment that harbored many threats to the women's safety, Family members, who provided comfort and a sense of safety and security to the women were limited or restricted during the birth process. The women described an environment where disengaged care at each ecological level, and the perceived potential harm occurring from neglecting her symptoms. The trust and security of the home that the women are seeking is subordinate and disrupted by the needs of the institution.

Medical students, who were seen as an annoyance and a threat due to their lack of experience, were given unrestricted access to their birthing process. Adding to the feeling that the woman's safety was subordinate to the students' education, was the feeling that the woman's profound knowledge about her own body was not respected. Again, the concept of disengaged care (first articulated in the clinic setting) is heard emerging in the hospital. Advice regarding frightening surgical and invasive proceedures was offered by health care providers that the women did not always trust with the added perceptions and feelings that the women were not fully listened to

The most chilling experience of my nursing career was being in the room when a focus group participant shared: "***Like some people that do have bedside manner—they're like 40. They're like way older because they've been doing it. And now they just like looking at you like this is my science experiment, let me see what experience I can get out of it."***

Negotiating threat. Women voiced feeling themselves at risk as well as their developing baby threatened, and responded to their interpretation of their experience of fear and mistrust by *Negotiating Threat* at each ecological system level and point of contact in their care. Disparities and doubts voiced by the women about their health care and their providers resulted in negotiations to mitigate the threats to their well-being as well as that of their unborn infant. Explaining this *Negotiation of Threat* makes it possible to see where the health care system unintentionally erected barriers requiring vigilance, navigation and negotiation by each woman. These women subsumed all inequalities under the notion *medical students* and voiced being fed-up with generations of gender, race, and class marginalization that connected their past to the present as well as connecting the present to their past.

The Resurrectionists. In 1838, Dr. James Lawrence Cabell was elected Professor of Anatomy and Surgery, and one of his first acts was the construction of a dissection hall for the medical building. The medical students' anatomical opportunities were limited by the difficulty of securing cadavers. An interesting cast of characters responded to the need of the medical school for cadavers, and one of the earliest photographs of an African-American e medical school was taken in the dissections hall.

Title: Cadaver Society
URL: http://search.lib.virginia.edu/catalog/uva-lib:2169180/view

Figure 2.

Sarah Matthew writes "In addition to dogs and cats, slaves were the best source, though there was a tradition of grave snatching, referred to by the participants as 'anatomical expeditions'" (Matthews, undated). H.L. Thomas, who had been hired to supply cadavers for the University of Virginia, wrote in a letter, "In passing down the street today, I heard the darkies (sic) talking of a funeral tomorrow; if there be anything it, I will watch and endeavor to secure the commodity for you" (Letter from H.L. Thomas to John S. Davis, September 25, 1849). The wealthy and influential were able to hire attendants for the "graveyard shift" of the newly dead. Public officials rarely made an effort to apprehend those disturbing the graves of undesirables. Potters fields and African-American graveyards were sought as targets (Breeden, 1975). Stories like that of Dr. Cabell and the use of black bodies for learning are stories that have been passed on from generation to generation, contributing to women's perceptions of care by medical students today.

Eugenics research at UVA. Jefferson explored eugenics in his book, Notes on the State of Virginia (Jefferson et al., 1787), From 1915 until 1953, a span of thirty-eight years, Dr. Ivey Foreman Lewis was the Miller Professor of Biology and Dean of the University of Virginia. According to historian Michael Dorr (2000), the study of eugenics flourished under Lewis and in 1924 he organized and promoted the passage of Virginia's two eugenics laws. At the Nuremburg Trial, Nazi doctors attempted a defense by citing one of Virginia's eugenics law, *Buck v Bell,* crafted by Lewis at the University of Virginia. This law was not repealed until 1974 and the State of Virginia issued a formal apology in 2002 (Dorr, 2000). From 1932, three University of Virginia alumni and eugenicists (Hugh Smith Cumming, Taliaferro Clark, and Raymond Vonderlehr) designed and conducted the infamous Tuskegee Study of Untreated Syphilis in the Male Negro (Jones, 1981). The study, conducted from 1932 to 1972, deceived and denied 399 African-American men, their wives, and children treatment for syphilis. President Bill Clinton issued a formal apology to participants of the study in 1997. Once again, the threads of history can be seen in the ways that women view their care today—that is, bodies to be experimented on and whose bodies can be practiced on.

Macrosystem Level

Women's experiences within the macrosystem included interactions with local, State, and federal agencies as well as the policies that govern these agencies. An interrogation of the data at the macrosystem level informed the understanding of the extent that individual and institutional difficulties faced by the women are rooted in a larger historical, social, and political context.

This woman explained, "***People say that 'You have Medicaid,' or 'You have food stamps'—if I work and I pay taxes, no matter if it's little or big, we all pay taxes, we all take care of each other"*** and envisioned an expansive health care home where **"we all take care of each other."** Care for a pregnant woman is not easily measured because it does not consist of a single intervention but occurs on multiple levels. We provide a series of assessments, health promotion education, psychosocial interventions and medical treatments that play out in a variety of community and federal program settings during her 9-month term. Women were seen by WIC (Women, Infants, and Children) Food and Nutrition Services workers, lactation consultants, social workers, home health visitors, financial screening workers, and Medicare and Medicaid personnel. In seeking a health care home, women were hoping to be cared for in a connected web in which **"*we all take care of each other.*"** Instead of a home, the women voiced sources of health disparities that are complex, involve many participants at several layers, including administrative and bureaucratic processes. The dissonance between what the women sought for their care and what they actually experienced was shown in women's disparaging remarks about having to deal with Medicare, feeling as if they are treated as supplicants versus consumers of care.

Historical context of marginalization. In his 1963 "I have a dream…" speech, Dr. Martin Luther King Jr., stood in front of the Lincoln Memorial in Washington D.C., and said:

> But one hundred years later, the Negro still is not free. One hundred years later, the life of the Negro is still sadly crippled by the manacles of segregation and the chains of discrimination. One hundred years later, the Negro lives on a lonely island of poverty in the midst of a vast ocean of material prosperity. One hundred years later, the Negro is still languishing in the corners of American society and finds himself an exile in his own

> land. In a sense we have come to our nation's capital to cash a check. When the architects of our republic wrote the magnificent words of the Constitution and the Declaration of Independence, they were signing a promissory note to which every American was to fall heir. This note was a promise that all men, yes, black men as well as white men, would be guaranteed the unalienable rights of life, liberty, and the pursuit of happiness (King; 1963)..

In discussing their travails with Medicare and other aspects of the institution that provides poor women with care, women's concerns continue to reflect the failure of our systems to care for them equally, treatment they voiced as re-traumatizing because it connected a historical context of a marginalized past to each of their present encounters with the health care system.

When President Kennedy asked Congress in 1964 to prohibit discrimination in all programs receiving federal aid, 98% of Southern African-Americans were still in totally segregated schools. The carrot for integration proved to be the threat of withholding federal money for schools, the same way that federal money was the impetus for hospital desegregation, and Lyndon Johnson made desegregation the basis for obtaining federal funds. The four years following the enactment of the 1964 Civil Rights Act became the only period in which there was active support for integration. Federal education officials, the Department of Justice, and the high courts all maintained strong and reasonably consistent pressure for achieving desegregation. During this period our nation's thinking was transformed from a very gradual anti-discrimination policy to one of rapid and full integration. In 5 years the South moved from almost total racial separation to become the nation's most integrated region (*School: The Story of American Public Education* (film), 2001). Yet maternal/child health disparities continued. A landmark document that laid the groundwork for investigating these confounding factors in health care research, *The Report of the Secretary's Task Force on Black and Minority Health* (1985), was commissioned by Secretary of Health and Human Services Margaret Heckler to investigate the "sad and significant fact: there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation's population as a whole" (1985, letter introducing the report). This led to the Institute of Medicine (IOM) report that recommended a national policy of enrolling all pregnant women into a system of prenatal care (PNC) as a strategy to reduce their risks. The US Congress enacted a series of legislative initiatives that expanded Medicaid eligibility to low income pregnant women and children (IOM, 1985). Two observations are notable: During the last 25 years policy makers have been expanding a one-size-fits-all model of PNC for all patients (Krans & Davis, 2012). While one would expect this access to care would improve outcomes, as rates of PNC enrollment increased, the rates of low birth weight and preterm births have also increased (Fiscella, 1995).

What we can learn from the women in this study? The lessons underpin the implications of practice that are discussed in this study. For African-American women living in the neighborhoods with the highest IMR, the memory of Vinegar Hill and the racial diaspora that followed the neighborhood's destruction was an invisible presence. Her mother was acknowledged as the central point of contact while she was pregnant, and the narrative of Monticello's architecture and master/slave dichotomy that subordinated African-Americans during Jefferson's times, continues to be symbolic in the narrative of the women's perceptions of the present structures, codes, and conventions that characterized her care at Mr. Jefferson's university. Trauma is an element of the women's historical context, and the current cycles of events reinforce the historical trauma and leads to the women's hyper vigilance of the expectation of disrespect and awareness of threats. Destabilizing the women's search for the safety of a *health care home*, the evidence would support that the women in the study had constructed a new epistemology that evolved out of their lived experience, an ontology that posits only 3 point of care as valuable and contributing to the notion of the health and safety of a *home*: a pregnancy test, a sonogram, and the delivery of her baby. Also within this epistemology of her lived experience, she described a strategy of *negotiating threat* as an attempt to minimize the harm that may occur to her or her infant when navigating care within *an institution*.

When examined through an ecological framework and feminist lens, the processes that make up the lived experience of childbirth for African-American women appear incredibly complex. This study provides an opportunity for health care providers, and especially students, to conceptualize how care can be offered in new ways that foster trust and respect. This new perspective has the potential for an opportunity to care for women in a connected way, an opportunity to celebrate a model of care with a new narrative that comes from the women themselves: "***we all take care of each other*.**"

An informed model of their lived experience, with interpretive explanations that address variations in the way that health care was voiced by the women in the sample, has a potential to appropriately tailor the way we provide care for pregnant African-American women who are seeking a health care home, and thus influence their neonatal outcomes.

Findings in Relation to the State of the Science

This paper interrogated how African-American women in the focus groups have described their birth experiences in Charlottesville. The University of Virginia has been described by the women in the research sample as a space of dread, an enterprise designed from its founding to the present day as a space to train medical students by what women perceive to be experimentation on African-Americans. There is a perception, from the Three-Fifths Compromise to the present contemporary political climate, that black lives matter less. Women articulated a novel concept, not previously discussed in the literature, of their perceptions of discrimination as well as a strategic negotiation to mitigate the threats of discrimination and harm.

While there is a dearth of research to inform what we know about the lived experience of African American women who seek PNC at the UVA Medical

Center, the findings of this study complement other bodies of research. I will discuss how these findings of *seeking a health care home*, *finding a health care institution,* and *negotiating risk* are related to the relevant lines of research in the extant literature that have been employed to account for differences in birth outcomes for vulnerable women.

Seeking a Health Care Home

It is apparent from the data that pregnancy marked a significant change in the lives of the participants. Change was observed in the woman's relationship with her own mother, and her mother became the major source of information and emotional support that guided her through the experience of childbirth. In addition to knowledge, the women mentioned that financial support was also supplied by their mothers. A key task of the pregnant woman was *seeking a health care home* through nurturing relationships that had a beneficial outcome for her developing pregnancy. The importance of social support for improved health is well documented in the literature, and social support for improved pregnancy outcomes is mentioned by Cook (1999), Kitsantas (2012), Sable (1990), and Sunil (2010). All four studies focused on barriers to care for low SES women. It is noteworthy that the women reported their trusted family members were excluded from providing safety and security during the delivery of her infant, but students who were strangers were given unlimited access to her birth.

The data supports the assertion that there are three strategic points that are the catalyst for change in the women's' relationships: the initial pregnancy test, the sonogram, and the birth of her baby. A positive pregnancy test was an opportunity to reconnect and strengthen ties with the father of the baby, but it is apparent from the data that the woman's mother is her main source of information guiding her decisions throughout her pregnancy. The reliance on her mother also destabilizes the notion of home and homemaking because the woman's mother may be hyper-vigilant to the contextual qualities that signify safety and security for the community, factors that can affect her daughter's health and the outcome of her developing grandchild.

Research supports the hypothesis that community context is an important factor in pregnancy outcomes. Vinikor (2008) mentions that residence in a predominantly African-American community was associated with a decrease risk of low birth weight and preterm delivery among African-American women, and this association existed independently of the woman's own economic status. Discrimination constitutes an independent risk factor for preterm birth, according a study by Collins (2004). A study that surveyed African-American women reported that women's trust in their health care providers was related to the woman's history of perceived racism in the community (Peters, 2014). My study, thus, has verified findings that community matters and discrimination faced in a community is translated into perceptions of care and may impact birth outcomes.

African-American women are not a monolithic group, but this study organized data in a new way that broadens and expands the concept of *seeking a health care home* to show the multiple factors that constitute the notion of a safe and trusted home. It came from community perceptions of systemic racism, but participants also voiced persistent daily perceptions that they were treated without respect. Factors related to the notion mistrust can be profound lapses in judgment, as in the Tuskegee study, but can also occur due to small missteps such as asking a patient their name over and over again. Because pregnant African-American women are engaged in *seeking a health care home* due to childbirth, they voiced that they were forced to engage the world on an individual, Microsystem, Mesosystem, Exosystem, and Macrosystem level that others, either because they not pregnant or male, were not. Rather than an evidence-based *state of the science* operating to provide safety and security, perhaps as Heckler stated, it is the *state of the systems* operating in the community that must be understood. Extending this notion of *seeking a home*, by including a historical context, offered a thicker description of the intergenerational factors, as well as the intersectionality, that nuanced the participant's search for a trusted and secure health care home. Hoffman (2016) provided research evidence to support a hypothesis that Whites are more likely to engage in behaviors that justify and maintain the status quo whereas non-Whites are more likely to engage in behaviors that challenge and change the status quo. Indeed, research has shown that minority medical students, nurses, and physicians are more sensitive to racial bias in healthcare and therefore may be more motivated to prevent it. Greenwald (2014) demonstrated that discrimination is often in-group favoritism as opposed to out-group hostility. Holly Edwards observed: "***I'm thinking that in our neighborhood, we lack African-American health care workers who are visible consistently, you know, really visible. I think that if more people saw people who looked like them I think that might help"*** **(Interview, 2013).**

Placing people in racial systems involves a hierarchy, it posits one group in the superior position and offers a license for better positions in all ecological systems levels. The sociologist Bonilla-Silva's work (2006) introduces the notion of *racism without racists* and helps us unpack the present findings of this study. The focus group data are consistent with historical analyses suggesting that the women's perception of the care they received served to maintain a racial status quo that advantage Whites and/or disadvantage African-Americans without any racial animus. Racializing African-Americans into the subordinate position has moved from overtly racist policies of the Jim Crow South to more covertly racist policies of the present. Racialized medicine, using the artificial construction of race as a defense of slavery, and a response to abolitionist opposition to slavery, attempted to provide "scientific" evidence to support White supremacy and African-American inferiority (Seth, 2017). A methodology that acknowledged this deep historical context offered a more detailed picture of the lived experience that helped to frame the women's negotiations of the health care system. By exploring the women's voiced resistance in the face of complicity with being dehumanized by others, negotiating the complex structures at the Mesosystem and Exosystem levels may be at the root of factors that have contributed to IMRs in Charlottesville. Rather than science animating her care, this may be a system level example of “racism without racists” (Bonilla-Silva, 2006) that shapes the way that her care is performed and understood.

Finding a Health Care Institution

The reaction of the women to students participating in their care was very surprising, as I have worked closely with many students during my 30-year nursing career. Previous literature identified two distinct gaps in care that had the potential for contributing to health disparity: *structural* variable and *process* variables (Peters, 2014). After the data were analyzed, the students were variables in both categories thus verifying and extending the findings of this previous study in profound ways that tied into the deeper historical context of the community and the mission of the medical school. A structural variable contributing to disparity was identified as not consistently being seen by the same provider. Participants of the study voiced that a new health care provider was present at every encounter, thus spending valuable time ensuring that the provider was familiar with the woman’s medical history.

The structure of medical and nursing education dictates that students rotate through areas of the hospitals and clinics. Another structural variable is the practice of asking the patient for two identifiers, typically their name and birthdate, to establish the patient’s identity. So complex is the student/patient interaction that quite contradictory possibilities result from this introductory remark, “Tell me your name, and your date of birth,” which is usually the first sentence spoken by the care practitioners. The research sample participants viewed this question from a deeply suspicious tension, and the students view the practice as establishing a culture of patient safety.

The second gap that the literature identified as contributing to disparities is termed *process* variables (Peters, 2014). In the unpredictable world of a medical institution, where care is provided by multiple actors at multiple points of contact at multiple locations within that institution, the women voiced wariness at each encounter. Analysis of the data verified *process* variables, and the sample groups voiced very sharp insights regarding the students’ lack of technical skills in addition to the interpersonal aspects the women found lacking in a student provider relationship.

Negotiating Threat

The search for a *health care home* is troubled by historical contextual factors, events that can confirm a racist past. The notion of *finding an institution* is also troubled by factors that can confirm a racist past, as well as a racist present. Women articulated a novel concept, not previously discussed in the literature, of their strategic negotiations to mitigate the threat of discrimination and harm to themselves and their fetus or infant. In addition to the threats posed by women’s strong perceptions of medical students using them as science experiments, there were: the perceived threat of losing wages or employment due to extended and inexplicable waiting times in the clinic; threat of mistakes or misdiagnosis resulting from not knowing the patient, the patient's history, or even the patient's name; learning expeditions led by students involving multiple vaginal exams with the threat of for infection and complications; financial threats resulting from paying high fees for medical care that is perceived as free; harm as a result of neglected symptoms due to the threats of the "deaf ears" of health care providers; the threat of a 2-tiered health care system that does not value Medicaid recipients; and the menace of physical harm occurring to her infant at a medical center where there continues to be a very vivid community-transmitted legacy of bad outcomes for women and their babies.

Research verifies the findings of this study related to the hyper-vigilance the women voiced when students provided care. One study conducted at the University of Virginia (Hoffman, 2016) described results demonstrating that White medical students and interns held false beliefs regarding pain assessments and treatments of African-American patients. Despite advances in microbiology that have challenged conventional racial thinking (Cooper, 1997), false beliefs by health care practitioners may be maintaining the status quo of racialized medical care postulated in the 1760s as a response to abolitionists' moral opposition to the practice of enslaving individuals (Seth, 2017). There is evidence to support false beliefs about racial differences continue to shape the care provided for African-Americans (Hoffman, 2016). Women in the focus groups pointed out actors at many points of care complicit with the very structures of discrimination that were critiqued in the Racial-Genetic Model in literature (Hoffman, 2016).

Suggested ACOG standards include an initial office visit at 8-10 weeks of pregnancy; followed by visits every 4 weeks for first 28 weeks; then every 2 – 3 weeks until 36 weeks gestation; and finally a visit every week after 36 weeks gestation until birth (See figure 2). Many women endorsed that only three encounters were necessary as a strategy to mitigate threats during their pregnancy trajectory: an initial pregnancy test, a sonogram, and the birth of the baby (see figure 3). Legal scholars have begun to question if maternal child health interventions as currently practiced would pass the Supreme Court's "strict scrutiny test" that ensures that a policy is "race neutral" and are finding that current policy actually disadvantages African Americans (Forde-Mazrui, 2013). The number of prenatal visits and the timing of the visits may disadvantage African American women with one or two visits routinely scheduled early in the pregnancy with the majority of the visits stacked weekly at the end of the pregnancy (Chiswick, 2008; Hack & Fanaroff, 1999). An example of care that disadvantages African American women is evidenced in Bacterial Vaginosis, a sexually transmitted infection that is diagnosed in 20 – 50% of African American women, and oral treatment with metronidazole or clindamycin reduces preterm birth rates by roughly 50%, but there is no Bacterial Vaginosis screening during routine prenatal care (Fiscella, 1996).

Table 2. Routine Prenatal Care Model.

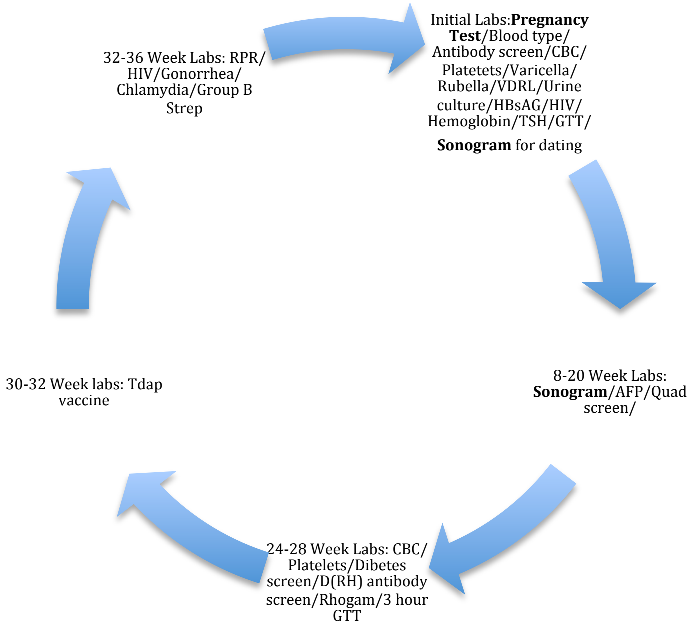
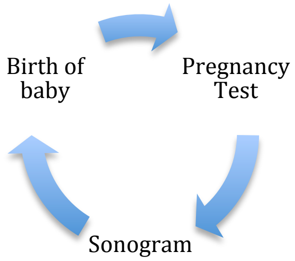


Table 3. Meaningful Encounters.



Rigor in Application of the Thematic Analysis Method

Combined with a feminist lens (Campbell & Bunting, 1991; hooks, 1981) and an ecological framework (Bronfenbrenner, 1977), intersectionality provided a new and useful lens and provided a richer, more nuanced context for my study. Intersectionality also provided a lens to view how women's multiple identities collided during their pregnancy and birth experiences (Denzin & Lincoln, 2005). Validity was attempted by triangulation; meeting regularly with Holly Edwards, a community leader and Westhaven community parish nurse; my dissertation chair; and research colleagues at the TJHD; to review the transcripts and verify the meaning making that I had assigned to each transcript.

The coding and analysis of the transcripts was an iterative process of refining themes and identifying the narratives that the women's voices revealed. Data from focus groups were transcribed verbatim to reflect women's subjective experiences. The analysis was verified with women from similar social contexts to ensure applicability (Lincoln & Guba, 1985) at bi-monthly meetings conducted with members of the TJHD Improving Pregnancy Outcomes committee to discuss the credibility and dependability (qualitative evaluative criteria that parallels reliability and consistency) of my judgments regarding emerging codes and themes.

Strengths and Limitations of the Study

This study has several limitations. Study participants were all volunteers and a small incentive was offered for participation, which might have resulted in selection bias. Most of the recruitment took place where maternal-child health services are offered; participants therefore could be more likely to access health care than other women in the community.

Despite these limitations, this study was the first to pay attention to the multiple analytical dimensions of the historical, social, and political figurations contributing to the lived everyday experience of women's lives in Charlottesville, acknowledging that African American women's voices in the neighborhoods with the highest IMRs are particular and uniquely situated to bring a nuanced understanding of nursing implications that can inform targeted interventions for promoting maternal/child health.

Implications for Nursing Practice

The salient findings of this study were the structural issue impacting the care we provide, and the way the women interpreted that care. Women in the study provided us with many examples of missed opportunities, and a desire for personal relationships with health care providers represents an opportunity for nurses to improve delivery of care services. Implications for practice consist of two parts: the first are the short-term strategies that we can accomplish now; the second part are long-term structural changes that require time and cultural shifts. In the short-term, nurses have an opportunity to take the lead in creating strategies that improve communications. Basic strategies like taking time to read and/or recall the patient history before entering the exam room and calling a patient by her first name could facilitate open dialogue and help down-regulate anxiety and increase trust and respect. Further, perhaps a simple intervention, like giving rationale for repeatedly requesting one’s name and date of birth would dispel suspicion and irritation that has the potential to frame the remainder of the care interactions.

The disappearance of the nurse in the women’s narrative provides an opportunity to locate that space that is left empty by the effacement of the nurses’ role in providing care. More intentional strategies to enhance communication could be developed--not a module that is completed once and checked-off a list of assigned modules--but a practice performed every day that becomes a trait characterizing the manner in which one conducts every interaction. Rediscovering the place of the nurse in the narrative, especially when students are providing care, has the benefit of expressing the themes of trust and respect at every point of care. The women in the study voiced that every act performed by healthcare providers was placed within a bipolar world of *looking for a home* versus *finding an institution*.

When describing the notion of *finding an institution*, a surprising finding of this study was the focus on the medical students in the women’s lived experience of childbirth. It is notable to analyses how the notion of *student* was constructed: the term was not specific to an individual person; several discourses are attributed to the notion of *student*; and any act interpreted as creating an obstacle to *finding a home* was attributed to a *student*. Long-term interventions require structural changes, such as developing a course for medical and nursing students emphasizing the contextual histories that patients have experienced before the students ever encounter a patient. Events do not affect all cultures in the same way. For example, the knowledge of the patient's name reveals status and acknowledges individuality within a culture that has been historically deprived of respect. Again, I take this opportunity to point to the Heckler report's observation that "Sensitivity to cultural factors is often lacking in health care of minorities" (1985, p. 10). With these works included in the education of students, there are opportunities to design enhanced curricula highlighting implicit bias and structural injustice that impact health care delivery.

In addition, evidence-based programs may provide a venue for meeting patients' desire for personal connections with their providers. Group prenatal care and education programs like CenteringPregnancy™ owe some of their clinical success to the relationships formed in a group setting. Parkland Hospital suggested that their success in reducing preterm births were tied to their midwifery service model of care (Levino, 2009). Research shows that participation in such programs improves knowledge of healthy behaviors, increases the likelihood of attending health care appointments, increases birth weight, reduces the incidence of preterm births, and increases satisfaction with care (Grandy, 2004; Ickovics, 2003, 2007).

There was care that women voiced as meaningful (pregnancy tests, sonograms, and delivery of the baby), and things that were obstacles to care (not connecting with a health care provider, lack of respect and trust). There is room for an expanded model of care that incorporates community agencies in concert with UVA to provide care for pregnant women. The key things that need to be incorporated in this cooperative model are the services that the women are seeking in a healthcare home—connection, trust, and respect. This cooperative model can build upon the services provided by the University of Virginia Medical Center that the women find meaningful while creating partnerships with local agencies to provide the warm connections that the women are seeking. An approach to establishing and/or improving relationships between patients and providers is to use trained lay or paraprofessional community members who can serve as outreach workers, home health visitors, and health educators in partnership with hospitals, health departments, or community organizations. Programs utilizing home visits and lay health workers have been shown to increase healthy behaviors during pregnancy (Olds, 2004; Rodgers, 1996).

The finding of this study provide an opportunity to reflect upon the number of visits, as well as the timing and nature of the content. This study offers several avenues for future work applying knowledge gained from this study. The UVA Midwifery service has obtained March of Dimes grant funding to initiate a pilot CenteringPregnancy™ prenatal program, to start this May. As this is a pilot program aimed to decrease IMRs in the most vulnerable populations, there is an opportunity for me to follow the pilot group for outcomes measures and future grant applications for future funding.

The participants in the study had very sharp observations regarding the medical students. Foucault and discourse analysis provides a way forward in future work to deconstruct and understand the perception of care performed by medical students. Foucault's concepts of "the gaze" and the "medical gaze" developed in his works *Discipline and Punish* (1975)*; Birth of the Clinic* (1963)*;* and *History of Sexuality* (1976) could serving as a point of departure for focus group data to inform practice.

A feminist study framed by a post colonialism lens would inform future practice presented in the novel concept of *negotiating threat*, as African-American women appeared to be constructing a new epistemology based on their lived experience.

The work of research psychiatrist Mindy T. Fullilove (2004), as articulated in her book *Root Shock,* mirrors the experiences of African-Americans documented in this study who lived through the Vinegar Hill diaspora. The women living in this neighborhood continue to see the highest IMRs in Charlottesville, and the work of Fullilove can guide and shape continuing education classes and curricula development for health care practitioners and students.

Summary

This dissertation interrogated how the University of Virginia, an enterprise designed to train medical students by learning via the use of African-American bodies from its founding to the present, has been imagined as a space of dread by African-American women seeking prenatal care. The search for a health care home is troubled by historical contextual factors. The Vinegar Hill neighborhood has animated the African-American discourse since the Charlottesville city council plotted the destruction of African-American's homes leading to their diaspora to the Westhaven public housing development. Rooted in slavery to the present contemporary political climate, there is a perception that society continues to reinforce the notion that black lives matter less. Women voiced a new concept, not previously discussed in the literature, of negotiating these threats.

Medical students—as focus group participants perceived—are unwittingly disruptive agents. Students, with no ill intention, play havoc with women's cherished assumptions about the safety of finding a home, overturning medically prescribed recommendations for care for that which is familiar, respectful, and trusted. Women reject what clinicians believe to be best practices in prenatal care, instead, valuing only three health care encounters during their pregnancy trajectory: an initial pregnancy test, a sonogram, and the birth of the baby. The sonogram, in particular was of high significance to the women. It determined the baby's sex and allowed women to concretely see and track the size and health of their baby. Sonogram is an artifact of the appointment that is tangible and visible; a photograph can be printed and taken home from the clinic making the prenatal appointment worthwhile.

Unimpressed by Mr. Jefferson's University and skeptical of any medical interventions, except those provided by the most trusted, experienced clinicians, women believed that medical students providing health care badly compromised the assumption that the Past is something different and remote from the Present. This is illustrated in the quotes: "***So, I avoided all of that because I feel like sometimes these people do try to kill your baby.*** " as well as "***And now they just like looking at you like this is my science experiment, let me see what experience I can get out of it.'***

There are neighborhoods in Charlottesville that continue to have infant mortality rates that are four times the rate for the rest of the city. These deaths are in communities that literally stand in the shadow of the University of Virginia Medical Center. Why are we not serious about bringing about a better future, different from the past and present?

There is a dynamic tension between the women in the community living in a world where they feel that they are not respected and have no trust, and the world of the healthcare provider who can't comprehend why a woman would not want to return to the hospital where she fears for the life of her baby. The role of the nurse lies in being able to transcend both worlds.

The decision to seek health care services is a complex intersection of many structural and psychosocial factors. Developing a personal, trusting health care home between patients and their care providers is the single greatest factor in improving pregnancy outcomes and improving IMRs in Charlottesville. Efforts to improve maternal/child health for African-American women cannot focus on the examination room. Policymakers, educators, and care providers must work in concert to improve the lives of African-American women on every ecological systems-level. We can achieve a world, as voiced by a study participant, where “***we all take care of each other***” and change the intergenerational narrative that sustains health disparities in Charlottesville.

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