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Exploring the mechanisms of racial disparity in infant mortality: A grounded theory approach

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Abstract

Exploring the Mechanisms of Racial Disparity in Infant Mortality:

A Grounded Theory Approach

by

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MPH, Wright State University, 2010

MS, Franklin University, 2003

Dissertation Submitted in Partial Fulfillment
Of the Requirements for the Degree of
Doctor of Philosophy
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Abstract

Infant mortality (IM) is a critical health-disparity problem in the United States. Of the 23000 infants who die each year, the highest number occurs among African Americans. Previous studies implicated a mix of health determinants and risk factors, but no study has explored the mechanisms by which IM predictably persists among African Americans. This study uncovers the complex network of risk factors that underlies racial death disparities in infants. Two theoretical lenses chosen for this study were *social systems theory (SST)* and *critical race theory (CRT).* SST explains human behavior as an intersection of interrelated systems. CRT interrogates inherent social contradictions. Two research questions are considered: the risk factors African American women identify and, the sociocultural factors they identify as buffers against adverse birth outcomes. Interviews with 6 African American women in Franklin County were analyzed using open, axial and selective coding to arrive at 4 themes of major risk factors, and 2 positive health determinants associated with improved pregnancy outcomes. A midrange substantive theory of racial death disparity emerges, implying that eliminating IM depends on the ability to predict and control risk and protective factors. The implications for positive social change include informing policy makers and healthcare providers about the vulnerability that women feel, to get them to listen and engage more intently. Averting threats of racial death disparities requires modification of the social determinants of health. That could be a major contribution to public health practice. Study offers a strong basis for quantitative research to test the new theory and, closes knowledge gaps and fosters equity-focused patient-centered practices.

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Dedication

I dedicate this dissertation to all who would not allow their dream, passion or aspiration to be muted or mummed by misfortunes, detractors and life's extraordinary challenges.

To the following belong great triumph and acclaim: All parents who have to live each day with a hole in their hearts; Johnny Randall, whose unexpected death sparked a real quest in me to join in the search for answers; Dr. Rebecca Boyd, my adopted mother, for her untiring motivation and positive affects through this journey; Sir Earl Pannell, my adopted father, for believing in me always, all the way, till the end; Martha Ijeoma Eneh, my biological mother, who at age 24 years had buried a daughter and, eventually would die giving birth to my twin brothers; Julia and Matt Randall, whose loss and grief set my heart on fire. I thank them for the gift of their sorrow, faith and hope.

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Chapter 1: Introduction to the Study

Introduction

More infants die in the United States than in other developed countries—in 2013, the United States ranked 51st internationally, comparable only to Croatia (Chen, Oster, & Williams, 2014). These deaths occur despite record advances in medical sciences, unprecedented innovations regarding the use of technology to improve the practice of public health prevention, promotion, education, and policy development programs, and that 17% of U.S. GDP per capita is spent on healthcare (Montague, 2007) To this day, infant mortality (IM) figures and the difference in death rates among racial and ethnic groups remain among the most insidious and critical health disparities in the United States (Centers for Disease Control and Prevention [CDC], 2013; MacDorman & Matthews, 2011; U.S. Department of Health and Human Services, 2013). The highest rate of incidence occurs among African American women (Kaiser Family Foundation, 2013). For this reason, mortality differences between African American infants and those of other races are a persistent and striking disparity in public health research. In Ohio, IM rates among racial and ethnic groups were as follows in 2016: 5.8% Whites (610 infant deaths), 15.2% African Americans (369 infant deaths), American Indians (two infant deaths), 3.8% Asian/Pacific Islanders (18 infant deaths), 7.3% Hispanic (54 infant deaths), and 6.3% unidentified races (25 infant deaths) (Ohio Health Department, 2016).

Previous empirical studies have focused mainly on causative risks and aggravating factors in preterm birth and death disparities. However, no known study has specifically explored the central mechanisms of adverse birth outcomes in African

American women, meaning the structural pathways by which death disparities actually happen within the African American community (Giscombe and Lobel (2005). Granted that factors such as the ethnic differences in health behavior and socioeconomic status, higher levels of stress in African Americans, greater susceptibility to stress, the impact of racism and, the ethnic differences in stress-related neuroendocrine, vascular and immunological processes have long been associated with adverse birth outcomes; nonetheless, they contend these factors do not fully account for ethnic disparities in adverse birth outcomes (p. 662-683).

Patterns of disparity in IM consistently point toward social mechanisms (David & Collins, 2007). Very little is known about how these complex risk factors act, interact, and/or influence one another, to ultimately result in persistent racial death disparities among African American infants in the United States.

The purpose of this study is to determine the threshold at which underweight birth and preterm birth led to death for African American infants in Franklin County, Ohio. Uncovering the mechanisms through which adverse pregnancy outcomes ensue is critical to generating a data-informed theory that will advance evidence-based strategies to reduce death rates among affected infant populations. In this study, I used the grounded theory approach (GT) to answer two key and five sub-questions:

RQ1: What specific disease burden (risk factors or negative or exacerbating mechanisms) do African American women believe influences their birth outcomes, and explain persistent negative birth outcomes in their community?

SQ1: What specific actions, interactions, relationships, conditions, and behaviors do they associate with their negative birth outcomes?

SQ2: In what specific sequence (serial order) do these risk factors manifest themselves to influence birth outcomes?

RQ2: What sociocultural factors (positive or protective mechanisms) do African American women identify as potential buffers against adverse birth outcomes for them and other women?

SQ3: What are these health determinants?

SQ4: In what particular order or sequence do these play out in real life?

SQ5: Are these available to majority of African -American women?

The researcher carefully selected a very small study sample of six (Creswell, 2009) affected African American women from 18 cities in Franklin County to answer these questions. The researcher also attempted to understand this problem from the point of view of the research participants.

A further purpose of this study is to pursue an analysis and achieve a systematic and holistic account of participants' perspectives. Moving beyond plain narrative accounts of these events to create a conceptual framework regarding racial death disparities in infants is desirable for quality, validity, rigor and credibility of findings in this qualitative GT research (Hammersley, 1987; Corbin & Strauss, 2015). Above all, understanding the conditions and the social contexts that predispose African American women toward disproportionate infant death disparities will help with finding lasting remedies.

To this end, a theory of the sequence of events, conditions, behaviors, actions and relationships that underlie racial death disparities was believed to assist with making sense of this problem, especially for the people affected by it. As a result, this study is socially relevant inasmuch as it furthered the search for evidence-based, equity-focused and cost-effective strategies to eliminate death disparities among infants. In addition, the study managed to advance the discovery of effective sets of interventions that are likely to prevent preterm delivery. The leading causes of hospitalization among pregnant women are prematurity and death disparity among U.S infants (CDC, 2015; MacDorman & Matthews, 2011). In this chapter, I present the background to the study, as well as the following key information: the problem statement, the purpose and nature of the study, research design methods and key research questions, key terms, researcher assumptions, scope of the study, and delimitations and limitations.

Background of the Study

IM refers to more than the number of dead babies. It is a reference indicator for societal health status (Willis, McManus, Magallanes, Johnson, & Majnik, 2014). IM is an index of how well a society is doing to assure the health of its women and infants (CDC, 2013b; Hawkins & Thompson, 2006). In the U.S., preterm and underweight births are the leading causes of IM. According to Elder, Goddeeris, and Haider (2011), 90% of IM incidents stem from the differential fitness of an infant at birth, as measured by birth weight (underweight) or gestational age at birth (preterm birth or > 37 weeks of gestation), and a combination of multiple pre- and post-neonatal conditional factors, prominent among which is the racial and ethnic background of the infant's mother.

In 2010, 18% of African American infants were born before 37 weeks of gestation, compared to 12% of White infants (Burris, Baccarelli, Wright, & Wright, 2015; Burris & Collins, 2010). African American infants are twice as likely as White infants to be born with a low-birth weight and to be born prematurely, and three times as likely to die in infancy (Carpentier, 2010). While the intersections between IM and complex socioeconomic risk factors have been well documented, the effects of longstanding social inequities have not been explored, such as social stratification; individual, institutional, or structural racism and discrimination; and other forms of social inequities. Other possible factors that have not been explored that might account for the observable racial disparities among African American women and infants in the United States include: structural and institutional racism; residential and cultural racism; ecological differences, particularly the social environment external to healthcare; prolonged maternal exposure to chronic stress; and epigenetics. While socioeconomic determinants are clearly known to play causal, proxy, or intervening roles in IM (Link & Phelan, 1995), the actions, interactions, conditions and events extant to IM are not adequately understood.

Problem Statement

IM remains a critical health disparity problem affecting many minority women in America. Substantial disparities and unfavorable birth outcomes exist among African American, American Indian and Puerto Rican women (MacDorman, 2011). Twenty-three thousand infants die each year in the United States (CDC, 2014), and the highest incidences of adverse birth outcomes occur among African American women

(Dominguez, 2008). Eighteen percent of African American infants are born preterm, compared to12% of White infants (Aron, 2013; Burris & Collins, 2010; Christopher & Simpson, 2013; Matthews, Hoyert, & MacDorman, 2013). Whereas uneducated Caucasian women are predicted to attain the ‘Healthy People 2020’ objective of 6.0 infant deaths per 1000 live births, highly educated African American women are less likely to achieve this goal, at 10.6 deaths per 1000 live births (Loggins & Andrade, 2014). IM is persistent mostly along racial lines (CDC, 2011; Spong, Iams, Goldenberg, Hauck, & Willinger 2011). Low birth weight and the gestational age of an infant at birth, along with post-neonatal mortality-related factors, partially explain death disparities for African American infants (Florido, 2014).

In addition, the health status of infants from lower socioeconomic families often suffers because of their families’ lower income status (Chen, Oster, & Williams, 2014). An infant’s health can additionally be undermined by a wide range of determinants, including maternal health status and behavioral characteristics, such as lifestyle, marital status, education and income levels, occupation, employment, health insurance status, and having timely access to quality prenatal care (CDC, 2011; Plough, 2015; Spong et al., 2011). The race and ethnicity of the mother, as well as prolonged chronic maternal stress, have greater influence on poor pregnancy outcomes than was initially perceived. These factors carry greater health implications and social consequences for women and their infants (Daoud et al., 2014; Heckler, 1985; World Health Organization [WHO], 2011).

Furthermore, IM is a preventable health problem (WHO, 2016). No prior study has been undertaken to uncover relationships among all risk factors, particularly how these factors separately and jointly interact among themselves to contribute to negative birth outcomes. Understanding the relationships and interactions among these interconnected health determinants and risk factors allowed us to unlock the mechanisms of racial death disparities among infants. Therefore, to the extent that we are able to decode these underlying mechanisms regarding racial death disparities among America's infants, we can begin to take appropriate steps to narrow existing gaps regarding knowledge, practice and policy interventions. GT provided a basis for evidence-based practice, health education, health policy, and advocacy to reduce infant death disparities in America.

Purpose of the Study

The purpose of this qualitative GT research is to explore the events, conditions, behaviors, actions, interactions, relationships and processes that underlie racial and ethnic disparities in IM among African American women in their optimal (ages 18-45) child-bearing years. The women chosen for this study reside in Franklin County, Ohio. Uncovering the structural sequence of all associated risk factors helped in understanding how these factors interact, and to explain to these communities the nature and scope of the constraints associated with IM.

Another aim of this study is to generate a data-informed midrange scientific GT or big-picture framework of racial death disparities among infants. The racial death-disparity landscape was tightly fitted, along with the underlying patterns of human behaviors and actions (causes, contributing and intervening risk factors) that precipitate and perpetuate untimely deaths of African American infants. Successfully stringing all associated factors will help solve a major medical and public health problem in the United States healthcare system. Similarly, discovery of theories regarding racial death disparities holds great promise for more evidence-based practice in public health related to reducing mortality rates for infants, especially in terms of program design, prevention initiatives, health education planning, health policy development, and organizational effectiveness (Alio et al., 2010).

In this study, the researcher built on existing knowledge while seeking to generate new knowledge and fresh insights from collected field data. This study was intended to lead to future quantitative research that might test generated theory. The grounded theory (GT) methodology was deemed most fitting for this study since it can ensure that participant voices, perspectives, and meanings were fully explored to explain racial death disparities among infants. In addition, it assisted with unraveling behaviors; structures and processes related to racial death disparities. In this study, GT strategy was complemented by data drawn from participant demographic information to illuminate, validate, and enhance the rigor and quality of the research findings. Qualitative research must be both scientific and creative, and should lose neither its characteristic elegance nor innovativeness in its final product (Whittermore, Chase & Mandle, 2001).

Research Questions

There are two main research questions guiding this theory-oriented qualitative study:

RQ1: What specific disease burden (risk factors or negative or exacerbating mechanisms) do African American women believe influences their birth outcomes, and explain persistent negative birth outcomes in their community?

SQ1: What specific actions, interactions, relationships, conditions, and behaviors do they associate with their negative birth outcomes?

SQ2: In what specific sequence (serial order) do these risk factors manifest themselves to influence birth outcomes?

RQ2: What sociocultural factors (positive or protective mechanisms) do African American women identify as potential buffers against adverse birth outcomes for them and other women?

SQ3: What are these health determinants?

SQ4: In what particular order or sequence do these play out in real life?

SQ5: Are these available to the majority of African American women?

Conceptual Framework

The conceptual framework chosen for this qualitative GT study is the social systems theory (SST), which explains “human behavior as the intersection of influences of multiple interrelated systems and subsystems” (Jackson, 1985), among which are social and environmental factors (Nguyen, 2015). The SST helped present complete, holistic, and coherent viewpoints. Racial death disparities in infants are the consequence of an aggregate of the effects of inequitable systems (micro and macro), in effect the sum total of individual, familial, communal, organizational, cultural, political, and socioeconomic levels of influences. When these factors come together as bio behavioral, sociocultural, political, economic and environmental health determinants, they can negatively upset birth outcomes in ways that we do not fully comprehend yet, although such knowledge could be used to predict, plan and prevent.

The SST offered a multidimensional perspective on the simultaneous analysis and exploration of the relationships between human perceptions and conceptions of the world they represent, with the goal of making the complex dynamics of human biopsychosocioeconomic, cultural, and political changes vividly intelligible (Laszlo and Krippner, 1998).

The SST has been used to analyze the social production of disease disparities that established the primacy of social structure, or the context of individuals, as determinants of racial differences in terms of disease, morbidity and mortality. This theory has also been used to appraise the multiple ways in which racism in all its forms might contribute to or exacerbate health inequalities in the United States, particularly the distinctive effect of racism on infant and women's health (Williams & Sternthal, 2010). For this reason, Ludwig Von Bertalanffy (Laszlo & Krippner, 1998) and the proponents of SST argued that there are underlying principles of organization at work in both social and natural systems of social organization. As a result, the success of the natural sciences in explaining, predicting and controlling natural systems is largely due to their ability to diligently explicate and make more comprehensible the mechanisms associated with the vast array of events, conditions, behaviors, actions, interactions and relationships in the social realm. Unmasking both internal and external mechanisms of racial IM has substantially enhanced our ability to explicate, predict and control these influential forces.

The second applicable theory in this study was the critical race theory (CRT), developed by Horkeimer, Adorno and Marcuse of the Frankfurt School (Robert Wood Johnson Foundation, 2008) for the purpose of critiquing, challenging and changing society by interrogating inherent contradictions. CRT has been used to clarify the connection among economic, political, social, environmental and cultural dimensions of contemporary society (Kellner, 1993). Proponents of CRT insist that organized and differentiated energies among these variant factors can be adequately harnessed and effectively used for totality of social change action. CRT is radically illustrative, practical, and normative in its analysis of the social human realities that more often than not favor a few persons, and discriminate against the majority. SST and CRT were appropriate lenses for this research and its stated purpose.

Although identifying the theoretical concepts at this stage in a GT qualitative research paradigm has the potential to introduce unintended bias, the principal purpose of a GT study is to generate an explanatory theoretical framework. In this case, the purpose is to explain death disparities in IM among African American infants. I introduce these theoretical lenses at this stage in the study to meet Walden University's research requirement.

Corbin and Strauss (2015) suggested that GT could competently assist with uncovering the underlying structural systems imbedded within persistent racial and ethnic death disparities in infants. While SST specifically addressed the mechanisms related to the risk factors for negative birth outcomes (RQ1), CRT focused on the protective sociocultural mechanisms associated with improved birth outcomes (RQ2) for African American women.

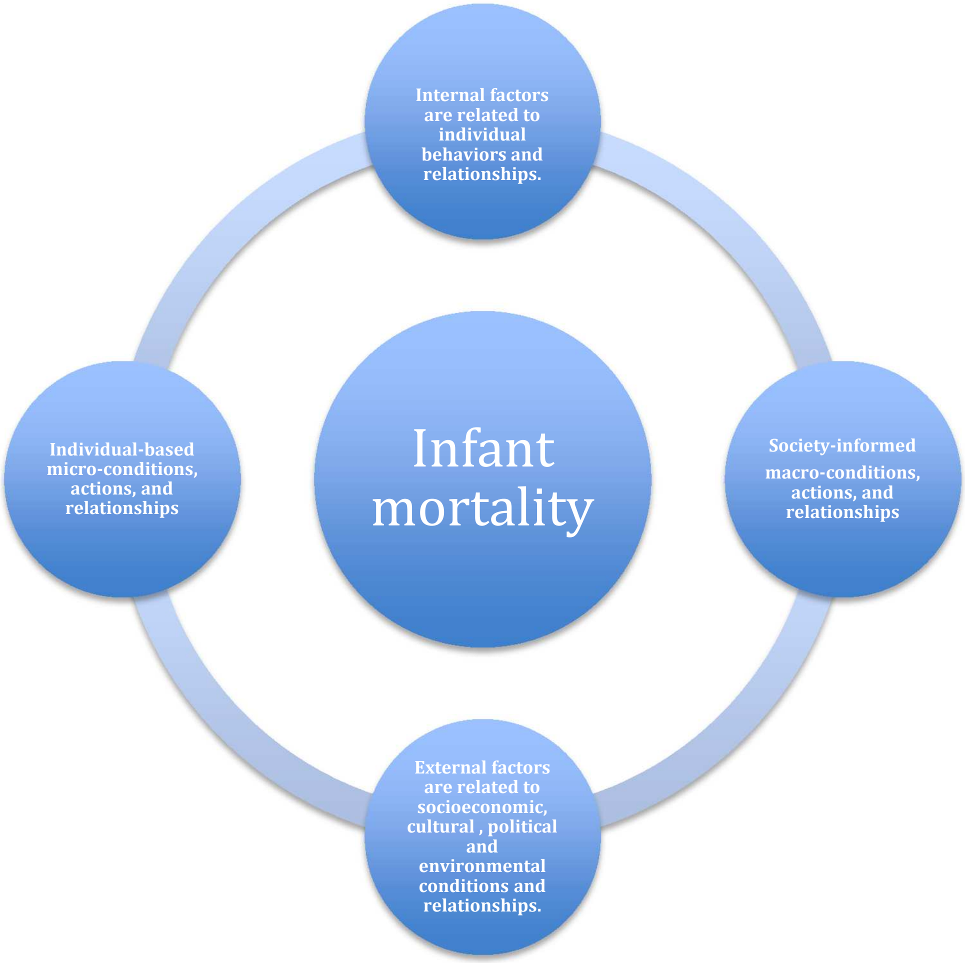

Figure 1. Conditional consequential matrix

Nature of the Study

The qualitative research design chosen for this study was the GT research methodology, which uses a systematic and inductive strategy (Ng & Hase, 2008; Glaser, 1978). It could be used as a constructivist or interpretative research approach to discover the underlying social structures that shape actions, interactions, and behavioral patterns of a group in their natural setting (Becker, 1993; Laws & McLeod, 2004; Morse &

Richards, 2002). According to Glaser (1998) and Elliott and Lazenbatt (2005), GT is a combination of research methods that includes data collection, theoretical sampling, and constant comparative data analysis and memoing, to enhance rigor, quality, validity, worthiness and the scientific merit of research findings.

To generate data for this study, the researcher collected and analyzed the views of 6 African American women who reside in 18 cities in Franklin County, Ohio. These women had firsthand experience with preterm underweight birth and infant deaths, within the last 5 years. The women were willing to share their experiences of pregnancy and birth, leading up the death of their infants. The information they provided was analyzed to understand more fully the general processes and behavior patterns that may have influenced the deaths of their infants.

Therefore, the goal of GT in this study was to generate a data-informed theory that explained how the various aspects of the social worlds of the African American women worked in reality (Ke & Wenglensky, 2010; Creswell, 1998; Dick, 2002) for, and/or against their pregnancy and, infant birth outcomes.

Using data from the field, and GT methods, the researcher tried to explore all relevant issues, by specifying the sequence of events that more than likely helped to shape adverse birth outcomes for these women. Rich (2012) said that with GT, researchers look for the central ideas or concepts that answer the question, ‘What is going on here?’ To answer this question, the researcher analyzed the complex processes that constituted the major events in these specific contexts, to arrive at a substantive theory of associated events and conditions. This whole process required a creative abstraction of the lived realities of this group of women, toward providing an unmistakable picture of what was really going on for these women.

GT has been used to unravel complex behaviors and relationships (Stern, 1980). GT is more appropriate in cases where a holistic understanding of the lived experience of research participants is desirable (Wright, 2009). GT has been used to facilitate the generation of a scientific theory to explain specific aspects of racial IM (Wilson & Hutchinson, 1991). In this study, GT was intended to capture the mechanisms that portend negative birth outcomes for large portions of African American women.

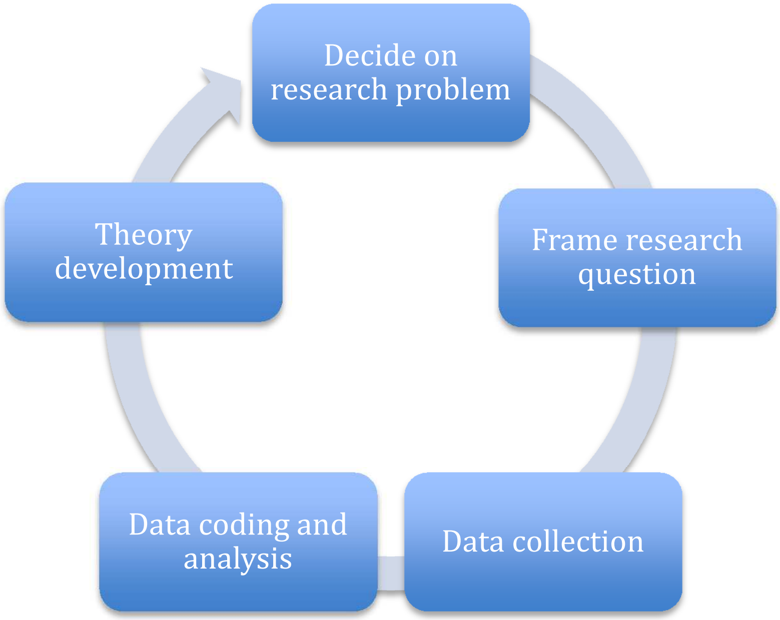

Figure 2: The GT research process

Research Design and Method

This study collected, described, analyzed and interpreted the perspectives of African American women (ages 18-45) who had lost infants during the last 5 years due to preterm, underweight birth or IM incidents. Since this study involved the generation of a theory that was grounded or rooted in real data, it was my goal to generate a sophisticated and reliable explanation for the trends in racial death disparities among infants. As a result, I closely examined collected data for the theory demonstrated by them. As in all approaches to qualitative data analysis, this GT study followed the classical procedures for data analysis, such as data collection, memoing, coding, theoretical sampling, constant comparative analysis, generalization, and the comparison of generalizations to established theories and constructs. (See research Figure 3.)

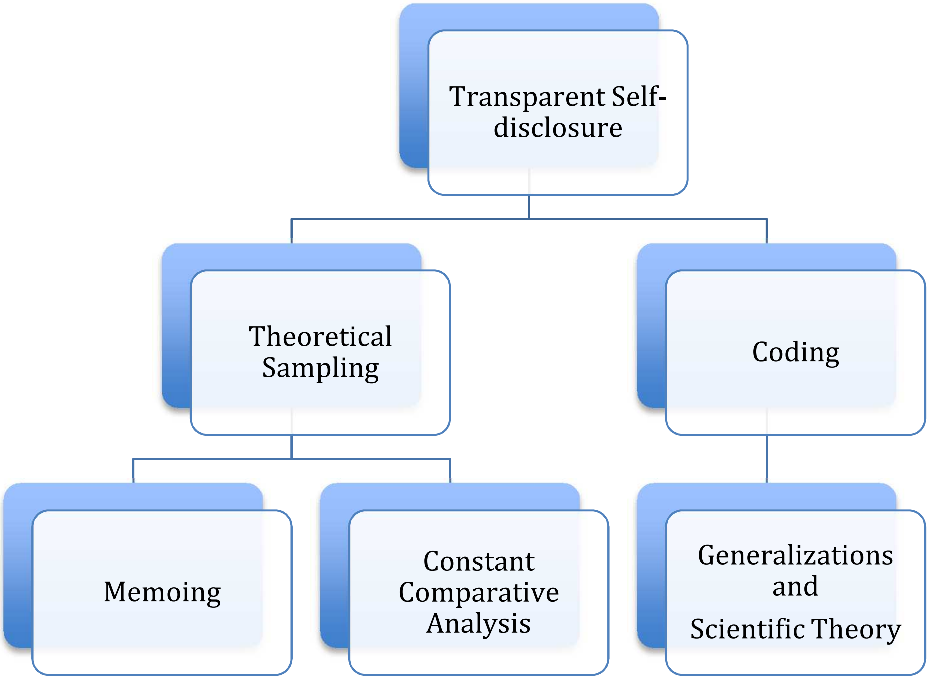

Figure 3: Research design flow chart

Operational Definition of Key Terms

Infant mortality (IM): The death of a baby before his or her first birthday (CDC, 2014). This refers to an estimate of death of infants for every 1000 live births (Sarto et al., 2014). It serves as an indicator of the health status of a population (Vanderbilt &

Wright, 2013). Therefore, IM is a reference indicator for societal health status (Willis et al., 2014).

Preterm birth: Refers to infants born with < 37 weeks of gestation (Burris & Collins, 2010).

Very preterm birth (VPT birth): Refers to babies born with < 32 weeks of gestation (Kramer & Hogue, 2009). VPT birth occurs in roughly 2% of all infants born in the United States. A low birth weight infant can be born too small, too early, or both. Generally, low birth weight babies and preterm infants are at greater risk for not surviving than full-term babies. Hence, low birth weight and preterm birth are considered high-risk factors for mortality among all infants.

Disparity: Refers to systematic and plausibly avoidable differences in the rates of disease, injury, disability, morbidity and early death burden among socially disadvantaged subgroups in a population (Braveman et al., 2011; Schetter et al., 2013). Braveman (2014) argued that many disparities are associated with social, economic, racial/ethnic and environmental disadvantages, as well as accessibility to healthcare.

Racial infant mortality: denotes obstetric outcomes that are linked primarily to maternal race and ethnicity (Bryant, Worjoloh, Caughley, & Washington, 2010). In the United States, low birth weight, preterm birth, and IM are generally higher for African American women compared to many other racial female groups. For the most part, poor socioeconomic conditions and other factors have been associated with prematurity, underweight birth and higher mortality risks in African American babies.

African American: Americans of full or partial African ancestry; otherwise called Afro-Americans or Black Americans (Merriam-Webster, 2014).

Epigenetics: A branch of biology about the causal interactions between genes and the products that bring a phenotype into existence (Epigenetics, 2016; Waddington, 1968). In recent times, it has come to refer to the study of changes in gene function that are inheritable but do not entail a change in DNA sequence (Wu & Morris, 2001). Epigenetics may be useful in guaranteeing genomic stability for upcoming generations of infants (Dupont, Armant & Brenner, 2009). Scientists consider it a promising corridor to the modification of biological genes and, the control of the environmental influences that often upset desirable birth outcomes.

Grounded theory approach: A systematic but flexible qualitative research methodology that uses a series of cumulative coding cycles and reflective analytic memoing to develop major categories, for generation of a substantive theory from empirical data. GT has been used to produce a model map of why the world is the way it is, from the perspective of research participants. It is a simple explanation of what is, what works, what is going on in a particular environment, and why.

Researcher Assumptions

An underlying assumption in this study is that there is a relationship between the higher prevalence of IM rates in Franklin County and the mothers' race or ethnicity, in addition to their prolonged exposure to stress and harsh socioeconomic conditions, and the epigenetic conditions of the infants. Being an American of African descent, I have substantial lived experience that has led me to believe that some relationships might exist among these risk factors that all too commonly and negatively affect African American birth outcomes. In addition, Alio et al. (2010) argued that a complex web of factors might have a direct effect on women's birth outcomes. These factors include the historical experience of African American women in the United States, plus maternal and family characteristics, as well as the particular socio-ecological context.

Scope, Limitations, and Delimitations of the Study

This study was limited in five major ways. First, the study samples from Franklin County residents could not serve as a true representation of African American women between the ages 18 and 45 in the United States who have lost their infants in the last 5 years. Second, study participants were limited to those who use publicly funded and privately run clinics, hospitals, and healthcare systems. In Franklin County, 20% of all wage earners received 48% of total household income, while the bottom 20% earned 3.2% of household income in 2010 (Santa Clara County Public Health Department, 2012). The health of residents is tied directly to their personal economics, and to their livelihood and conditions in their environment. Access to healthcare services is among the critical determinants of health for women and their infants (Public Health Institute, 2015). Third, this study was not concerned with trends in fetal and perinatal mortality. Fourth, study participants did not include women who had lost infants due to Sudden Infant Death Syndrome (SIDS), through medically induced abortion, or any other forms of intentional injuries to an infant. Fifth, the study also excluded all involuntary pregnancy losses such as miscarriages, ectopic pregnancies, fetal deaths, and stillbirths (Van & Meleis, 2002).

This study was delimited because while the perspectives of male parents of deceased African American infants were collected, they were not included in the data analysis and interpretation. Future research concerning African American infants who died before their first birthday could focus on analysis of the perspectives of male parents.

Despite the inherent limitations and delimitations of the present study, the researcher took appropriate steps to ensure that research questions were thoroughly addressed, with nominal methodological weaknesses and biases, so as to increase the degree of generalizability. In this way, emerging theories could be adaptable to comparable populations and research settings.

Rationale and Significance of the Study

To the best of my knowledge, no previous study has offered an explicit, holistic and integrated bigger picture of the relationships among the network of complex root causes and contributing and intervening risk factors, using a framework robustly grounded in the experiences of African American women. Qualitatively understanding the role of multifarious sociocultural, ecological and economic determinant factors (explicit and implicit)—such as the nuances of little-known threats of ethnicity and structural racism (Cascari-Stone, Wallerstein, Garcia & Minkler, 2014)—on maternal health and safe infant birth will help to unravel the mechanisms of IM. By closely analyzing these contextual influences, we have come to better comprehend the challenges they pose to maternal and infant health. Consequently, the best we can hope for is that this study will lead the way in the design of innovative interventions and strategies to counter infant fatalities.

Although it is granted that IM is the result of confluence of factors (the five levels of influences), most notably individual, interpersonal, institutional, community and public policy factors, no prior study has explored African American women's birth preparation. Furthermore, beyond conventional risk factors such as income, education, prenatal care, marital status and substance use (Giscombe & Lobel, 2005), no study has demonstrated how the totality of events, conditions, actions, behaviors and relationships might result in a horrendous loss experience over a long period of time.

By all accounts, IM has immense capacity to permanently change natural pregnancy outcomes for minority women (Dominguez, 2008; Hauck et al., 2011; MacDorman & Matthews, 2011).

Another major contribution of this study is its ability to identify existing gaps in current literature. This is an important step in the theory discovery process. This discovery is an original contribution to the field of health services, and community and public health sciences. This discovery will likely facilitate a speedier transition to a more equitable, evidence-based and efficient public health delivery system. The discovery of a theory of racial death disparities in infants stands to benefit health practitioners, funders, administrators, policy planners, health service researchers, program development experts, health advocates, program evaluators, and community members. This was part of my goal to make an original contribution to the field of health services and healthcare administration.

Summary

IM continues to affect ethnic and racial minority infants, including Americans of African ancestry in Franklin County, Ohio. While previous studies pointed to numerous risk factors as causes or influences, no study yet has explicitly demonstrated how the myriad set of risk factors interacts and actively gestates to persist at current crisis proportions. In some ways, IM serves as a microcosmic illustration of the health disparities inherent in the larger U.S. society. Therefore, determining reasons for death disparities for African American infants is the purpose of this study.

Given the magnitude of this problem, IM is probably a real test of Americans' determination to guarantee equitable, quality, efficient, timely and cost-effective healthcare for U.S. women and their infants. A healthy pregnancy is perhaps the best promise of, and an excellent starting point for, healthy new generations of Americans (Val Hal, 2010). Maternal health and birth outcomes are hardly inseparable. Therefore, any investment in women's health can yield inversely proportional gains for infants over time.

By mapping the structural sequence of associated risk factors over time for disparities in infant outcomes, this study has contributed to an improved understanding of racial death disparities from the perspective of America's most at-risk population.

In this chapter, I presented the basic elements of qualitative GT research. Chapter 2 offers viewpoints from extant literature, showcasing major themes and gaps in the available literature.

Chapter 2: Literature Review

Introduction

This literature review examines previous frameworks used to analyze the mechanisms of racial death disparities in African American infants. Corbin & Strauss (2015) and Becker (1986) maintained that in a GT study, the literature review must improve data analysis and theory discovery. The literature review, at this stage in this study, is undertaken primarily to comply with Walden University's requirements, and raises some concerns about the possibility of bias in this particular approach. However, typical to all GT research, the literature review is generally shelved until the data collection and analysis have been conducted. This is in part because the literature review at this stage in the research has the potential to inject unintended bias, which in effect would constrain theory discovery and reflexivity.

Research Strategy

I searched multiple databases, including Google Scholar, NCBI, EBSCO host, Thoreau and ProQuest through the Walden University Library. I searched the following databases for reviews regarding IM: PubMed, CINAHL Plus, Cochrane Database of Systematic Reviews, Database of Abstracts of Review of Effects (DARE), Education Research Starters, MEDLINE with Full Text, Opposing Viewpoints in Context, Political Science Complete, PsychBooks, PsychCritiques, PsychExtra, PsychINFO, SAGE Knowledge, SAGE Premier, SAGE Research Methods Online, ScienceDirect, SocIndex with full text, Web of Science, and ProQuest Health and Medical complete. I searched all articles containing the key terms: racial and ethnic disparity in IM and African American women. Then, I restricted my search to studies conducted in the United States. I sourced additional information from county, state and national agencies, as well as health program websites, and reviewed reference lists for additional relevant information. While there was broad agreement that a complex web of factors contributed to death disparities in Black/White perinatal mortality (Alio et al., 2010), there was little evidence that any particular study had pursued this line of thinking.

Infant Mortality

In global health, the infant mortality rate (IMR) is considered a significant reference point and a reliable indicator for the overall health of a society (Willis et al., 2014). In 2010, the U.S. IMR was at 6.1 infant deaths per 1000 live births, ranking 26th among the Organization for Economic Cooperation and Development (OECD) member countries, immediately behind Slovakia at 5.7 (MacDorman, Matthews, the National Center for Health Statistics et al., 2014). IMRs in the United States are approximately 42% higher than in comparable OECD countries (Gonzales & Kamal, 2015). Between 2000 and 2013, IMRs in the United States declined by 13%, to approximately 5.96 infant deaths per 1000 live births (Gonzales & Kamal, 2015; Xu, Murphy, Kochanek & Bastian, 2013). Yet, during the same time period, ominously higher mortality rates persisted among African American infants (Matthews, MacDorman, & Thoma, 2015). At the time of this study, African American infants were twice as likely as Whites in the United States to die in infancy or before their first birthday (Rodriguez, Bound, & Geronimus, 2014).

The overall number of infant deaths in the state of Ohio was 1024 in 2017, up by 19 more deaths from 2016 (Ohio Department of Health, 2017). At the present time, Ohio ranks near the bottom nationally in IMR, mostly for all racial groups, and particularly for African American infants. While infant death rates dipped in the 1990s for all races and ethnic groups, in 2015 1005 infants died before they could reach their first birthday, and that number increased by 21the following year. With a nearly 2% annual increase in infant deaths for White, Black and Hispanic infants, Ohio is too far along to meeting the national average. According to the Ohio Department of Health (2016), there were 138 198 live births in Ohio, with total infant deaths of 1024, or an IMR of 7.4. During the same period, there were a total of 18 955 live births in Franklin County. However, 167 babies, or 8.8 per 1000 live babies (20 more babies than in 2015), never lived to mark their first year.

Ordinarily, the opportunity for health and wellness for all infants is impacted by maternal stress, racism and related factors (Giscombe & Lobel, 2005), as well as lifestyle-related variables such as income, education, prenatal care, marital status and substance abuse. There is a growing awareness that while maternal work, pay and play affect birth outcomes, these factors do not fully account for the disparity in outcomes (Giscombe & Lobel, 2005). In recent times, researchers have shown that maternal stress, ethnicity and residential neighborhood-related issues may affect an infant’s chances of survival long before use of medical care services (Santa Clara County Public Health, 2011). Consequently, unearthing the root causes (biological, genetic, epigenetic), the contributing risk factors (ecological, socioeconomic and access to timely healthcare), and enabling social conditions (such as cultural, political and social relationship factors) have the potential to spur positive social changes, and to compel innovative program designs to reduce IM in affected populations.

Key Components of Infant Mortality

The CDC (2013b) classified IM into two distinct post-delivery age periods: *neonatal* (death less than 27 days after birth) and *post-neonatal* period (death between 28 and 364 days after birth). A greater proportion of infant deaths occur in the neonatal period, resulting mainly from a combination of any of the five leading causes of death in infants: preterm complications, birth defects, maternal health conditions, labor/delivery complications, and the lack of timely access to adequate care at the time of delivery (CDC, 2013b).

Post-neonatal deaths typically result from SIDS (Shin, 2012; Pearson, Ward-Platt, & Kelly, 2011), assault, injury, infection (largely from pneumonia), and low birth weight (Chen et al., 2014). Chen et al. (2014) said that post-neonatal mortality is a key driver of U.S. high infant death rates, and might also explain regional and geographic death rate variations among U.S. infants.

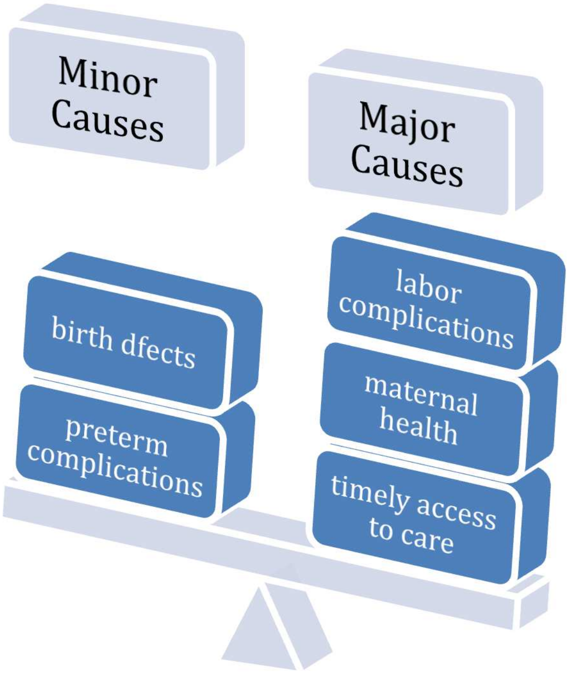

Figure 4: Leading causes of death during the neonatal period

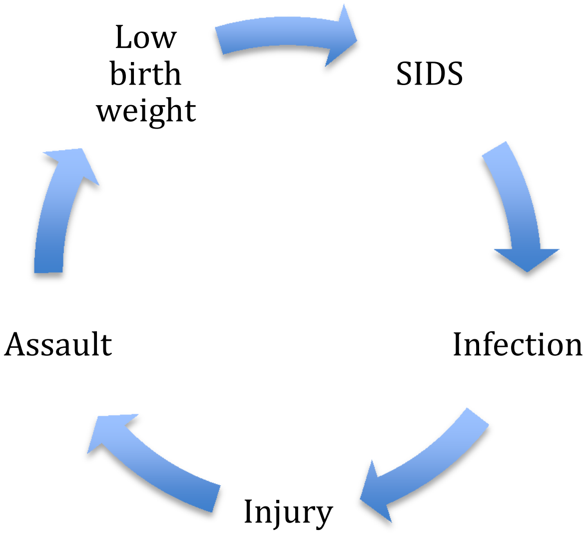

Figure 5. Leading causes of death during the post-neonatal period.

Preterm Birth

In the United States, premature birth (<37 weeks of gestation) is an intermediate cause of IM and morbidity (Kramer & Hogue, 2009). Preterm infant deaths for African Americans occur nearly twice as frequently as for Caucasian infants (CDC, 2013b). Available evidence suggests that the United States' low-ranking status among member nations of the OECD is largely due to the high percentage of preterm deaths among African Americans (MacDorman & Matthews, 2010; 2014) and other minority infants. In 2013, the overall preterm birth rate was 11.4% for all groups, 11.3% for Caucasians, and 16.3% for African Americans (Martin et al., 2013). In 2013, the prevalence of *low birth weight* (<2500 grams) for all races was 7.9% for all births, 6.97% for non-Hispanic Whites, and 13.18% for African American infants (Child Health USA, 2013). Overall, preterm and low birth weight babies are at greater risk for IM (6.1 infant deaths per 1000 live births); African American infants are at twice the risk for death (11.5 per 1000 live births) as Caucasian infants (5.2 infants per 1000 births).

VPT and Underweight Birth

Very preterm live births (<32 weeks of gestation) account for a considerable number of infant deaths in any given year. In 2009, approximately 2% of all live births lived to be less than a month. In that time period, African American women had 2- to 3-fold elevated risks rates compared with White women, for reasons that are not exactly known (Kramer & Hogue, 2009). The causes and contributing factors associated with VPT births include under-weight or/and very low birth weight birth (<1500 grams).

Underlying Risk Factors for Racial Disparities in Infant Death

Over the years, persistent racial and ethnic disparity in IM has been attributed to complex causes and contributing risk factors interacting together to produce the high rates of morbidity and IM in the United States (Kramer & Hogue, 2009). There are numerous studies where researchers focused on maternal characteristics such as biological, genetic and behavioral factors (e.g., maternal age at pregnancy, marital status such as single motherhood, education level, employment status, and income level) as the root causes for significant differences in low birth weight and premature birth among racial groups. Recent studies have also emphasized the central role of interpersonal relationships (at individual, family, community, organizational and societal levels) in adverse pregnancies. In their theory of fundamental causes, Link and Phelan (1995) and Phelan, Link, and Tehranifar (2010) argued that there was a substantial association between the scarcity of socioeconomic resources (money, knowledge, prestige, power, opportunity and beneficial social connections) and mortality of women and infants.

Recently, a large body of research has used the ‘social determinants of health theory’ approach (economic and environmental influences, such as work, life and play opportunities), to explain the disproportionate differences in health status and death rates among racial groups. These studies rigorously analyzed each of these factors as either a risk or protective factor for IM (Jackson, 2007). However, Smedley (2012) asserted that a growing body of research has illuminated the mechanisms through which racism and discrimination might influence the health status of people of color.

As defined by Jones (2003), racism is a system of structuring or restructuring opportunities and assigning values that is based purely on phenotypic properties (e.g. skin color and hair texture). In short, it is a way of thinking and acting in the world that intrinsically segregates "us and them." Racism may operate in different forms, at individual, internalized, institutional and structural levels (Santa Clara County Children's Health Assessment, 2017; Smedley, 2012). As a consequence, the Institute of Medicine (IOM, 2002; 2003) established an overwhelming body of evidence to validate the claim that racial bias or discrimination (in housing, mortgage lending, education, employment opportunity, and access to healthcare) and associated stereotyping might underlie health inequities and death disparities (Smedley, 2012). Lu and Halfon (2003) and Lu et al. (2010) additionally discovered that everyday exposure to racism-related chronic stress permanently alter the physiology of a pregnant woman, and thus can indirectly upset the outcome of her pregnancy. Therefore, unconscious racism and its accompanying implicit biases (including microaggressions, and daily verbal and behavioral indignities) have the potential to increase the risk for morbidity and mortality even for the very young (Hartil, 2014; Jackson, 2007). Put mildly, maternal stress felt mostly through direct brushes with racism is broadly considered an implicit risk factor or stress mediator for low birth weight, premature birth and adverse birth outcomes for women in these situations.

Genetic, Biological, and Lifestyle-Related Risk Factors

Genetic and maternal behavioral characteristics (Jackson, 2007), including high teen-pregnancy rates, lower education, lower income levels, and marital status (such as single motherhood) have been used to explain the differences in infant death rates among races. The behavioral factors that have commonly been associated with racial death disparities include the following: maternal drug and alcohol use, sexual promiscuity, cigarette smoking during pregnancy, poor nutritional choices, and other unhealthy maternal gestational behaviors that sometimes expose infants to unfavorable pregnancy outcomes (Carpentier, 2010; Salihu & Wilson 2007). However, these claims have been forcefully challenged by the findings of Lu et al. (2003) of statistical differences in the incidence of IM between foreign-born and U.S.-born African American women. In addition, Wingate and Alexander (2006) have argued that there was substantial evidence to support ‘the healthy migrant effect’ on pregnancy outcomes.

Effects of Smoking during Pregnancy

The effects of maternal smoking during pregnancy have been shown to alter newborn DNA methylation in the genes, predisposing at-risk infants to increased likelihood for adverse perinatal outcomes, including low birth weight and long-term health risk consequences, such as high blood pressure, obesity, and behavior-related disorders (Richmond et al., 2015). Salihu and Wilson (2007) also found that smoking during pregnancy accounts for a 20-30% infant risk of stillbirth and a 40% risk elevation of death from SIDS. According to Dietz et al. (2010), prenatal smoking remains one of the most preventable causes and contributors to disease and death in U.S. infants. While the risk of death among infants may vary across racial and ethnic groups, the risk of death tends to increase considerably more during the post-neonatal period than during the neonatal period (Salihu, Aliyu, Pierre-Louis, & Alexander, 2003).

Role of Nutrient Deficiencies

In their groundbreaking research, Dunlop, Kramer, Hogue, Menon and Ramakrishan (2011) found that nutrient deficiencies are potential contributors to the disparity in preterm birth between African American and Caucasian women. Available data also suggests that the pre-conception period may be the most important period for determining and intervening to positively influence pregnancy outcomes. Additionally, African American women are at greater risk than Caucasian women for nutrient deficiencies of iron, folic acid, zinc, vitamin D, calcium and magnesium, and the imbalances of *w*-3 and *w*-6 polyunsaturated fatty acids (Dunlop et al., 2011) during pregnancy. Hence, available evidence points to varying degrees of association between nutrient deficiencies and preterm low birth weight and IM.

Medical Decisions and Healthcare Access

There is widespread agreement that early-onset use of prenatal care (during the first, second, or third trimesters of pregnancy) is both cost-effective and markedly associated with reduced risk for low birth weight and improved pregnancy outcomes, especially for women with limited education or increased medical and social-risk factors (Institute of Medicine, 1998). Hence, women who do not seek prenatal care early (in the first trimester) in the course of pregnancy are more likely to be at greater risk for IM. Such complacent behavior can be devastating for infants and their mothers.

Socioeconomic Risk Factors: Social Determinants of the Health Model

Some health scientists contend that social phenomena such as IM should be studied within the broader context of human relationships (e.g. an individual woman’s relationship to her family, her residential neighborhood, cultural community, and the larger social systems, including her access to economic opportunities such as good-paying jobs). They maintain that each of these relationships could potentially have either positive-protective or negative-accelerating influences on women's physical, biological, emotional and psychological health and wellbeing (Jackson, 2007). Chen et al. (2014) further suggested that IM might vary strongly across socioeconomic groups and the demographic characteristics that sometimes emulate existing social inequalities.

In its support of this position, the National Research Council (2013) reiterated that differences in income are likely to impact mortality gaps and health inequality. Hence, the disproportionate rates of (post-neonatal) IM among disadvantaged groups in the United States (Chen et al., 2014) may be associated with socioeconomic deficits. Currie and Cole (1993), Baker (2008), Almond, Hoynes, and Schanzenbach (2011), and Hoynes, Miller, and Simon (2012) subscribe to the idea that income disparity might be related to health and to death disparities among infants.

Racism, the Ecological Perspective, and Social Relationships

Recent studies have shown that social relationships can have enormously positive or negative implications for pregnancy outcomes (Jackson, 2007), in the same way that social relationships can enhance the chances for positive or adverse birth outcomes.

Despite the levels of sophistication and social integration achieved in most of America's diverse cities, race and ethnicity remain monumental markers for differential exposure to disease, disability and death, and are a major determinant for access to guaranteed societal resources (Williams & Jackson, 2005) and economic opportunities

(Mehta, Lee, & Ylitalo, 2013). Mays, Cochran, and Barnes (2007) went on to say, “it may seem quite ironic that something as simple as the color of one’s skin may be the decisive factor for who lives or dies, how and where they live, work and play” (p. 3). And while there is growing consensus that discrimination (actual and perceived) could harm individual and public health (Krieger, 2012), scientists have yet to clarify with predictable certainty the degree to which racism or discrimination might influence women’s health and birth outcomes. In the meantime, available evidence points to the malicious effects of racism and discrimination as likely underlying forces behind persistent death disparity among minority infants (Clark, 2003; Clark et al., 1999; Mays, Cochran, & Barnes, 2007).

Williams (1999) and Williams, Mohammed, Leavell, and Collins (2010) have argued that race, ethnicity and socioeconomic status are considerable burdens, which are likely to weigh heavily on birth outcomes for many minority groups. They suggested that these factors might actually contribute to gaps in racial death disparity through their masked social appearances. These include promotion of a feeling of inferiority; restriction or outright denial of access to socioeconomic opportunities and of upward economic mobility; increased bias in medical care and treatment; bias in the allocation of places of residence; the denial of full social integration; and prolonged associated stress on women and their infants. A case could also be made that the chronic stress of racism and its lingering socioeconomic consequences might have devastating effects on pregnancy outcomes for African American women (Dominguez, 2008), more than we realize.

Racism and Cultural Variations

Recently, Burris, Baccarelli, Wright, and Wright (2015), and William and Mohammed (2013), discovered important contributing factors to racial disparities, namely, cultural variations and racism, and residential or geographical segregation and discrimination (Clark, Anderson, & Williams, 1999; Dominguez, 2008; Engeland et al., 2015; Giurgescu, Zenk, Templin, Johnstone, & Kanitsaki, 2008; Krieger, 2000). Lu et al. (2010) and Goosby and Heidbrink (2013) have also maintained that the experience of interpersonal and structural discrimination may be more of a major stress factor for pregnant African American women than was originally thought. Racism, they asserted, is intimately linked to adverse pregnancy outcomes. Structural racism, in particular, exerts substantial negative effects with its characteristic socioeconomic depravity and the accompanying systemic discrimination (Jackson, 2007; Wallace, Mendola, Liu & Grantz, 2015). More and more evidence hints at racism-associated stress contributing to increased stress levels, and the chances of adverse birth outcomes (Lu et al., 2003; 2010). Overall, racism may manifest in one of three ways: as internalized, personally mediated, or institutionalized (Contra Costa Services, 2010).

Social forces, such as structural racism with its class gaps and social systems of skewed power dynamics, generally produce inbuilt mechanisms that commonly influence society’s policies, procedures, practices, norms and values in persistent and permanent ways (Jones, 2016). It reinforces a system that privileges a select segment of society at the expense of another. At the very least, racism has been shown to perpetuate formalized discriminatory institutional systems of governance (institutions), economics (businesses), education (schools), housing (residential and business), healthcare delivery (Eyles & Woods, 1983; Jones & Moon, 1987; Smith, 1988), and social justice systems (law courts) that are designed to limit opportunities for certain ethnic and racial groups (Jackson, 1985; 1989), almost exclusively to the benefit of another group. As a result, Williams and Jackson (2005) emphatically argued that ‘race’ is a little-known marker for differential exposure to multiple disease-producing social factors and pregnancy outcomes.

Ecological Perspective, Residential Neighborhood Environment, and Transportation

The ecological perspective, or social environmental approach (Yen and Syme, 1999), emphasizes the role that interdependent multiple factors play in health behaviors and wellbeing of individual members of a society (Barry & Honore, 2009; National Cancer Institute, 2003). The extent that the social context in which one lives, works and plays might actually impact one’s susceptibility to disability, disease and death (Yen & Syme, 1999) is astonishing. These factors can exert considerable consequence for one’s overall health status at one of five levels: individual, relational, environmental, system and structural (Scott & Wilson, 2011). Until recently, researchers have underestimated the role that disparities in residential neighborhoods play on health, yet the role that access to safe, healthy housing and to means of transportation play in individual social economic status and overall population health and longevity is still underestimated (Litman, 2013; Wahowjak, 2016; Williams & Collins, 2001; Williams & Jackson, 2005).

Massey and Denton (1993) famously compared U.S. residential segregation to South African apartheid, which prevented native African residents from fully integrating and taking root in their own society. Similarly, Williams and Mohammed (2009) claimed that institutionalized racism not only shapes access to other resources and opportunities for education, work and income, but also that it can influence residential choices for generations of African Americans (Brondolo, Gallo, & Myers, 2009). Furthermore, emerging evidence increasingly supports the idea that residential segregation is an enduring vestige of structural or institutional racism in the United States (Becares et al., 2012; Landry and Marsh, 2011; Sullivan, 2013). Evidently, racial differences in socioeconomic status, neighborhood residential conditions, and access to medical care are critical contributors to racial differences in disability, disease and death. Put simply, health and wealth disparities, as it were, are embedded within the larger historical fabric, and the geographic, sociocultural, economic, and political contexts of U.S. society.

As a result, racial disparities in health should be better understood, not merely in terms of individual-behavioral characteristics but more broadly in the light of socially mediated racial inequities that often grant or deny access to opportunities to some ethnic groups. For instance, because of residential segregation, some African American middle-class families are compelled to live in poorer neighborhoods, even when they could easily afford to live in a more affluent neighborhood, like their White counterparts of similar economic status. To the contrary, some Caucasian families with lesser economic success are often privileged to live in more health-supportive neighborhoods than African American families with greater economic success. On the whole, African Americans are more likely to experience increased levels of residential segregation than their Latino, Asian and Caucasian counterparts, regardless of their levels of economic success.

There is mounting evidence that segregated residential areas increase the risk of adverse birth outcomes (Bryant, Worjoloh, Caughley, & Washington, 2010). Hence, obstetric outcomes may surprisingly differ by maternal race and ethnicity. Furthermore, there is evidence that these factors significantly contribute to higher rates of infant and maternal mortality among minority groups (Mehta, Hedwig, & Ylitalo, 2012), because of their enduring association with social and economic opportunities and resources. For this and similar reasons, African American women are disproportionately exposed to not merely unhealthy neighborhood environments (Giurgescu, Zenk, Templin et al., 2015), but may also have limited access to socioeconomic opportunities, and severe income disparity that are likely to increase their chances for outright poverty, and perhaps for adverse obstetric outcomes.

As a result, Polednack (1991) and Bird (1995) maintained that beyond socioeconomic constraints (Gesler, Bird, & Oljeski, 1997), a good predictor of Black-White differences in IM was residential dissimilarity. Again and again, as a risk factor, residential segregation generates anxiety and stress-related health problems for minority women (Schoendorf et al., 1992), before, during, and after their pregnancy. Frequently, this condition will result in increased chances for low birth weight in their infants (Newland, 1981). Hence, Buckner-Brown et al. (2011) harped on the idea that the health of an infant is almost always indirectly embedded within the larger context of socio-environmental policies, organizational practices, and the availability or lack thereof of supportive social networks.

In many ways, these factors constitute the structural pathways to racial disparity in infant death (David & Collins, 2007). And in much the same way, the availability of efficient, integrated, equitable and cost-effective transportation policies and planning decisions might positively sway maternal health and wellness (Litman, 2013). As a result, Gaskin, Dinwiddie, Chan, and McCleary (2012) suggested that disparity in the utilization of healthcare services is also directly related to ethnic and racial identity. That being the case, any lasting solutions to address current pervasive residential differences must also tactically confront the structural segregation that often sustains these practices.

In conclusion, while race/ethnicity disparities in infant and adult outcomes are well documented, very little is known about how the patterns and trends in race and racial-ethnic relations actually affect infants' birth, survival and death. At this time, it is difficult to tell with a high degree of certitude how racism affects the quality of obstetric care, from pre-conception to the prenatal, intrapartum, and postpartum care phases. According to Burris and Collins (2010), and Hauck, Tanabe, and Moon (2011), what we do know for sure is that partial access to health services, poor utilization of available prenatal care, and the presence of stressful life events before, during, and after pregnancy (in addition to early-life programming and cumulative wear-and-tear factors) all contribute to the noticeable differences in infants' death rates in African American infants (Burris & Collins, 2010; Carpentier, 2010; Class, Khashan, Lichtenstein, Langstrom, & D'Onofrio, 2013; Eberhardt & Pamuk, 2004; Neelon et al., 2014).

Political Forces

Rodriguez et al. (2014) have shown that the political system may also be a lesser-known component of the underlying mechanisms of racial IM. It continues to engender vast disparities in health and death for U.S. infants. Take for example, across nine presidential administrations, IMRs have been shown to decrease when the president was a Democrat, and increase when the president was a Republican (Rodriguez et al., 2014). Nevertheless, much is unknown as to why these contrasts exist, and why the sociopolitical factors continue to place undue constraints on infants' health outcomes (Williams & Sternthal, 2010), and on the quality, availability of care, and health resources for minority women and their infants (Eyles & Woods, 1983).

More often than not, the decisions that influence health, lifestyle choices, living conditions, and birth outcomes are made not in the legislature, the executive mansion, or courtrooms, but in corporate boardrooms (Freudenberg, 2012). Corporate interests often trump community health and wellbeing. Hence, advancing multilateral partnerships among stakeholders—public, private and hybrid pro-health groups (Goldberg, 2012; Malhotra & Heiman, 2012), health services organizations, research institutions, foundations, and faith and business communities—is both desirable and imperative. Hence, this study will benefit community participants, healthcare practitioners, and health researchers alike.

Epigenetics and Maternal Exposure to Prolonged Chronic Stress

While other factors may affect health disparities, review of the literature indicates that racial disparities in pregnancy outcomes often result from prolonged exposure to chronic stress, which “cause[s] the fetus to develop chemicals that turn their individual genes on or off” (Carpentier, 2010), and thus may precipitate or prolong latent genetic predisposition for specific disease risks. In this context, epigenetics, or the study of chemicals that mediate the expression of genes, is a crucial component of our solutions strategy for eliminating disparities in pregnancy outcomes (Burris & Collins, 2010; Carpentier, 2010).

Current evidence shows that understanding the “interplay between environmental exposures and human epigenome” (Bollati & Baccarelli, 2010), specifically the changes in phenotypic expressions and influences on the fetus, would likely help to explain the underlying mechanisms for racial death disparities among infants. In some ways, epigenetics posits that the future health of an infant can be predicted from its early life environment (Osborne, Fu, & Lane, 2013; Strunk, Jamieson, & Burgner, 2013). As Jimenez-Chillaron et al. (2015) put it, “epigenetics could be the missing link between genotype and phenotype.” Epigenetics is perhaps the best illustration for how racism can get ‘under the skin’ and effectively overturn the biological order of human physiology (Smedley, 2012), and effectively activate a health-risk propensity that under a different circumstance would remain latent in the human body. Beyond the socioeconomic and political consequences of racism, Sullivan (2013) reasoned that epigenetics is a real biological and physiological manifestation of the effects of generations of white privilege, white supremacy, and white prejudice, and years of racial discrimination against the Black race. It is a vivid reminder that the effects of racism are far more endemic and extensive today than had been previously discussed, admitted to, or accounted for in the literature. Nonetheless, it is still unclear precisely how these influences work themselves into actual differences in health and death disparities in ethnic minority populations (Burris et al., 2015).

Lu et al. (2003; 2010) and Carpentier (2010) have argued that the negative biological conditions of chronic stress are both leading and limiting factors for disparate pregnancy outcomes. However, it is still a guessing-game as to what extent prolonged stressful life events and unfavorable life conditions stemming from a woman's race, gender and socioeconomic status (Pearlin, 1989) act as negative biological factors for pregnancy in African American women (Rosenthal & Lobel, 2011). Regardless of how plausible this might seem, a growing body of evidence suggests that this does not fully explain the persistent racial disparity in pregnancy outcomes for African American women (Lu & Halfon, 2003). Yet, women who have experienced personal and institutional racism have been shown to report higher incidence of low birth weight and preterm birth (Carpentier, 2010). Although there is limited research at the present time, the role of these factors on pregnancy outcome is not at all in question. Few studies have pointed to epigenetics as a crucial link in the developmental stages of an infant (Jimenez-Chillaron et al., 2015). Nevertheless, Cortessis et al. (2012) maintained that epigenetics could potentially be a conduit for individual, generational and environmental disease risks. Burris et al. (2015), and Osborne-Majnik, Fu, and Lane (2013), suggested that epigenetics might also contribute to disease risk transmission and fetal fatality.

Limitations in the Literature

At the present time, it is unclear what the mechanisms associated with known and unknown risk factors for racial differences in infant deaths are, particularly how these elements interact and influence one another over the course of pregnancy to result in negative birth outcomes for some women. Understanding these dynamics is crucial to the prospect of eliminating death disparities among infants in the United States. Moreover, any compelling strategy to eliminate racial death disparity in infants must also be coherent, holistic, sophisticated, far-reaching and empirically robust in its approach. Such a solution must also seriously factor in the role that biology, environment and individual behaviors play (Kramer & Hogue, 2009); the capacity of rational maternal education to improve birth outcomes (Gage, Fang, O'Neill, & DiRienzo, 2013); and the effects of nutritional supplementation to address genuine nutrient deficiencies in some populations (Dunlop et al., 2011). Any effective solution must analyze cultural, organizational and institutional barriers, as well as other delimiting practices, behaviors and policies that even remotely play a key role in creating the current crisis level of IM.

Putting Strategy into Social Action to Eliminate Disparities

Social scientists maintain that social factors (e.g. the social causation of disease) influence biological risk factors in substantial ways (Anderson, 1952; Waitzkin, 1981; Wilkinson, 1990). Therefore, health status, and particularly that of infants, is at best the surface manifestation of the underlying social forces that govern it (Dear & Wolch, 1987; Gesler, 1991). As a result, there has been increased interest in studying these social factors at greater depth, and heightened commitment to translate research findings into actionable real-world health priorities. These include programs, policies, practices and interventions aimed at improved pregnancy outcomes. Effective interventions to eliminate disparities in IM must seriously consider highly integrated multisectoral collaboration across a broad social base. The care continuum must span from pre-conception through adulthood, pregnancy, postpartum and beyond (Hauck, Tanabe, & Moon, 2011), to level off current negative pregnancy outcomes for a sizable proportion of minority women.

Lu et al. (2003) discussed a 12-point plan to address social and health disparities that they argued were linked to adverse pregnancy outcomes for African American women (Carpentier, 2010). Their points included access to pre-conception care and quality prenatal care, active father engagement, a coordinated and integrated family, community support systems, as well as efforts focused at closing gaps in education and wealth, and eliminating racism. In addition, health experts, researchers and practitioners recommend a proactive infant death-prevention strategy, which must begin during the pre-conception period, with increased focus on health assistance to women of childbearing age (CDC, 2013b). In many ways, the opportunity to reduce the current rates of racial infant deaths is linked to the use of an efficient framework for tackling the causative, contributory and associative risk factors.

In addition, Koh et al. (2010) have suggested that any effective solutions must include a “whole stream” approach that encompasses the *upstream* or policy reforms, *midstream* improvement of the healthcare delivery system, and lastly, the *downstream* protective practices that foster individual behavior-change intervention. Put differently, any lasting solution must include changes in individual behavior, prevention and public policy, as well as changes in organizational practices to improve cultural and organizational practices, and to improve the environments that put some women at greater risk for adverse obstetric results than their counterparts (Buckner-Brown et al., 2011). Finally, health leaders must make the decision to remove limiting barriers to equitable care, maternity care needs, and the complex human conditions that sometimes "postmark" some women from certain social backgrounds for adverse pregnancy, and implicitly leave their infants at greater risk for disability, disease or death (Aquino, Edge, & Smith, 2015).

Summary

There is ample evidence to suggest that meaningful improvements in infant and maternal health would require considerable modifications of the social determinants of health (Freundenberg & Tsui, 2014). Much as "differential access to technology-intensive medical care" (Chen et al., 2014) is critical to infant survival during the neonatal period, perhaps of greater significance for decreasing post-neonatal mortality rates in the U.S. will be the presence of evidence-based interventions such as policies, patient-centered healthcare practices and programs for infants who face greater risks, given that they often come from lower socioeconomic backgrounds.

The health status of an infant is unvaryingly intertwined with the health of its mother (Genowska et al., 2015). Hence, the health of women and their infants is characteristically influenced by complex multiple factors known as the social determinants of health. These factors may include how much the infant's parents earn, their level of education, their race and ethnicity, their opportunity for meaningful employment, their access to timely quality healthcare, their access to health-affirming residential neighborhoods, or simply the circumstances into which they were born, work, play and live (Santa Clara County Public Health, 2012; Scott & Wilson, 2011). These factors largely underlie current disparities in IM among minority women.

With a rapidly-increasing diverse ethnic population in Franklin County, there is the need to better understand the etiology, social anatomy, epidemiology and, more pertinently, the theory behind infant death disparity in these communities. Understanding the peculiar pathways to inequities in birth outcomes within the social context of African American women will help us to begin to advance responsive countermeasures to adequately address the negative obstetrics disparity currently on full display.

This study is intended to help deepen our understanding of the principal mechanisms at work in racial infant death disparity. In addition, the study aims to identify evidence-based interventions that will effectively tackle the elements of this phenomenon: behaviors, actions, relationships, conditions and practices that directly or indirectly influence IM disparity rates within the African American community. In the end, building upon lessons learned over several years, to invest in safe, evidence-based policies and effective prevention and intervention strategies, complemented by meaningful advocacy measures, will help to stave off the ravaging effects of this fast-spreading death epidemic for African American infants.

In chapter 3, I will discuss the core methodological components of a qualitative GT methodology.

Chapter 3: Research Design and Methodology

Introduction

GT is one of five qualitative research strategies commonly used in human, social and health sciences. GT allows the core concepts in empirical data to emerge (Strauss & Corbin, 2008; Bitsch, 2005; Kolb, 2012), and for meaning to be co-created through a mutual partnership between the researcher and participants during the research process (Meyrick, 2006; Mills, Bonner, & Francis, 2006). GT does not seek the participants' full accounts as evidence; instead it favors a sensitive analysis of participants' narratives, for the purpose of finding more developed and abstracted meanings embedded in the narrative or empirical data.

As a research methodology, GT is best suited for gaining holistic and comprehensive insights into a study of a phenomenon. GT easily lends itself to the idea that any successful attempt to eliminate the death of infants in our society, by implication has to be cognizant of the diverse elements of the social systems that potentially militate against positive pregnancy outcomes for women. There is evidence that these factors have the potential to mitigate or aggravate the risk level for adverse birth outcomes for racial minority women.

Research Rationale and Design

Strauss and Corbin (1998; 1990) defined GT as a qualitative research method that uses a systematized set of procedures to develop and inductively derive a theory about a phenomenon. The experience and sophistication of researchers is vitally important to the quality of discovery in a GT approach. Creswell (2013) articulated the basic feature of

GT as a focus on actions, interactions and behavior patterns. I used GT to gather data through theoretical sampling, coding, memoing and constant comparative analysis. At its core, GT is a method that emphasizes a bottom-up theory creation through simultaneous data collection and data analysis (Maxwell, 2013; Patton, 2002). Denzin (1997) called GT the most influential paradigm in qualitative research in the social sciences.

Method of Inquiry: The GT Approach

There are five processes associated with GT, namely: choosing the research question, framing the research question, data collection by theoretical sampling, data coding and analysis, and theory development until theoretical saturation is achieved (Bitsch, 2005).

Rationale and Justification for GT

GT was considered most fitting for this study because it is effective for explaining the basic social processes. As Chenitz and Swanson (1986) said, GT is effective for discovering the basic human patterns common in the lived social life of a group. GT is particularly valuable where existing knowledge is inadequate, inaccurate, incorrect or totally biased (Creswell, 1994).

Furthermore, the constant comparative dynamics of GT make it suitable to uncover the processes by which related risk factors and health determinants—including biological, socioeconomic, cultural, ecological and racial/ethnic diversity factors—interact and influence infant birth outcomes. I chose the methodology for the purpose of gaining a new and better understanding, for taking appropriate actions in terms of planning, containing, and for changing the vexing adverse social conditions, events and behaviors that predispose African American babies to premature death.

GT was better equipped to present coherent and comprehensive explanations for the beliefs, behaviors, logic, emotions, actions and interactions at the root cause of racial death disparities. GT was preferred because I wanted a robust mid-range substantive theory that could explicitly explain the processes, pathways and intrinsic relationships among all risk factors. Given that all known risk factors have been shown to be individually incomprehensive and inadequate in explaining death disparities among U.S. infants. GT enabled me to generate underlying mechanisms of racial disparities in IM. GT was a valuable tool for organizing and linking emerging concepts. Corbin and Strauss (2015) said that GT would enable participants to 'own' their lived experiences while seeking plausible explanatory theory for their reality.

Strengths and Limitations of the GT Approach

The strength of GT lies in its orientation toward objectivity and realism, and its insistence on solving complex human and behavioral problems by identifying and clarifying the responsible social contributors (Stern, 1980). From the onset, GT required that the researcher eliminate all bias by publicly declaring them. GT maintains "scientific respectability" (Bryant & Charmaz, 2010), strewn with reasonable measures of rigor, self-reflexivity and adept creativity in data collection and analysis (Patton, 2002). Furthermore, GT maintains a healthy balance between objectivity and sensitivity (Strauss & Corbin, 1998), by capitalizing on theory generation as the heart-and-soul of scientific inquiry. The use of a GT approach insures that a researcher collaborates closely with participants (a power-sharing process), from data collection to data analysis, and all the way to theory generation (Strauss & Corbin, 1990). This guarantees that the evolving theory is not deduced a priori from pre-existing general models. As a result, GT design demands that the researcher takes appropriate steps to ensure that generated theory is discovered "in data" through closely-aligned empirical processes (Yin, 1991).

As Corbin and Strauss (1990) stated, GT must focus on production of rich descriptions, which invariably leads to the emergence of a systematic theory that would likely raise political consciousness (Corbin & Strauss, 1990) about pertinent social issues. Draucker et al. (2014) shared the view that GT can contribute to health-disparity study, and continues to retain the capacity to advance better understanding regarding the health experiences of people of color. For Moriarty (2011), GT is suitable for investigating sensitive topics, such as the experiences of under-researched, disadvantaged and vulnerable populations. All in all, GT remains a reliable method for constructing a mid-range theory to explain events, processes and mechanisms that likely influence participants' exclusive experiences.

GT is equipped to provide new and fresh insights into the activities that lead to the advent of a phenomenon of interest. As a result, meaning was discovered through interpretational processes that allowed for higher levels of categories of interpretation to go on (Parker & Roffery, 1993) until theoretical saturation was reached (Creswell, 2013). Likewise, coding and analysis went on until the evidence of theoretical density or theoretical saturation was reached (Hutchison, Johnston, & Breckton 2010). By this time, the core categories were saturated (Glaser, 1978), and theoretical completeness had been achieved (Glaser, 2001). Hence, GT is equipped to gauge participants’ views, beliefs, behaviors, attributes, preferences and perspectives (University of Arkansas, 2012). GT can provide rich description of current trends and characteristics of empirical data (Creswell, 2009), and was suitable for a study whose chief goal was to account for a myriad of cross-sectional influences: actions, interactions, conditions and behaviors that underlie persistent racial infant death disparity among the study population. In the words of Patton (2002), GT has opened the door to qualitative inquiry in social sciences, by emphasizing the importance of theory generation to explain a seemingly obscure phenomenon.

Despite all the advantages that may result from the use of GT methodology, it has a tendency to become overly prescriptive (Hodkinson, 2008), largely because of its emphasis on the production of a new theory. While the strengths of GT by far outweigh its limitations, Thomas & James (2006) cautioned that its universal acceptance, legitimacy and popularity among the social sciences are largely due to its positive contributions to the field of science since its introduction in 1967.

Role of the Researcher

The researcher played several important roles in this study: first and foremost was to listen attentively to participants as they provided their narratives in the form of semi-structured interviews, and to thoroughly analyze collected raw data (Chong & Yeo, 2015). Second, the researcher adequately interpreted emerging codes, concepts, categories and budding propositions. As in all qualitative inquiries, the researcher actively served as a key instrument in this study; he sought written consent from all research participants before any data collection, and maintained confidentiality with respect to participants' personal information and collected data. Equally notable, the researcher took appropriate steps to create an atmosphere of mutual trust and respect for all research participants.

For a study utilizing the GT design paradigm, there was a parallel between the personal values and beliefs of the researcher (Miles, Bonner, & Francis, 2006) and those of the research participants. It seems almost always true that GT is driven by a researcher's obsessive search for deeper understanding, meaning and change in a given circumstance. Hence, Miles, Huberman, and Saldana (2014) cautioned the GT researcher to be attentive to participants' own experiences, offering empathic understanding and, as much as possible, suspending all judgment and preconceptions in their recording and accounting of events and conditions of researched reality.

Moreover, the researcher must endeavor to gain a holistic (systematic, all-encompassing and integrated) view of the research context, so as to capture more accurately the perceptions of each participant (Miles et al., 2014). As a result, this researcher pursued a constant comparison of collected data, by contrasting and analyzing emerging codes, concepts, themes, categories and patterns as he constructed propositions for thorough review by study participants. Furthermore, the researcher had to certify that all collected data passed at least two important quality-assurance standard tests: (1) that samples was representative of selected research participants, and (2) participants' perspectives or viewpoints were present in the emerging theory to illustrate precisely the processes that led to infant death disparity. In addition, the researcher ensured that participants' rich descriptions of their realities (their views, values and voices) were adequate to answer the questions posed in this study. Lastly, the researcher then worked with a *debriefer* to review and improve the quality and worthiness of research findings, and the emerging new theory (Creswell, 2013).

Researcher Bias

Unlike quantitative studies, the outcome of this research could have potentially been affected by the researcher's belief system, personal values, biases, philosophy and assumptions. Hence, Miles et al. (2014) recommended that the researcher be consciously self-reflective, open and forthcoming with any and all known influences that have even a remote potential to sway research process and outcome. For this reason, the researcher seriously considered how his personal philosophy, experiences, professional background, personal interests and opinions might infiltrate to influence the research outcome (Corbin & Strauss, 2015). For this same reason, Rudestam and Newton (2015) advised that a researcher start by "owning his or her own perspectives." This allows readers to objectively interpret, evaluate and understand the research conclusions. Most importantly, a researcher has the ethical responsibility to ensure the highest possible quality for their work. In light of this, Corbin and Strauss (2015) suggested that researchers keep a daily logbook or a detailed daily diary (Corbin & Strauss, 2015) of the research experiences and processes, mostly for reference purposes.

Methodology

Research Types and Data Sources

Data for this study was collected purposively from a series of semi-structured interviews and field observations of research participants in their own natural settings. Face-to-face semi-structured interviews were combined with document reviews and a demographic survey questionnaire that was administered during the scheduled interviews. The combination of survey data with face-to-face semi-structured interviews assisted with theoretical sampling in a GT research tradition (Currie, 2009); this enhanced the researcher's understanding of the nature, severity, relevance and trends in IM disparity across key segments of the study population (Maxwell, 2013). These sources presented a comprehensive view of the phenomenon.

According to Corbin and Morse (2003; 2015), the major benefits of semi-structured qualitative research interviews (Brinkmann & Kvale, 2015) are as follows: participants are in control of the interview, they can speak more freely about the issues and determine the pace of the interview, as well as the order of interview questions and to what depth to explore the issues. The researcher was able to maintain appreciable consistency over the concepts that were covered in the interviews. In addition, these interviews gave the researcher the opportunity to follow up in subsequent interviews, should the need have arisen to elaborate on emerging concepts in an iterative process of theory creation. The use of research interviews also created an opportunity to verify information obtained from participants, to guarantee that their views and interpretations were incorporated in the final theory product (Patton, 2002). Through fieldwork and constant comparative analysis process, the researcher went on to break down empirical data into codes, concepts, categories and propositions (Lingard, Albert, & Levinson, 2008; Miles, Huberman, & Saldana, 2014). As in all GT research, data collection and analysis continued until theoretical saturation was reached, and there were no further concepts emerging from collected data. Remarkably, at this time the generated theory has also become satisfactorily validated (MAS, 2011). At this stage, interview data had produced new knowledge that exhaustively uncovered the lived experiences of African American women who had lost infants; interviews also helped participants to frame the meanings and interpretations that they gave to all associated actions, interactions, relationships, conditions and behaviors (Brinkmann & Kvale, 2015).

Research Setting: Ohio, and Franklin County

With 88 counties and a 2010 population of 11 536 504 people, the state of Ohio is ranked as the 7th most populous state in the United States (U.S. Census Bureau, 2010). However, in 2015, Ohio ranked 45th nationally in IM, mostly because of the rates of race-based death disparity for African American infants (Zelter, 2015). With an IMR of 7.33, the state is 21% above the national average at 5.96 deaths per 1000 live births. For African American mothers, 13.57 infants died in every 1000 live births in Ohio, compared to White babies at 5.96. This trend explains why the U.S. continues to rank 26th among 35 OECD countries in IMR measures, lagging three times worse than Iceland, Finland and Japan, and two times worse than Norway, the Czech Republic and Denmark (American Health Rankings, 2016).

IMR remains an important measure of the overall health of any nation, and a long-standing concern of public health. IM refers to the death of a live-born baby before his or her first birthday – the *neonatal* period is 0-28 days after birth and the *post-neonatal* period is 29-364 days (Ohio Department of Health, 2017). According to the Ohio Department of Health (2016), Ohio's goal has been to achieve fewer than 6.0 infant deaths per 1000 live births in every racial and ethnic group, and to eliminate racial infant death disparity by 2020 (Viviano, 2017). These targets are consistent with the national *Healthy People 2020* objective that sets the standard rate at 6.0 or fewer infant deaths per 1000 live births. In the meantime, Ohio continues to experience significant disparity in IM and *birth-outcome rates* (Ohio Department of Health, 2017) for all racial and ethnic groups. Data from the Ohio Department of Health Vital Statistics (2017) show that in 2012 for every 1000 live births, on average 13.93 (Black), 6.37 (White) and 7.57 (all races) infants died.

At the present time, Ohio ranks near the bottom nationally in IMR for all racial groups, and particularly for African American infants. While infant rates dipped in the 1990s for all races and ethnic groups, in 2015 some 1005 infants died before they could reach their first birthday, and that number increased by 21the following year. With nearly 2% annual increase in infant death for White, Black and Hispanic infants, Ohio is far along to meeting the national average. According to the Ohio Department of Health's Bureau of Vital Statistics (2016), there were 138 198 live births in Ohio, with total infant deaths of 1024, for an IMR of 7.4. During the same period, there were a total of 18 955 live births in Franklin County. Sadly, 167 babies, or 8.8 per 1000 live babies (20 more babies than in 2015), never lived to celebrate their one-year birthday. This rate is much higher for African American infants in the state than for any other racial group (Viviano, 2017).

Target Population: Franklin County

With a population of 2186.1 per square mile, Franklin County is considered one of the most important counties in Ohio. For instance, the county capital Columbus is also the Ohio state capital. In addition, Columbus is the home of the Ohio State University football team, the Buckeyes; it houses several universities, and has had a steady population increase, up to some 1.26 million residents at the end of 2016 (Narcisco, 2017; U.S. Census Bureau, 2016; U.S. Census Bureau, 2017). In 2017, Franklin County gained an estimated 14 249 new residents, 5476 of whom were new international migrants. A total of 27 558 were lost to domestic migration (Exner, 2017). In addition, recent growth in the healthcare and education sectors has given Franklin County nearly 18% more jobs since 2010 (Narcisco, 2017).

According to the Census Bureau (2016), the population breakdown for Franklin County is as follows: males 566 499, females 596 915, and a median age of 34 years (Census Reporter, 2017; U.S. Census, 2016). At the end of 2017, the population of Whites was 805 617 or 69%; Blacks or African Americans was 247 225 or 21%; Hispanics or Latinos was 55 718 or 4%; Asians was 44 996 or 3%; American Indians, Native Hawaiian Pacific Islanders and Native Hawaiians constituted the remaining 3%. Approximately 9.9% of the population was foreign-born, while 12.5% spoke a language other than English at home (U.S. Census Bureau, 2017).

An average of 2.46 persons lived in each household, on a median household income of $54 037 per annum (Ohio Demographic Spreadsheet Reports, 2016). This amount was slightly lower than the national income average of $57 617 per household (Census Reporter, 2017). Perhaps this accounts for why the population migration averages upward of 20.1% annually. Remarkably, 9.2% of Franklin County residents were 65 years or older and had no health insurance coverage, and 16.6% lived below the national poverty threshold. Even with a high school graduation rate of 90.4%, just 38.4% go on to pursue a college degree. On the whole, 5.5% of women aged 15 to 50 years give birth in the county in any given year (Census Reporter, 2017). Meanwhile, the IMR in Franklin County is at least 1.3 times higher than for Ohio's average of 7.4%, and 2.7% greater than the national average of 6.0%. While Franklin County (8.7%) and Cuyahoga County (8.7%) may appear to be doing better than Clark County (13.0%), Franklin County lagged considerably behind Lorain County (4.5%), Warren (5.3%), Mahoning (6.0%), Clermont (6.5%), Montgomery (6.8%) and Butler (6.9%) counties. Between 2012 and 2016, 770 infants or 8.2% out of 94 000 live infants born in Franklin County did not live to celebrate their first birthday.

The 18 cities that constitute Franklin County are as follows: Columbus, Lancaster, Westerville, Reynoldsburg, Grove City, Upper Arlington, Gahanna, Hilliard, Pickerington, Whitehall, Dublin, Worthington, Bexley, Franklin, New Albany, Canal Winchester, Grandview Heights and Groveport Village.

Leading Causes of Infant Death in Franklin County – Proportion of Causes

Data from the Franklin County Public Health Department (2016) shows that every year in Franklin County, approximately 150 infants die before they reach their first birthday. According to the Ohio Department of Health (2016), there are several leading causes of infant death, including: *Prematurity/preterm-related conditions*, for example *preterm* birth before 37 weeks of gestation, *low birth weight*, respiratory syndromes, neonatal hemorrhage, birth defects and *obstetric conditions* such as pregnancy complications, lack of access to appropriate care, genetic problems and maternal health conditions. Ordinarily, babies delivered at less than 37 weeks' gestation, particularly with low birth weight, face an increased risk for respiratory distress and bacterial infections. Two thirds of these infants die within the first month of life, due to preterm/prematurity-related causes. Similarly, one-third of infant deaths during their first year of life are due to sleep-related causes, SIDS, suffocation, asphyxiation and external injuries. According to the Ohio Fatality Review Board, quoted by the Ohio Department of Health (2016), 117 out of a total of 1024 infant deaths in 2016 (5.8% Whites, 7.4% all races, 3.8% Asian/Pacific Islander, 7.3% Hispanic, 15.2% Black, and 6.3% unknown races), and 84 of 1005 infant deaths in 2015, were sleep-related, and as such were considered potentially preventable. Nationally, 36% of infant deaths are attributable to prematurity and preterm births. In Ohio however, that number is more like 50% (Zelter, 2015). In the meantime, 44% of deaths of African American infants were determined to be due to preterm-related causes, and the causes of death disparity are broken down as follows: neonatal deaths of 120 (6.3); post-neonatal deaths of 45 (2.4) and infant deaths of 165 (8.7).

Sampling Strategy

The semi-structured qualitative research interviews targeted African American women of child-bearing age (18 to 45 years) who had lost infants in the last five years, were resident in one of the 18 cities in Franklin County, and willing to share their unique pregnancy and delivery experiences (before pregnancy, during pregnancy, during birth, and after the death of their infant). Sampling started simply with identifying primarily where these women 'hang out'–churches, sororities, clubs, fitness centers, libraries, volunteer centers, shelters and specific electronic media platforms.

However, it was equally important that participants meet certain criteria, before they could qualify to participate in this study: female; currently or previously pregnant; and have had firsthand experience with preterm, underweight birth, or IM in the last five years, with a minimum of 3 months since the infant death event. At the initial contact with each participant, the researcher broached the research topic, offered a brief purpose statement, shared the expected time commitment, the research benefits, researcher considerations for participant privacy concerns and strategies to manage collected data, and to gain their interest and secure buy-in. Participants were then encouraged to discuss their questions or concerns for further clarification. Thereafter, a participant *informed consent form* was presented for signed consent. Following participant consent, a four-page *face-to-face survey questionnaire* document, designed to collect specific demographic characteristic information, was presented to each participant for his or her completion.

Participant Selection

According to Michael Patton (2002), “the logic and power of purposeful sampling lie in selecting information rich study participants.” For the current study, this means individuals from whom the researcher could learn a great deal about the issues central to racial death disparity in infants, for the purposes of producing a robust, data-fruitful, and deeper understanding of the research questions (Rudestam & Newton, 2015). As a result, the researcher carefully chose a purposive, convenient sampling method for this study. A meager sample size of 6 African American women (ages 18-45) was selected, each of who had lost infants in the last five years. Although this sample size is relatively small, Depaulo (2000) argued that such a size would still be large enough to allow for the full range and variations of perceptions from study participants, and, vitally, be helpful for better understanding to uncover the meanings that these women gave to their unimaginable child-loss experiences. The researcher reached out to these women individually through Facebook publication of the study poster.

Inclusion and Exclusion Criteria

To ensure representativeness and high quality of collected data, the researcher carefully selected from a diverse sample of average (typical), above average (outlier), and below average (unusual) participants to form the study participant pool. To achieve the best possible outcome, the *maximum variation heterogeneity sampling strategy* (Patton, 2002) and the *theoretical sampling strategy* (Corbin & Strauss, 2015) were applied in this study to foster cumulative and progressively deeper understanding of the issues involved. The *maximum heterogeneity sampling variation strategy* allowed the researcher to maximize variations in a very small sample size, and in which each research participant was unique, different and diverse. As it turned out, an important characteristic of this study sample was the variations in both homogenous and heterogeneous attributes of study participants in the pool.

Furthermore, the researcher used the *matrix of diversity* to construct the sample size, mainly by targeting individuals from diverse cities, ages and backgrounds. The *homogenous characteristics* of study participants included the following general attributes: race (African American), sex (female), residence (Franklin County), parent status (mother), and bereaved status. The *heterogeneous sampling inclusion criteria* included discrete descriptive statistical data (Frankfort-Nachmias & Nachmias, 2008): geographic location (urban/city or suburban area), study site (formal or informal), ethnic diversity (U.S.- or foreign-born American of African descent), pregnancy status (pre-/post-delivery; wanted or unwanted pregnancy), family size (large, small, none), and demographic data (age, marriage, employment status, nature of work, city of residence, salary, insurance and health status). This set of data was collected via face-to-face survey questionnaires, completed by each participant prior to the scheduled semi-structured research interview segment of the fieldwork.

The strength of the *maximum variation heterogeneity sampling strategy* lies in its capacity to utilize a very small select sample size of vast diversity (Patton, 2002), to generate fairly representative and coherent themes from such diverse data. The value of the *descriptive demographic data* in this study was mostly to summarize and better organize primary evidence in an effective and meaningful way (Frankfort-Nachmias &

Nachmias, 2008; Rudestam & Newton, 2015), such that the statistical distribution of data can persuasively convey the emerging patterns in the collected data. As such, an important value of the maximum variation heterogeneity was that it offered readers a better representation of the study sample. In the end, the high-quality and detailed description of the collected data added to the shared common experience of study participants, as well as to the core patterns that cut across the limitations generally associated with the maximum variations and heterogeneity sampling strategies.

A primary strength of qualitative fieldwork lies in the researcher being compelled to follow wherever data might lead (Patton, 2002). On the other hand, the maximum variation heterogeneity sampling strategy was suitable for this study because of resource constraints (money, materials, time and personnel). In addition, this particular approach meant that the key questions outlined for this study would be adequately answered without any risk for discovery failure or error (DePaulo, 2000), or both.

In conclusion, the researcher persevered with the maximum variation heterogeneity sampling strategy within the GT strategy of *constant comparative analysis* of all collected data until meaningful *data saturation* was reached, and robust core categories emerged to inform a newly generated theory.

Ethical Considerations and Protection of Human Participants

By the nature of this study, women who had experienced the death of an infant were asked to share their individual experiences regarding the likely causes and contributing factors to their personal tragedy, and how these factors might have interacted to influence their birth outcome. The researcher was aware that this could be a very sensitive matter, with a high probability of triggering deep emotional and psychological breakdown in some participants. As a result, the researcher planned to take appropriate steps to make professional referral where necessary. Prior to the interviews, the researcher arranged professional counseling support service for all participants, to take care of their emotional, psychological and spiritual needs during and even after the interview sessions. As a result, the researcher retained a licensed grief-counseling psychologist and a board-certified chaplain during all scheduled interviews. The researcher also compensated these professionals for their services, where voluntary options were not immediately available. The goal was to mitigate stress on all research participants, and to ensure that participants were not exposed to any preventable physical, mental or psychological risks because of their involvement in this study.

At the start of each interview, the researcher explicitly described the nature of the research undertaking to the participant, provided some detail about potential risks and benefits of the study, and thereafter formally requested and obtained the participant’s informed written and signed consent. Furthermore, the researcher tried to alleviate participants’ concerns about sensitive personal information getting into the wrong hands, by discussing the steps taken to safeguard their personal information from start to finish: data collection, storage, management, analysis, interpretation, publication and the dissemination of research findings. At every phase during the research process, the researcher ensured that participants’ rights were judiciously safeguarded, and that any accruing research benefits were equitably distributed between the researcher and the research participants.

Rudestam and Newton (2015) had emphasized that the elements of informed consent needed to be discussed during a researcher's preliminary contacts and disclosure. Consequently, the researcher disclosed to participants all information regarding who was conducting the study, the nature of study, why participants were selected, the expected time commitment, potential benefits of the study, and all applicable risks and plans to manage and mitigate them. From the start, the researcher emphasized the voluntary nature of research participation, and participants' freedom to withdraw at any time that they begin to feel unsafe or ambivalent about their involvement in the study. It was also my expectation that an honest discussion about the limits of confidentiality and the non-compensatory nature of this research would help to put each participant at ease.

Data Collection Procedures

The researcher carefully reviewed available literature to identify studies that had evaluated the influence of multiple risk factors for underweight birth, preterm birth, and IM. The search was carried out on NCBI, PubMed, EMBASE, CINAHL and Google Scholar using keyword searches, such as "underlying mechanisms for racial-ethnic disparity, infant mortality, African American women." All articles included in this study came from studies published January 1, 2010 through December 31, 2016. This strategy yielded several articles that were then reviewed to determine whether there was evidence of a distinct risk factor, and its potential mechanisms.

Given that the purpose of this study was to better understand the potential influence of convergent risk factors (micro and macro) in racial death disparities in infants in the U.S., the researcher chose to include only studies that had been conducted in the United States. Studies in non-U.S. settings, and those conducted in lower resource countries, were excluded from the review. In this way, the researcher was able to gather all available studies. Just as Corbin & Strauss (2015) and Becker (1986) had remarked, a key consideration in this GT study was how to use available literature to enhance data analysis, and not to constrain or stifle the discovery of new knowledge.

Participant Demographic Questionnaire: Face-to-Face Survey

The themes explored in the face-to-face survey questionnaire were socio-demographic and socioeconomic status information, including gender, age, race/ethnicity, employment status, marital status, nationality, language status, education, income level (SES), and city of residence. Elder, Goddeeris, and Haider (2016) found that differences in these factors are associated with racial-ethnic gaps in infant death. Hence, participants' answers to these questionnaires were extensively analyzed and interpreted in the participant profile summary, as well as in the results and discussion sections of this study, to shed more light on the descriptive characteristics of research participants.

Access to Research Participants

Access to research participants began with identifying those who were in the best position to provide rich answers to the key research questions. The researcher made an effort to establish rapport with participants in one of three ways: through direct primary contact with *information-rich key informants*, through *snowball chain sampling* strategy (Patton, 2002), or simply by asking better-placed informants to identify people in their network who might know more about the issues, and were willing to take questions about their experiences with the pregnancy, birth and death of their infants.

After my initial attempts to recruit study participants through the agency of public and privately-run healthcare and public health institutions in Santa Clara County, CA, failed, at the urging of a close friend who lives in Ohio, I discussed with my chair about the possibility of moving my study site and population from Santa Clara County, CA, to Franklin County, Ohio. As will be seen later in this study, the two populations have much in common. However, since I was living in Ohio while I attended graduate school, I had the privilege to work at the Ohio Health Department as a public health intern, for about 15 months. Now, in Franklin County, I targeted my public announcement ads at women who were unaffiliated with any community, and, by implication, had no identifiable public platform. I coordinated my outreach with my contact in Franklin County, to make sure that I could recruit an adequate sample size for my study for this new population. Furthermore, I decided to diversify my recruitment effort as well as sample size for the purpose of increasing the internal reliability or validity, and the external generalizability, of study findings (Creswell, 2009).

Semi-structured Interviews

There were six semi-structured interviews for this study. To maintain consistency (Corbin and Strauss, 2015) during the face-to-face semi-structured qualitative interviews, the researcher applied a three-tier sequential and successive approach: before, during and after the interviews.

(1) *Before the interview* the researcher conducted a pilot test of the interview questions with comparable participant demographics, and then revised and improved the questions based on feedback received from a sample participant.

(2) *During the interview*, the researcher commenced each interview with a transparent self-disclosure and introduction, a statement of the purpose of study, duration of the interview, some discussion about the use of research findings, confidentiality and consent issues, and any other concerns that a study participant might have. Furthermore, the researcher attempted to establish rapport; he obtained a written informed consent before he proceeded to administer the survey questionnaire. During the interview, he began each interview encounter with grand-tour questions and then eased into the central phenomenon of the study. All interviews were tape-recorded simultaneously with note–taking, and successfully ended on a positive note.

(3) *After each interview*, the researcher immediately transcribed taped interview proceedings, conducted initial data coding and data analysis, and proceeded to the open coding, axial and selective coding as he rigorously teased out embedded data codes, concepts, themes and categories in a qualitative theoretical sampling strategy.

Data Analysis Tools and Procedures

Three computer-assisted qualitative data analysis software (CASDAS) programs had been identified for use in data collection, organization, storage, analysis, management and dissemination (Banner & Albarran, 2009), namely: ATLAS.ti7, for its multimedia integrated style and support for easier work flow; QSR Nvivo, to facilitate the analysis of contents from participants and to uncover their connections and streamline insights across collected data; and HYPERRESEARCH, to facilitate coding, data retrieval, theory formation, visual diagram building and data transcription.

According to Strauss & Corbin (1990), open coding, the first step of the theoretical analysis, primarily "uncovers the texts, naming the emerging thoughts and ideas and developing the meanings and concepts therein" (p. 102). Open coding highlights data that possess significant importance beyond the sheer description of events and conditions; they set the stage for higher-order conceptualization, including code-to-code comparison, incident-to-incident comparison, and the search for similarities and differences (Ng & Hase, 2008) among collected data. Charmaz (2002) recommended that asking a very important question (*What really is going on here?*) facilitate a constant comparative analysis process.

Open coding was immediately followed by *selectively coding* for the variables, meanings and characteristics that relate to aspects of the core or basic category (Glaser, 1978). *Theoretical coding*, on the other hand, enables the array of meaning, scope, behavioral patterns and relationships between categories to emerge "as hypotheses to be integrated into a theory" (Glaser, 1978). As a result, Glaser (1978) recommended that researchers be sensitive and adherent to the rigorous and systematic procedures in this dynamic "journey of emergence" (Ng & Hase, 2008). To summarize, the six major steps in *constant comparative analysis* (Glaser & Strauss, 1967; Miles & Huberman, 1994) are as follows: read through the entire set of data, chunk it down into smaller meaningful parts, labels and compare new chunk of data with previous codes, group by similarity to identify them with a common theme, and return this data to the field for member checking (Leech & Onwuegbuzie, 2007).

Data Analysis Procedures

Through fieldwork and the constant comparative analysis process (Lingard, Albert, & Levinson, 2008; Miles et al., 2014) empirical data were reduced to codes, concepts, categories and final propositions. As in all GT research, data collection and data analysis were conducted simultaneously until theoretical saturation was reached—that is, when new concepts ceased to emerge from collected data, and the generated theory had become satisfactorily validated (MAS, 2011). In the best of cases, data analysis in GT follows three significant steps (MAS, 2011), each of which might result in a basic element of the GT, namely: (1) Open coding, or line-by-line review of transcripts, which identifies and codes available data to create major concepts. (2) *Axial coding*, with principally organized and abstracted meaning gathered from available concepts to present a visual diagram or logic model of categories, the core or central phenomenon in datasets. (3) *Selective coding*, which mainly identifies emerging prominent ideas to develop key story lines or narratives, which unveil intersection of relevant categories to arrive at theoretical propositions, or the emerging theoretical constructs at the core of the GT study (Corbin & Strauss, 1990; Corbin & Strauss, 2015; Creswell, 2013; Pandit, 1996).

According to Creswell (2013), while *categories* obtained from axial coding seek to uncover the central phenomenon under consideration—the causal-contextual conditions, strategies and intervening consequences of IM—the *propositions* from selective coding were used to describe the interrelationship of the categories in a visual or diagrammatic model. In effect, the codes, concepts, categories and propositions were here developed and emerged through a lively and dynamic process commonly referred to as the iterative process (Pandit, 2011). As was deemed necessary, the researcher had used the discriminant-sampling strategy (Creswell, 2013) to collect additional information from participants outside the select core-participant pool—in this study, two male unofficial participants who accompanied their spouses served this use.

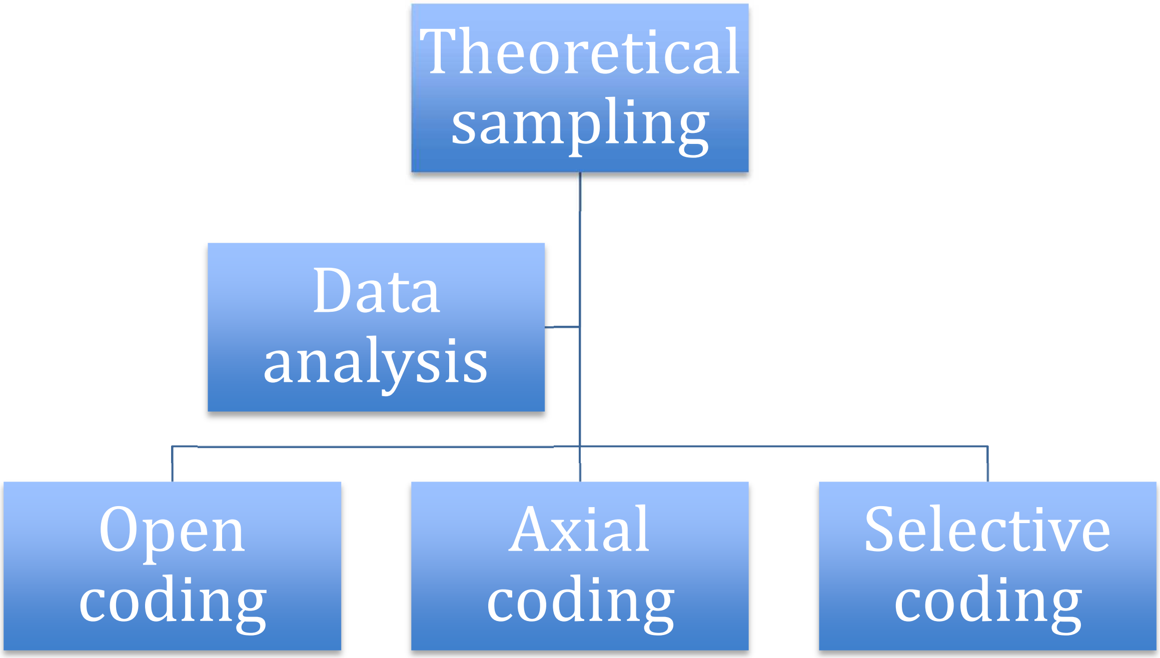

Figure 6. Data analysis in GT methodology

Data Storage and Management

Preventing data loss and data overload, and facilitating ease of retrieval, required the creation of effective data storage, data organization, and data management strategies for the entire duration of research. Miles et al. (2014) described this approach as data accounting, record keeping, and auditor's reference. An effective data management procedure assisted with keeping track of all collected and analyzed data. Miles et al. (2014) cautioned that the management procedures could have a propensity to inadvertently influence analysis results by introducing vulnerability to research quality, and ultimately the validity of the findings. Hence, the researcher planned against this in advance.

Given the stated goal and nature of the study, it was critically important to maintain healthy research relationships (power/knowledge sharing) with research participants throughout the duration of the research—before, during, and after the study. By and large, the researcher sought out “more naturalistic contexts for research and pursued holistic understanding of study participants in their society” (Todd, Nerlich & Mckeown, 2004, p. 4), by interpreting IM with the meanings that participants brought to it (Banister, Burman, Parker, Taylor, & Tindal, 1994; Denzin & Lincoln, 2005). Through this approach we gained greater insights into this problematic incidence (Leech & Onwuegbuzie, 2007) of infant death disparity in the United States.

Trustworthiness, Credibility, Transferability, Confirmability and Reliability

The researcher followed appropriate procedures in data collection, data analysis, and interpretation that were consistent with a conventional GT approach. Using cumulative coding and analytic memoing cycles, the researcher quickly developed major categories for theory formulation (Miles et al., 2014) that could guarantee that the four central features of GT would be present in the final product, namely: emerging categories would fit real-world data; be easy to understand, even with the introduction of the elements of abstractness and generality; that the emerging theory would be thoroughly applicable to a real-world issue such as IM; and, lastly, that the findings would be viable solutions to adverse pregnancy outcomes (MAS, 2011). In addition to the above quality criteria, Popay, Rogers, and Williams (1998) argued that quality in GT must include elements such as the presence of subjective meaning, a thorough account of the social context of the study, and a full report of participants' own accounts of the incidents.

Strauss and Corbin (1990) developed 7 additional questions by which to judge the quality of a GT study: (1) how was the original sample selected? (2) What major categories emerged? (3) What events, incidents, actions and interactions led to the major categories? (4) Were the categories representative of the theoretical samples, and how did they proceed? (5) What was the conceptual relationship among the categories, and were they grounded on empirical data? (6) How were the discrepancies between actual data and emerging categories accounted for? (7) Why and how were the central categories selected—by sudden, gradual, difficult or easy processes?

Each of these questions has been adequately dealt with in this study.

Despite the increasing acceptance and resounding success of GT as a qualitative research methodology, there still exist genuine concerns regarding the quality of GT studies (Bringer, Johnson, & Brackenridge, 2004; Charmaz, 2003; Hutchinson, Johnson, & Breckon, 2009). For this reason, Charmaz (2006) recommended that the quality of emerging theory must exhibit some pertinent characteristics: the theory must have *clear definitions of the major concepts and categories*; there must be an *increase in the scope and depth of analysis*; there must be established *strong theoretical links between emerging categories* and their properties; the theory must provide a *better understanding* of the phenomenon; and, the theory must have both *theoretical reach and depth* to explain the implications of the systematic analysis.

Corbin and Strauss (2015) went on to suggest that generated theory, in addition to being grounded in empirical data, must create a *fair representation* of both participant and researcher perspectives, while offering *greater insights* into all applicable human behaviors, interactions and contexts. In the final analysis, there is no perfect theory. In every instance, the credibility of a generated theory is amenable to improvement partially by increasing methodological rigor and trustworthiness (Leech & Onwuegbuzie, 2007). Put differently, the use of member-checking and the adoption of more than one analysis tool (Leech et al., 2007), plus the triangulation of categories, themes and interpretations, and the interpretation of data by an external independent reviewer (Rudestam & Newton, 2015), can raise the quality of theory and research finding in a qualitative GT method. All in all, the research results were evaluated by the very constructs that had been used to generate the research questions in this study (Elliott & Lazenbatt, 2005).

Limitations and Delimitations of Study

According to Oakley (2000), a distinguishing mark of a good qualitative study is the researcher's apt awareness and unabashed acknowledgement of his or her own errors, biases and limitations. In this study, the use of a purposive data collection approach (Patton, 2002) meant that the researcher was going to choose participants who had relevant experiences and insights that might enrich the researcher's understanding of the IM disparity crisis. Thus, by its very nature, a purposive sampling method has an intrinsic prospect of introducing some unintended bias. Moreover, the theoretical sampling strategy used in this research implied that the sample size had to be pre-selected until the actual GT field study could be originated (Elliott & Lazenbatt, 2005). In of itself, this practice undeniably has some inherent limitations.

Another important source of potential error or bias can come from the researcher's misinterpretation of data, which can invalidate an emerging theory. Even then, these errors can be corrected through member–checking, or the simple validation of emerging theory, as well as through a close accounting of the researcher's own reflexivity. Despite all attempts at objectivity, a researcher's personal worldview, values, beliefs, personal and professional experiences, and personal philosophy can always find their way into research products. Hence, Kolb (2012) suggested that we must take time to understand what these errors really are.

Data Presentation

Analyzing the perspectives of participants, the researcher explored the meanings that they gave to their specific experiences, as well as the causes and consequences that they associated with their adverse birth outcome (Maxwell 2004; 2008; 2011). The focus on meanings and interpretations that participants gave to their experiences was central to better understanding how the factors investigated in this study may well influence behaviors (Maxwell, 2013)—theirs, and those of other members of society. Consequently, the perspectives of individuals who have had firsthand experience with IM were important for this study, and will gravely impact any future interventions (Ke & Wenglensky, 2010; Wilson & Hutchinson, 1991) and policy changes. For this reason, understanding more than just the descriptive account of what happened to study participants, and how they actually occurred (mechanics of infant death), will help the researcher to construct a data-informed map of the relationships among all risk factors (Becker, 1993; Morse & Richards, 2002) implicated in adverse pregnancy outcomes, for all participants.

Dissemination of Research Findings

The target audiences for this study were healthcare professionals: practitioners in field practice; health scientists in research, in academia, and program design and evaluation experts; policy decision-makers, change agents, and public health advocates; and health funding agencies. As a result, the dissemination strategy focused on circulating study findings directly among these professionals through official and unofficial distribution media channels that are commonly available to them. Furthermore, study findings will be submitted for publication in peer-reviewed health services research journals that are typically within reach for policy makers, academia and field practitioners in the public health sector. My reasoning here was to have these professionals review and to possibly apply study findings in their field practices.

Summary

In this study, I addressed the lack of research into the logical sequence of events, foundational and intervening conditions, internal and external environmental contexts, actions and interactions, pathways and processes that potentially precipitate or perpetuate death disparity among African American infants. The researcher explored the variation of root causes, contributory and exacerbating risk factors—proximate (biomedical), intermediate (behavioral, lifestyle and cultural), and ultimate (socioeconomic, epigenetic and political risk factors) (Millard, 1994). These risk factors, in big and small ways, help drive the disproportionate death of African American infants.

In this regard, gaps in knowledge over time were more likely to give rise to gaps in personal and cultural awareness, prevention and practice, and policy interventions. Hence, the researcher was careful to investigate and underscore the root causes in IM, leaving us with the choice to design effective interventions and responsive solutions to this frustrating malady.

Given the relative novelty of this study within the domain of disparity studies, and the relevance of robust empirical evidence for a permanent remedy, it was fitting to deploy the GT approach. According to McCallin (2003), Strauss and Corbin (1994), and Denscombe (1998), GT possesses five basic premises that made it compelling choice for use in this study: (a) it is pragmatic; (b) it is grounded in empirical reality; (c) it focuses on a participant sampling situation; (d) it is able to generate new and reliable concepts; and, (e) it is an untested and unproven scientific theory. Hence, it was my utmost desire that this qualitative research would advance valid explanations for the research problem in this study. Not surprisingly, it was my goal to establish a strong foundation for future research in racial death disparity of infants. As is characteristic in GT, I was compelled to be thoroughly open-minded and willing to allow data to inform my understanding of how societal actions, interactions, conditions, relationships and behaviors are interrelated, influential and contribute to racial disparity in pregnancy outcomes. Although much remains to be known about death disparity in the U.S., central to this study was the researcher's determination to explore the views of research participants with no preconceived ideas or limits to the data's self-disclosures.

Chapter 4 explores the complex network of systems and subsystems that underlie racial and ethnic disparity in IM among African American women in their optimal childbearing years (ages 18-45).

Chapter 4: Research Results

Introduction

The purpose of this qualitative GT research was to explore what underlies racial and ethnic disparities regarding IM among African American women between the ages of 18 and 45. Two main research questions were used to guide the study. Each of the main questions was associated with sub-questions to provide further guidance to the research. The main questions and sub-questions were as follows:

RQ1: What specific disease burden (risk factors or negative or exacerbating mechanisms) do African American women believe influences their birth outcomes, and explain persistent negative birth outcomes?

- *SQ1*: What specific conditions, events, behaviors, actions, interactions and relationships do they associate with negative birth outcomes?
- *SQ2*: In what specific sequence (serial order) do these risk factors manifest themselves to influence birth outcomes?

RQ2: What sociocultural factors (positive or protective mechanisms) do African American women identify as potential buffers against adverse birth outcomes for them and other women?

- *SQ3*: What are these health determinants?
- *SQ4*: In what particular order or sequence do these play out in real life?
- *SQ5*: Are these available to the majority of African American women?

Chapter 4 includes a description of the setting of data collection, followed by a description of the relevant demographic characteristics of the study participants. It describes the implementation of the data collection techniques and data analysis procedures described in Chapter 3. Next, this chapter includes a discussion of the evidence of trustworthiness of the study's results, followed by a presentation of the results of the data analysis, and concludes with a summary of the research results.

Pilot Study

One participant and her husband took part in the pilot study, and provided invaluable feedback on ways to improve the quality of the questionnaire instrument, as well as the arrangement of the semi-structured interview questions that followed.

Research Setting

Two women brought their spouses along as their support system for the interview sessions. With the exception of one participant who elected to be interviewed at her home, all the interview sessions were held at the Good Shepherd Community Library, a branch of the Columbus Metropolitan Library System, between March 3 and March 10, 2018. The conference rooms at the library were reserved as soon as each study participant had selected an interview time and confirmed her availability. The library location was easily accessible to all participants.

Participant Demographics

Six African American women participated in the study. All participants were African American women between 18 and 45 years of age who resided in Franklin County and had lost an infant within the last 5 years. One participant and her spouse were foreign-born African Americans, and all other study participants were native-born African American women. The participant median age was 32 years. Four out of the six women reported losing their babies when the infants were less than 3 months of age, while the infants of the other two women were between 8 and 12 months old when they died. Four of the deceased infants were girls, and two were boys. Table 1 indicates the demographic profile for the study sample.

Table 1

Sample Demographics

Characteristic	N	%
Education		
High School	1	16.67%
College	3	50.00%
Graduate School	2	33.33%
Marital Status		
Single	4	66.67%
Married	2	33.33%
Age		
18-23	1	16.67%
24-29	3	50.00%
30-35	0	0.00%
36-41	2	33.33%
Income		
<$50 000	3	50.00%
>$50 000	3	50.00%
Immigration Status		
Foreign	1	16.67%
Native	5	83.33%

Note. *N*=6.

Participant 1

P1's husband joined her when she participated in the interview, which took place in the living room of her home. Her husband was there to provide emotional support and fielded interview questions when prompted by the participant. She was a foreign-born national who immigrated to the United States to attend graduate school, and met her husband on the college campus. She and her husband had earned professional graduate degrees. P1 and her spouse were professionals with full-time employment, which provided them with premium health insurance coverage, and allowed them to consult with quality physicians when she became pregnant with their first child. P1 described her overall health as good. She had a small household of three individuals, and had lost her female infant during the first 3 months of the infant's life. This was her first pregnancy. She and her husband had been married 2 years when the baby arrived.

The proximate cause of death for their infant was late maternal diagnosis with HELLP syndrome, a series of symptoms also known as hemolysis, which includes elevation of the liver enzymes and low platelet count (American Pregnancy Association, 2018). The syndrome affects between 2 and 6% of pregnant women. The diagnosis of HELLP syndrome prompted the premature delivery of the infant. P1 said she was not made aware of the potential risks of HELLP syndrome for her pregnancy, until it ended her pregnancy, causing massive infections for the infant, rapid deterioration of her intestines and several other medical complications. Both parents felt that their views were not sought as the gynecologist, pediatricians and attending nurses decided on courses of action. Nevertheless, P1 and her husband complied with all professional advice during her pregnancy and after delivery.

Participant 1 suggested that perhaps the insufficient knowledge of her medical history of her medical team might have contributed to the negative outcome. Being professionals themselves, Participant 1 and her husband felt they might have been too quick to acquiesce to the professional recommendations and decisions that led to premature delivery, and the infant’s continued care in the neonatal intensive care unit. Participant 1 recalled that at the Neonatal Intensive Care Unit, the attending staff were “blind sighted to believe that our baby would eventually get used to baby formula” after being abruptly weaned off rationed breast milk. In fact, the baby was unable to make that transition, and she died trying. This was a clear case of poor medical advice. Consequently, Participant 1 continued to feel that perhaps she could have advocated more forcefully for her daughter, particularly in favor of natural breast milk. At the same time, she admitted feeling extremely powerless given that, “I was not able to do what a mother should do,” namely she was unable to produce enough breast milk supply to feed her infant.

Participant 2

Participant 2’s baby died from apparent suffocation from having the umbilical cord wrapped around its neck multiple times. This condition was not detected on any of several ultrasound pictures that were ordered prior to delivery. The mother had access to maternity care professionals, whom she said did not have a good grasp of her medical history, and was scarcely available to her to provide much-needed advice and education about managing a risky pregnancy for a first-time mother. She reported that she could hardly get on the same page with her physician regarding the best course of action to achieve a healthy pregnancy and safe delivery. Time and again, “they will not take my calls,” so she felt ignored, neglected and abandoned at a critical time during her pregnancy. She agreed, however, that she might have ignored signs of a premature delivery when she decided that, “I just wanna wait it out and see if I’m gonna be able to have her vaginally.” As she recounts, her doctor’s response throughout the pregnancy was, “well, let me know what you want to do.” Her baby was eventually stillborn, on her due date.

Participant 3

Participant 3’s baby’s death was blamed on severe maternal weight loss about six months into her pregnancy. Participant 3 was also treated for severe depression, stress, anxiety and an acute mental health breakdown, following her experience of rape and abuse from a family member, whom she said was never charged for his abuse of an underage teenager. Also present in this circumstance were signs of dysfunction from a non-supportive family. As she reported, “I was never aware of my depression until after my baby was already gone.” In the month’s prior, she said that her providers continued to tell her, “hey, you are having a healthy baby, you are having a boy.” She insisted that, “they could have told me sooner at the time about my depression…they didn’t tell me that my not eating, that my depression was going to cause me to lose my baby.” She maintained, “I want to be a mother to the children that I have…I want them to have a better life, a better lifestyle and everything that I never had. That’s my biggest goal.”

Participant 4

For Participant 4, the baby’s death was ascribed to a maternal low or weak uterus during pregnancy, which eventually weakened the muscles of her uterus and “caused the baby to unplug itself and drop to an unsafe position.” Participant 4 reported that she had a history of worry, and a lack of a significant support system during her pregnancy. Although she continued to work to pay her bills up until several days before her due date, she denied being in any way stressed during her pregnancy. She said that she had other medical conditions that she did not believe had anything to do with her pregnancy outcome.

Participant 5

The evidence pointed to sudden infant death syndrome (SIDS as the probable cause of Participant 5's baby's death. The Mayo Clinic (2017) defined SIDS as the unexplained death, usually during sleep, of a seemingly healthy baby less than a year old. As Participant 5 recounts, her baby was at a familiar daycare when she suddenly lost consciousness while sitting on a chair. For whatever reason, the daycare staff thought that it was reasonable to let an eight-months-old baby sleep on a chair and not in a bed. Participant 5 said that all available evidence indicated that, "this was a hard case to crack. But there were no external bruises or anything like that and she was a healthy baby all the way." She reported having a smooth pregnancy; she was never sick, regularly attended all prenatal checks, ate well, exercised regularly, had no major medical issues, worked full-time through her pregnancy and received all necessary immunizations. She also read child-rearing manuals to confirm that all the milestones were happening for her baby. She summarized her experience in this way: "I know everything happens for a reason." However, since I had mentioned incidents of SIDS to be outside the scope of this study, this case was a non-count.

Participant 6

For Participant 6, several months into her pregnancy a random screening test showed the existence of a cyst or tumor in Participant 6's ovary. The cyst caused problems for the baby, eventually leading to a reduction of the fetus's oxygen supply, and thus stalling normal growth and development. Participant 6 recounted that her body was eventually no longer able to carry the baby. Consequently, she had an emergency surgery to remove the tumor and accidentally birthed the baby. Speaking about her pregnancy she said, "it was both a blessing and a curse at the same time. I have lived it, and I try not to relive it."

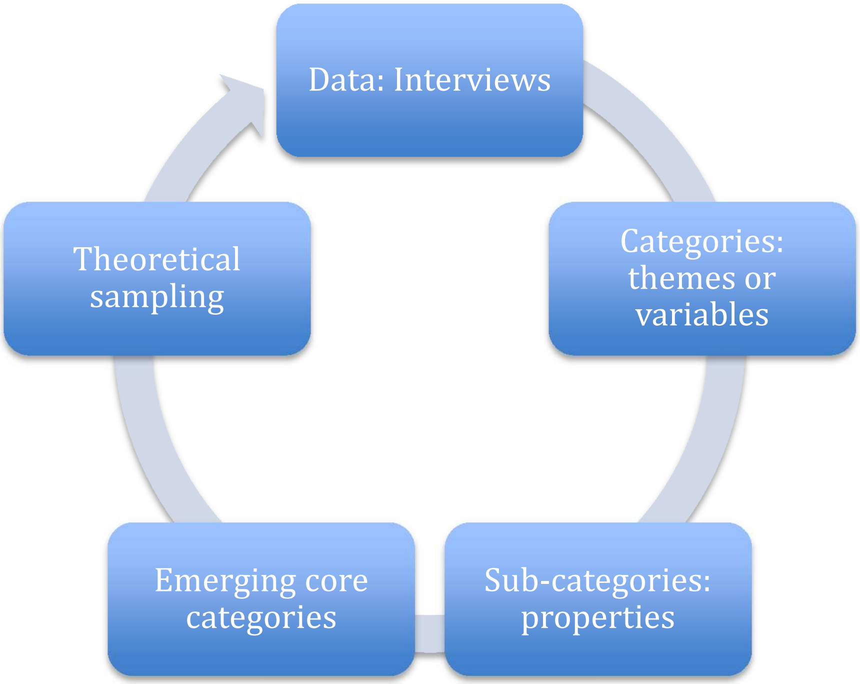

Figure 7: Theoretical sampling model: open and axial coding phases

Data Collection

The first two participants responded to the study flyer published on the researcher's Facebook page. Other participants were contacted via telephone call or email after another participant provided their contact information, using a snowball sampling technique. Each participant had lost an infant in the last five years, sometime between 2013 and 2017. Each participant completed an informed consent form prior to the semi-structured study interview. Of the nine candidates who originally signed up to participate in this study, only six met the selection criteria. The rest were either screened out or failed to meet one or more selection criteria before the deadline. Women whose babies had died in a short interval of three to six months prior to data collection were also excluded from this study—the researcher considered their loss too fresh and potentially evocative. Likewise, women who were non-residents of Franklin County were not admitted to the study. All interviews were audio-recorded and transcribed verbatim. After the interviews were transcribed, the researcher e-mailed the interview transcripts to participants for their review and feedback. None of the participants provided any additional information.

Data Analysis

Data analysis began with *open coding*, and then proceeded through *axial coding* and *selective coding*. Open coding served three purposes, including: breaking down collected raw data; giving conceptual labels to the broken-down data units; as well as fashioning new insights from collected raw data. In addition, open coding involved identifying the main events or the central phenomenon described in the data. During open coding, raw data were broken down into 68 codes or categories, each of which included between 1 and 6 discrete units of data. Descriptive labels assigned to the codes included, for example, *child lost consciousness*, which included the data unit, “[My baby] suddenly lost consciousness while sleeping in a sitting position on a chair" (Participant 5). The code *despair and reassurance*, as a further example, included the data unit, "I got to the point where the doctor, one of my other doctors saw that I had a sense of despair, and said that it was ok" (Participant 1).

The primary purpose of axial coding was to build relationships among the codes. Axial coding involved combining codes identified during open coding into groups or themes, which were given conceptual labels. The researcher then verified the data associated with each theme or axial code, to better understand the context of the emerging categories. During axial coding, the 68 codes identified in the open coding were grouped into 11 broader themes or categories. For example, the axial code *pre-hospital events* included the open codes *child lost consciousness*, *early labor signs*, *lack of fetal movement*, *maternal/paternal health factors*, *scared during pregnancy*, and the *notification that baby will be early*. The axial code *pre-hospital events* included a total of 14 discrete units of data, and 6 out of the 6 participants contributed data to it.

The purpose of selective coding was to give a comprehensive account of the relationships among the events, actions, conditions and concepts in this study. As the final phase of the data analysis process, selective coding involved establishing verifiable relationships among the axial codes, to create a single story line or narrative. During selective coding, four themes emerged to answer the two research questions in the study. The four themes are presented in detail in this chapter's 'Results' section.

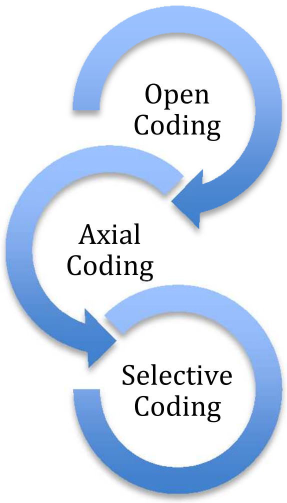

Figure 8: Coding process in GT

Evidence of Trustworthiness

Trustworthiness in qualitative research can be achieved by strengthening four interlocking factors or criteria identified by Guba and Lincoln (1989). The four factors are: credibility, transferability, dependability and confirmability. Each of these factors is discussed separately in the following subsections.

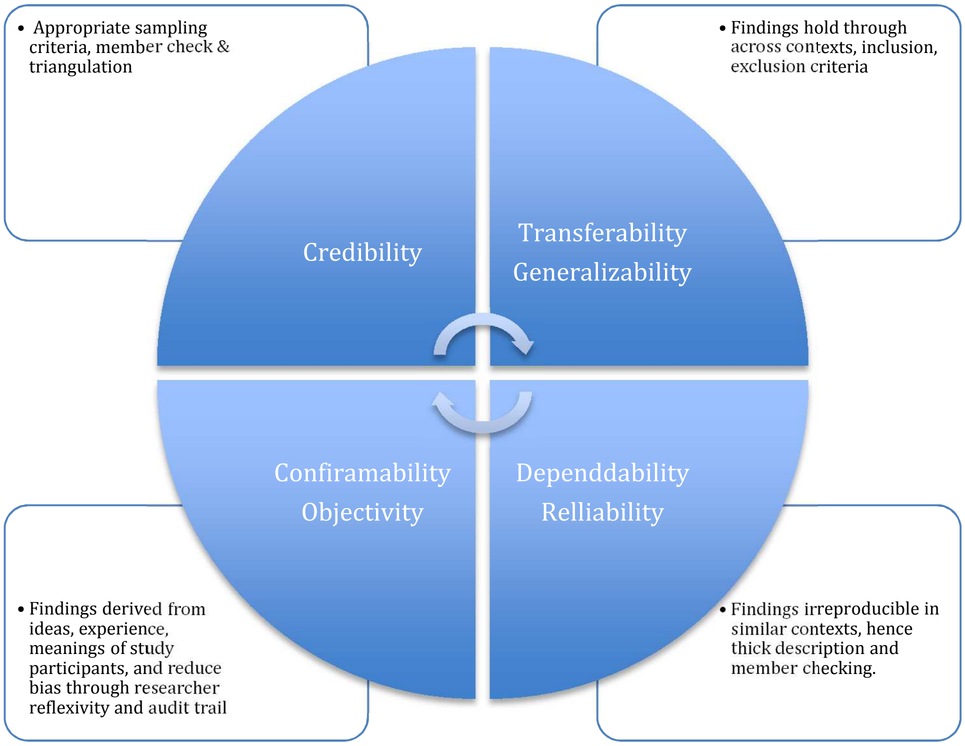

Figure 9: Strategies to ensure worthiness

Credibility

The findings in a study are credible to the extent that they accurately represent the reality they are intended to describe (Lincoln & Guba, 1985). To enhance the credibility of this study's results, the researcher screened potential participants according to the inclusion and exclusion criteria for the study. Additionally, the researcher enhanced credibility by ensuring participants that their identities and personal information would remain confidential; such reassurance encouraged participants to be honest with their answers. Furthermore, the researcher conducted member checking to enhance credibility, as recommended by Creswell (2013). In conducting member checking, the researcher e-mailed interview transcripts and preliminary interpretations to participants, along with a request for recommendations to improve accuracy. All participants reviewed the materials as requested, and the participants recommended no further changes.

Transferability

The findings from a study are transferable to the extent that they would hold true in differing or varying research contexts (Lincoln & Guba, 1985). The researcher assessed transferability, and the researcher was unaware of the specific circumstances in which another researcher might attempt to apply or transfer the findings in this study (Lincoln & Guba, 1985). To allow future researchers to assess transferability, the researcher has provided a detailed description of the inclusion and exclusion criteria for the sample, and detailed descriptions of the data collection methods employed in the study.

Dependability

According to Lincoln & Guba (1985), the findings in a study largely depend on the extent that another researcher in the same or similar research setting could reproduce them. Thus, the researcher enhanced the dependability of the study's results by providing a detailed description of the data collection and data analysis procedures employed. Member checking also enhanced the dependability of this study's results, as recommended by Creswell (2013).

Confirmability

Confirmability refers to the extent to which a study's results are determined by the ideas and experiences of the participants, rather than by any bias of the researcher (Lincoln & Guba, 1985). To enhance the confirmability of this study's results, the researcher provides in-depth methodological descriptions to allow the integrity of the procedures to be assessed by the reader.

Framework of Adverse Pregnancy Outcome

Below is an illustration of the cross-sectional social-world influences that cause or contribute to racial disparity in adverse pregnancy outcomes—these factors influence racial death disparity rates among African American infants. The factors show the dimensions of these influences, and how they affect women in their social world and eventually sway their pregnancy outcome.

Dependent variable **Intervening** **Independent variables**

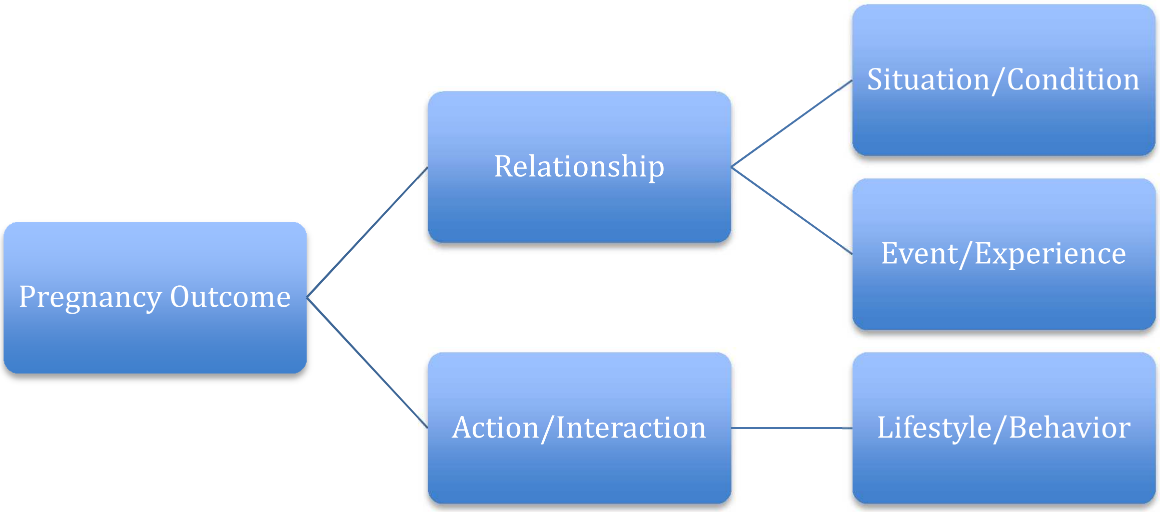

Figure 10. From codes to categories

Exploring the Theory of Racial Death Disparity among U.S. Infants

The *theory of racial death disparity* highlights the cross-sectional, social-cultural, economic and political influences that cause or contribute to persistent racial and ethnic disparity in adverse pregnancy outcomes for African American women. These factors underscore the patterns of influences—events, conditions, actions, interactions, relationships and processes—that underlie IM in the social world inhabited by African American women in the United States of America.

Development of the Theory of Racial Death Disparity

The racial death disparity theory suggests that disproportionate infant death disparity can be explained by analyzing 2 principal conditions that predispose African American women to adverse birth outcomes.

First is the presence of pre-existing vulnerability during pregnancy. This includes a lack of adequate medical expertise and inadequate medical information and guidance that might otherwise have helped women to make informed decisions pertaining to their baby's life. Also present were a history of severe neglect, of sexual abuse, or trauma-related psychiatric condition, the lack of a strong social-support network, as well as poor socioeconomic condition and late diagnosis of an inimical medical condition such as an ovarian cyst or the HELLP syndrome.

Second was the absence of adequate professional medical guidance that might have enabled women to make informed decisions about their health and that of their infants. Lacking such assistance is likely to guarantee a negative pregnancy outcome.

These factors were present in all cases of infant death here, and specifically relate to research question RQ1. Vulnerability is directly related to the SST, which asserts that individual human behaviors are influenced by cross-sectional multiple systems and sub-systems, which may include economic, social, cultural, political and ecological dimensions of society.

Two positive, protective sociocultural factors (buffers) were commonly associated with improved pregnancy outcomes among this group. First is women's timely access and utilization of prenatal care, which includes access to healthy nutrition, vitamins, immunization, and the absence of drug and alcohol use during pregnancy, and regular exercise during pregnancy. Second, research participants stressed the need for strong advocacy for women and infants during pregnancy and after delivery. These themes relate to RQ2, and largely support evidence from available literature.

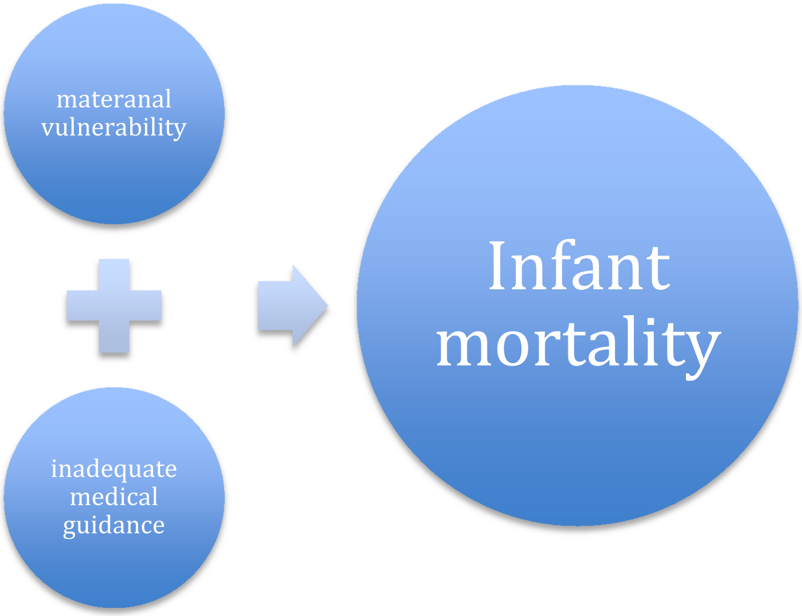

Figure 11. Risk factors for adverse pregnancy outcome.

Figure 12. Protective factors for positive pregnancy outcome.

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The Premise and Purpose of the Theory

The theory of racial death disparity is a 'pattern theory' of generalization of interconnectedness of concepts and relationships (Strauss & Corbin, 1998; Lincoln & Guba, 1985; Creswell, 2015). It aims to explain the relationship among aggregate risk factors for infant death, by offering a sophisticated theoretical framework. The framework addresses the underlying considerations that cause, sustain and mediate these factors to bring about incidents of IM in this population, such as social institutional conditions (policy-based principles, actions and interactions), relevant events (the experience of racism and discrimination), and lifestyle-related socio-cultural systems (behavior based-choices, personal relationships and social network). The presence of these conditions (upstream), events (mid-stream) and behaviors (down-stream factors) is more likely to signal the full manifestation of adverse pregnancy outcomes for women in this group. Thus, there is a causal consequence leading us to this analysis and the conclusion that follows. As a result, we can safely predict that "*the greater the conditions of maternal vulnerability and inadequate professional medical guidance for women during pregnancy, the greater the likelihood for their pregnancy to end up in infant death*." (H0).

Conversely, "*the greater the utilization of prenatal care and the presence of strong advocacy during and after pregnancy, the higher the probability for a positive pregnancy outcome for women and, the likelihood that such an infant will reach their first birthday*." (H1).

While it might not be safe to say that the risk factors for IM and the protective factors for positive pregnancy outcome are inversely proportional, it is safe to say that the risk factors are multi-layered, sequential and negatively influence birth outcomes. Below, a *Legend* is provided to help you better understand all associated concepts.

Legend

Outcome

- Refers to the consequence or end result of all social influences that affect women; most prominent are health determinants and risk factors.
- Short-term outcomes are the onset indicators of disease progress toward death disparity.
- Medium-term outcomes allude to real and successive evidence of death present in the disease treatment process.

- Long-term outcomes are the irreversible consequence of multiple risk factors. It can be measured by age of the infant (365 days). These mark the completion of the compound and complex interplay of behavior, actions, conditions, situations, events, and relationships of influences that emanate from the way that the healthcare delivery system is organized, operationalized and delivered (micro/macro and sub/systems).

Lifestyle or Behavior

- The way an individual acts in response to a situation or event or condition. Behavior may have been learned or inherited.
- For example, an individual lifestyle might include excessive smoking or alcohol consumption during the course of pregnancy.

Action and Interaction

- This refers to the process that one adopts to counter real challenges, potential conflicts and other barriers.
- Prolonged chronic stress, nutrient deficiency and epigenetics.

Condition or Situation

- This pertains to the circumstances or state of affairs in which one finds oneself.
- For example, biological and genetic factors, and one’s inherited race. African American women and infants have absolutely no control over this reality.

Event or Experience

- An encounter, a fact of life, or a happening in one's life, which carries significant health consequences.
- The experience of historical racism, one's residential neighborhood, or employment discrimination can have reverberating consequences for women and their infants.

Relationship

- Refers to the way in which people, objects or concepts associate, interact, relate and/or collaborate.
- For instance, the lack of timely access to a healthcare system or to a socioeconomic and supportive cultural network can shape the future for an infant.

Results

The presentation of the results of the data analysis is organized by research question. In relation to research question 1, results indicate which specific risk factors or exacerbating factors that participants believed had an influence on their birth outcomes. Results associated with research question 2 indicate the positive or protective sociocultural mechanisms that participants identified as potential buffers against adverse birth outcomes in their community.

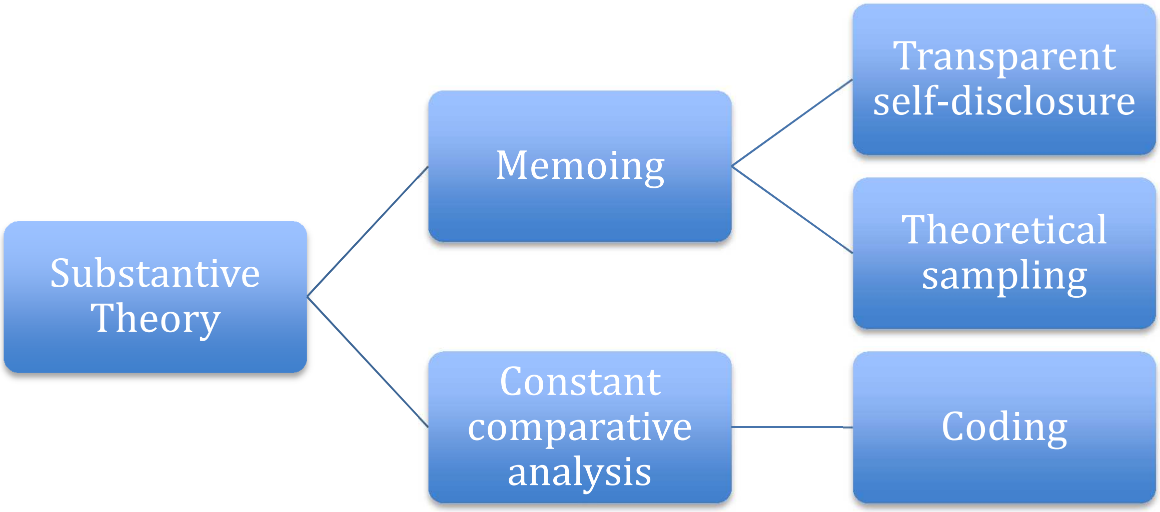

Figure 13. From Codes to Categories.

RQ1

RQ1 was: What specific risk factors (negative or exacerbating mechanisms) do African American women believe influence their birth outcomes, and therefore explain the persistent negative birth outcomes in their community? Research question 1 was associated with two sub-questions. Two themes emerged to answer the research question and its associated sub-questions. The themes are presented below, followed by a summary that applies the themes to the sub-questions.

Theme 1: Vulnerable mothers

Five out of six participants reported that they had experienced a condition of vulnerability during their pregnancy, and that they associated this condition with their negative birth outcomes. For Participant 1, the vulnerability was she and her husband's lack of medical expertise, which operated in conjunction with inadequate medical counsel to render them unable to make informed decisions affecting their baby's survival. For

Participant 2, the vulnerability was likewise a lack of medical expertise, operating in conjunction with inadequate medical advice. Participant 3 had multiple vulnerabilities, including a history of severe neglect and sexual abuse, being underage (she was 13 at the time of her pregnancy), lacking a strong support network, and having trauma-related psychiatric conditions including depression and anxiety. For Participant 4, the vulnerabilities included a disadvantaged economic condition, and a lack of adequate support that required her to work throughout her pregnancy, rather than getting the rest she needed. Participant 6's vulnerability was the development of an ovarian cyst, the surgical removal of which resulted in the accidental termination of her pregnancy.

Theme 2: Insufficient medical advice

Five out of six participants reported that they were asked or allowed to make decisions that affected their babies' chances for survival, without being adequately informed by health practitioners of the potential consequences for their babies. Thus, a condition, interaction, relationship or behavior that participants associated with their negative birth outcomes was that of receiving inadequate medical advice prior to the loss of their babies. The husband of Participant 1 expressed, at Participant 1's prompting, the sense of inferiority and discomfort that these participants felt when they were confronted with medical advice that went against their intuitions about the proper way to care for their baby:

> My biggest issue was not being a health professional, you don't know what is the best course of action to take sometimes. So, out of the blue, we were told that the child had to be delivered early. Because of the

> HELLP Syndrome. So you don’t know. If you disobey, you just keep the child in there. Because the longer the child is in there, the better. [But] you just follow the doctor’s instruction. (Participant 1’s husband.)

Thus, Participant 1’s husband expressed that he and Participant 1 had felt uncomfortable with the medical advice they received, but that they had complied with it in spite of their discomfort, because they did not want to “disobey” the doctor. Participant 1, and 4 other participants, believed that they and their partners (where applicable) were not sufficiently counseled by their doctors to feel that they were making informed decisions. Thus, regardless of the merits of their doctors’ advice from a medical perspective, the mothers were often unable to evaluate the advice in an informed and meaningful way. When they accepted medical advice, the mothers often felt that they were acquiescing to the arbitrary will of an authority figure, rather than working as full and active participants to protect their babies. At the time of study, Participant 1 and her husband still felt that they had no way of knowing whether delivering their baby early had been the right decision. They felt, however, that their consenting to their baby being switched from donor breast milk to formula might have contributed to her death.

Participant 2’s physician told her that she should deliver her baby via a C-section. The physician had made this recommendation after Participant 2 indicated that she was experiencing pain, and early, irregular contractions. When Participant 2 expressed her preference for a vaginal delivery, her physician simply said, “Well, let me know what you wanna do” (Participant 2). Participant 2 reported that her doctor had frequently taken this laissez-faire attitude during her pregnancy, and she indicated that the doctor's apparent indifference caused her to feel that the choice between a C-section and a vaginal birth was an arbitrary one. Her decision to wait for a vaginal birth rather than allowing her doctor to perform a C-section resulted in her baby's death, as the umbilical cord suddenly wrapped around the infant's neck. Participant 2 claimed that she had not been informed that this was a possible consequence of waiting for a vaginal delivery, or that the pain she was experiencing toward the end of her pregnancy might be an indication that something catastrophic had gone wrong with her child, or might go wrong. When her physician's apparent indifference and failure to inform her otherwise led Participant 2 to believe that the choice between a C-section and a vaginal delivery was arbitrary, Participant 2 allowed her preference to be decisive, and lost her baby as a result. Participant 2 referred to the need for doctors to keep mothers informed, particularly during a first pregnancy: "with me being a first time mom, I really don't know what to ask. All I want is for my child to be here, healthy…but I know that I am having [early contractions] and she [the physician] didn't tell me that those were signs of early labor."

Participant 3 also reported that practitioners did not give her sufficient information. She lost her baby as a result of the physical health consequences of the depression, anxiety and trauma she experienced after being raped repeatedly by her mother's boyfriend. However, her doctor did not inform her that there could be consequences for her pregnancy if her psychiatric and physical symptoms went untreated. Participant 3 was 13 years old at the time of her pregnancy, and did not have a strong support system. Participant 3 stated:

> I knew that I was losing weight around 6 months pregnant and stuff like that. I went from 200 pounds like down to 175 pounds in less than a month. So, that's why I don't understand why I wasn't told about my depression. Why they [physicians] didn't catch it in the midst of my pregnancy, as it was going on. I don't understand. It was never told to me till after I have the baby. (Participant 3)

RQ1 - Summary and Grounded Theory

SQ1was: What specific actions, interactions, relationships, conditions and behaviors do participants associate with their negative birth outcomes? Specific conditions, interactions and relationships associated with negative birth outcomes were: (1) pre-existing vulnerability on the part of the mother, and (2) a failure on the part of medical practitioners to give the mother sufficient advice and medical counsel to make an informed decision about her baby's health. Vulnerabilities associated with negative birth outcomes included: being a minor, being a victim of abuse, lacking a healthy support system, being a first-time mother, having a psychiatric or physical medical condition (such as Participant 4's weakened uterus, the cyst on Participant 6's ovary, and HELLP for Participant 1), or simply lacking medical expertise.

SQ2 was: In what specific sequence (serial order) do these risk factors manifest themselves to influence birth outcomes? First, mothers came to their physicians with vulnerabilities. When participants presented with conditions that threatened the survival of their babies, they were frequently not informed of the urgency of the situation (such as in the case of Participant 2), or of the potential consequences of following or not following the medical advice that was given to them (again, Participant 2). In the cases of Participants 2, 3 and 4, insufficient information from medical practitioners may have contributed to their babies' deaths by leaving the mothers unaware of the urgency of consenting to a necessary treatment or procedure. (Or simply of the need for rest, as in the case of Participant 4.) In the cases of Participants 1 and 6, inadequate medical information led them to consent to procedures that threatened the lives of their babies without a proper understanding of the potential consequences.

P5 was a partially discrepant case. The death of her baby was attributed to SIDS, and did not occur in association with medical advice. Participant 5 reported, however, that her baby's death might have been prevented if her caregiver had laid her baby down on a bed instead of letting the baby sleep in an upright position, sitting on a chair. She felt that the caregiver had made the choice to let her child sleep in a more vulnerable position perhaps because the caregiver was uninformed about the associated risks.

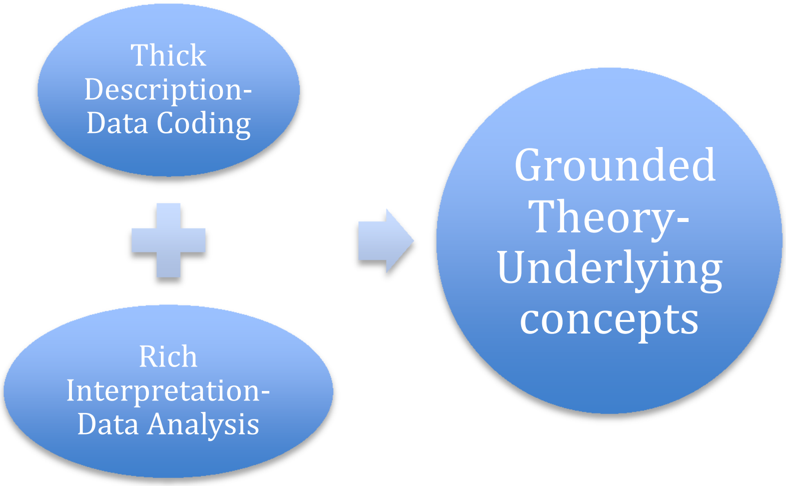

Figure 14. Phases of theory generation in GT.

RQ2

RQ2 was: What sociocultural factors (positive or protective mechanisms) do African American women identify as potential buffers against adverse birth outcomes for them and other women? Research question 2 was associated with three sub-questions. Two themes emerged to answer the research question and its three associated sub-questions. The themes are presented below, followed by a summary that shows the application of the themes to the sub-questions.

Theme 3: Prenatal care

Four out of the six participants indicated that a factor that may have acted as a potential buffer against adverse birth outcomes was prenatal care. Prenatal care included eating healthy foods, receiving immunizations (e.g. flu shots), abstaining from tobacco and alcohol, and attending prenatal checkups. Participant 1 reported that she had engaged in healthy eating and had attended all prenatal checkups, and she confidently added, “We had done everything we thought we ought to have been doing.” Participant 2 also attended prenatal checkups, ate healthy foods, followed medical advice, and exercised:

> I did everything right [during pregnancy]. I am talking about all the way to what to eat to what not to eat. What exercises to do, what not to do. I did every single thing right. I wasn’t around smoke, I did not drink, I did everything right and I listened to my doctor. If my doctor said do this I did it…I have never missed an appointment [prenatal checkup]. (Participant 2.)

Participant 3 stated, “I received prenatal pills, I received regular checkups, through the 9 months.” Participant 5 likewise reported that she ate well during her pregnancy and attended all prenatal checkups.

Theme 4: Strong advocacy

Three out of the six participants reported that a factor that might have acted as a potential buffer against adverse birth outcomes was strong advocacy on behalf of themselves and their infants. Participant 1 and her husband remembered asking practitioners in the NICU (neonatal intensive care unit) to keep their baby on breast milk instead of switching her over to formula: “I remember that when they had switched her to infant formula and we said, was it possible that they keep her on breast milk longer?” Participant 1 wished, however, that she had been a stronger advocate on behalf of her baby:

> Since we [husband and I] are not medical people, you tend to follow what the doctor says, whether or not you are sure. Part of me feels like, that I should have pushed more on the breast milk. Black women make a lot of noise. Maybe I should have made much noise and not care until somebody listened and said, “hey ok, let us consider this or like you said, give me the option to go run around and go find breast milk.” (Participant 1.)

P2 likewise wished that she had been a stronger advocate for her baby’s health, in this case by going to the hospital and insisting on receiving attention as soon as she suspected that something might be wrong in her pregnancy:

> I have actually talked to a lot of mothers, since this happened. I do tell them, if you feel any question, go to the doctor, go to the hospital. Because that’s one thing I do regret, even though it may not have made any difference. But I didn’t go to the hospital. But I still tell them to go, so they could say that they did everything they could for their baby. (Participant 2.)

Participant 6 equally advised women to be strong advocates for their babies, saying, “If you are having a problem, go to the hospital.”

RQ2 - Summary and Grounded Theory

Sub-question 3 was: What are these health determinants? Findings associated with research question 2 indicated two health determinants that participants identified as potential buffers against adverse birth outcomes: prenatal care, and strong advocacy. Prenatal care included: taking prenatal vitamins; eating well; exercising; attending all prenatal checkups; abstaining from tobacco, drugs, and alcohol; and following medical advice. Strong advocacy included seeing a doctor or going to the hospital as soon as the mother detected any sign of fetal distress, and “pushing” practitioners to do what the mother believed was best for the baby.

Sub-question 4 was: In what particular order or sequence do these play out in real life? Prenatal care and strong advocacy occurred at the same time, and were often intertwined. Women who did not “push” physicians to assist and advise them to the fullest extent, and so might have remained uninformed of proper prenatal care for themselves and their babies. This was the case with Participant 3, who was not informed of the risks to her baby associated with her psychiatric and physical symptoms, and with Participant 2, who was not informed that her baby might die if she did not proceed with a C-section when it was first suggested to her. Thus, strong advocacy may have been a prerequisite of proper prenatal and postnatal care, such that women needed to engage in it continually during and after their pregnancies. It should be noted, however, that not all pregnant mothers are able to be strong advocates for themselves and their infants. Participant 3, for example, was a 13-year-old legal minor without family support, and could not be expected to "push" physicians to give her the best possible care.

Sub-question 5 was: Are these available to the majority of African American women? Four out of the six participants indicated that they engaged in proper prenatal care routines, such as attending checkups, taking prenatal vitamins, and eating healthy foods. Thus, findings suggested that these forms of prenatal care were generally available. However, a further form of prenatal care mentioned by participants was following medical advice and receiving proper medical care, and findings indicated that adequate medical advice and care were often unavailable to women who did not "push" for them.

Summary

The purpose of this qualitative GT research was to explore the complex network of systems (macro) and subsystems (micro), and events, actions, interactions, conditions, behaviors, relationships and processes that underlie racial and ethnic disparity in IM among African American women in their optimal (ages 18-45) child-bearing years. To achieve this, semi-structured, one-on-one, in-person interviews were conducted with six

African American women who had lost their infants to IM between five years and six months before the time of the study. Two research questions were used to guide the study.

Research question 1 was: What specific risk factors (negative or exacerbating mechanisms) do African American women believe influence their birth outcomes, and therefore explain the persistent negative birth outcomes in their community? Specific conditions, interactions and relationships associated with negative birth outcomes were: pre-existing vulnerability on the part of the mother, and a failure on the part of medical practitioners to give the mother sufficient medical advice and counsel to make an informed decision about her baby's health. Vulnerabilities associated with negative birth outcomes included: being a minor, being a victim of abuse, lacking a strong support system (financial, emotional or sociocultural), being a first-time mother, lack of adequate medical information and advice, having a pre-existing psychiatric or physical health condition (such as Participant 4's weakened uterus, the cyst on Participant 6's ovary, or HELLP syndrome for Participant 1), or simply lacking medical expertise.

Research question 2 was: What sociocultural factors (positive or protective mechanisms) do African American women identify as potential buffers against adverse birth outcomes for them and other women? Findings indicated two health determinants that participants identified as potential buffers against adverse birth outcomes, including: prenatal care, and strong advocacy for the mother and her infant. Prenatal care included: taking prenatal vitamins; eating well; sufficiently exercising; attending all prenatal checkups and immunizations; abstaining from tobacco, drugs, and alcohol use; and following medical advice. Strong advocacy included seeing a doctor or going to the hospital as soon as the mother detected any sign of fetal distress, and “pushing” medical practitioners to do what was best for the baby. It was notable that women who did not “push” physicians to assist and advise them to the fullest possible extent often remained uninformed of proper prenatal care for themselves and their babies. Thus, strong advocacy may have been a prerequisite of proper prenatal and postnatal care, such that women needed to engage in it continually during and after their pregnancies.

Chapter 5 presents an interpretation and discussion of the implications of these results.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Losing the life of a newborn is a tragedy. Despite progress in medical technology, public health education and policy, the United States continues to have the highest rate of IM within the developed world (Chen et al., 2014; Montague, 2007). These statistics are not uniform across socioeconomic and cultural divides. The Kaiser Family Foundation (2013) found that IM rates are highest amongst African American women.

Race alone may not be the sole factor in IM rates, as socioeconomic conditions and health disparities between classes could contribute to the epidemic. Low income, coupled with an underprivileged living environment, further infant's risk of illness and death (Chen et al., 2014). For those in lower socioeconomic conditions, limited resources, marital status, education, income, occupation, and employment and health insurance status can contribute to health complications long before pregnancy (CDC, 2011; Plough, 2015; Spong et al., 2011). Race could be a variable that links all these issues, creating a need for further investigation. Burris et al. (2015) said that by comprehending the relationship between these determinants and risk factors, further insight into the IM rate among African Americans could be gained.

The purpose of this qualitative GT research was to explore what underlies racial and ethnic disparities in IM among African American women in optimum (ages 18-45) child-bearing years. Participants for this study were sampled from the 18 cities in Franklin County, Ohio. This study sought to reveal the structural sequence of all associated risk factors to better advance the knowledge of how these factors intermingle and overlap. I aimed to explain the nature and scope of IM among African Americans within the United States. By isolating the discrepancies between socioeconomic, racial and cultural differences, better policy could be crafted toward reducing IM in African American communities (Alio et al., 2010).

Previous studies had concentrated on expanding the individual characteristics of the risks and factors that cause the variations of IM within the United States. This study is unique because it specifically explored poor birth outcomes among African American women within their community. Minimal research exists on the varying risk factors and how they relate with each other, potentially furthering the IM rate differences between races.

The GT methodology was applied in this study, as it permitted the participants' voices, perspectives and meanings to be fully explored, toward explaining racial infant death disparities. GT can aid in uncovering the underlying themes, methods and systems that may contribute to IM. GT permits a systematic and inductive strategy toward interpretative research to uncover social systems and dynamics that can alter the interactions and behavioral patterns of a chosen group within its natural environment. This selected research method permits data collection, comparative data analysis, and theoretical sampling, while ensuring quality, validity and transferability of the results (Glaser, 1998).

Two research questions were asked within this research project:

RQ1: What specific risk factors (negative or exacerbating mechanisms) do African American women believe influence their birth outcomes and therefore, explain the persistent negative birth outcomes in their community?

RQ2: What sociocultural factors (positive or protective mechanisms) do African American women identify as potential buffers against adverse birth outcomes for them and other women?

These research questions yielded four themes. The themes for the first research question were: pre-existing vulnerability of the mother, and a failure on the part of medical practitioners to give the mother sufficient advice and counsel to make an informed decision about her baby's health. Participants mentioned that vulnerabilities associated with negative birth outcomes included: being a minor, being a victim of abuse, lacking a support system, being a first-time mother, having a psychiatric or physical health condition, or simply lacking medical expertise.

The second research question yielded two significant themes: prenatal care and strong advocacy. Prenatal care involves taking prenatal vitamins; eating well; exercising; attending all prenatal checkups; abstaining from tobacco, drugs, and alcohol; and following medical advice. The second theme, strong advocacy, means seeing a doctor or going to the hospital as soon as the mother detects any sign of fetal distress, and "pushing" practitioners to do what is best for the baby. Participants had noted that unless a pregnant mother pushed a medical professional to assist and advise, they would have remained uninformed and less capable of delivering care to their unborn or recently born child.

Interpretation of the Findings

RQ1: What specific disease burden (risk factors or negative or exacerbating mechanisms) do African American women believe influences their birth outcomes, and explain persistent negative birth outcomes in their community?

The first research question was about what participants may believe could account for the death of their infants. The two follow-up questions were:

SQ1: What specific actions, interactions, relationships, conditions and behaviors do they associate with their negative birth outcomes?

SQ2: In what specific sequence (serial order) do these risk factors manifest themselves to influence birth outcomes?

Once analyzed, these questions yielded two themes, which were vulnerable mothers and insufficient medical advice. Both of these themes point to concerns of racial disparity, both pre- and post-birth. The themes were also interrelated. Feeling vulnerable could be a direct result of receiving insufficient medical advice. Feeling vulnerable may not be race-related, as participants (especially first-time mothers) may feel anxiety or lack confidence about what they are going through. However, racial issues may have manifested in terms of the second theme, as socioeconomic conditions and discrepancies can result in sub-par or uneven medical advice.

Vulnerable mothers

The majority of mothers interviewed for this study felt that their feelings of vulnerability during pregnancy were connected to their eventual negative birth outcomes. Only one participant felt that this was not the case—P1 attributed her vulnerability to deficiencies in medical knowledge. Where the participants felt they were receiving deficient advice and treatment, they were unable to vocalize their discontent due to a lack of medical knowledge. This left them unable to make informed decisions. P2 also attributed her feelings of helplessness to poor medical expertise and advice.

While P1 and P2 noted that their feelings of vulnerability were linked to a paucity of medical advice, P3 noted that her defenselessness was due to her personal past, as she was 14 years old when she gave birth. She also had a history of neglect, sexual abuse, a poor support network, and had suffered from depression and anxiety. While these vulnerabilities may or may not correlate with socioeconomic conditions, P3's vulnerabilities went beyond those of the first two participants.

P4 was the first to directly cite socioeconomic conditions. P4 noted that she lacked the resources to give herself adequate medical treatment. Without proper medical treatment, the participant felt that she was at a disadvantage and felt vulnerable. While this feeling coincided with those of P1 and P2, P4 was the first to directly attribute this feeling of vulnerability to socioeconomic status.

P6's feeling of vulnerability was the first to be directly influenced by outside forces. Vulnerability did not come from her past, nor was it due to lack of access to medical care; instead, P6 had developed an ovarian cyst while pregnant. During the surgery on her cyst, her pregnancy was accidentally terminated. P6's vulnerability may have occurred due to poor medical advice, or it may have been a complication of the surgery. Either way, the process left her feeling vulnerable, and diminished her trust of the medical system.

Available literature can also offer better insight into these themes. IM is often associated with multiple variables, such as maternal stress, racism, socioeconomic condition, marital status and substance abuse (Ali et al., 2010; Berg, Wilcox, & d'Almada, 2001; Giscombe & Lobel, 2005; Gould & Leroy, 1988; Hogan et al., 2001; Schoendorf et al., 1992; Wise et al., 1985). The responses of participants 1, 2 and 4 can all correlate to maternal stress from limited knowledge and sub-optimal medical advice, and socioeconomic conditions. However, it was Participant 3 who dealt more elaborately with issues such as marital status and sexual abuse, which led to her feelings of vulnerability. The association between medical advice and socioeconomic conditions is not weak, as the Santa Clara County Public Health (2011) stated that maternal stress, ethnicity and geographic location could influence IM.

While not implicitly stated by the participants, the literature suggests that poor medical advice can stem from unconscious racism and implicit bias (Hartil, 2014; Jackson, 2007). These forms of racism can manifest in numerous ways, from micro-aggressions, to daily verbiage and behavioral indignities. These direct or indirect actions and communications can increase the risk of morbidity and mortality for infants (Hartil, 2014; Jackson, 2007). Evidently, poor communication between doctor and patient can lead to maternal stress, low birth weight, premature birth, and other antagonistic birth outcomes for new mothers.

Participant 3's experience encapsulates many of the adverse experiences found within the literature. Rates of teen pregnancy, lower education level, limited resources, marital status, and the unavailability of adequate medical care can all differ between races

(Jackson, 2007). Carpentier (2010) and Salihu and Wilson (2007) stated that racial disparities found within infant death rates can be attributed to maternal drug and alcohol use, sexual promiscuity, cigarette smoking during pregnancy, poor nutritional choices, and unhealthy maternal gestational behavior, any of which sometimes expose infants to unfavorable pregnancy outcomes. Yet, Lu et al. (2003) challenged these views by positing statistical differences between foreign-born and U.S.-born African American women. Participant 3 had also mentioned a poor support system. Jackson (2007) stated that social relationships and support systems play a great role in IM rates and pregnancy outcomes.

Responses indicated that vulnerability throughout the birth-giving process manifested in a variety of ways. Whether it was medical professionals' lack of information leading to parents making poor decisions, or being a victim of abuse or poor physical health conditions, these feelings can lead to a feeling of vulnerability. These sentiments are supported by the literature review. Giscombe and Lobel (2005) stated that stress and racism could create vulnerabilities, although they do not fully account for disparities in racial birth outcomes. Williams and Jackson (2005) and Mehta et al. (2013) stated that there are racial differences in disease, disability and death due to a lack of adequate access and advice.

Many scholars have asserted that malicious effects of racism and discrimination are underlying forces for minority IM (Clark, 2003; Clark et al., 1999; Mays, Cochran, & Barnes, 2007). Krieger (2012) disputed these notions, stating that research has been unable to ascertain how race and discrimination directly influence birth outcomes.

Despite this assertion, Dominquez (2008) concluded that the stress of racism and socioeconomic opportunism has devastating effects on pregnancy outcomes for African American women.

The first theme of vulnerability can be directly related to both conceptual frameworks. As SST states that human behavior is influenced by multiple systems and subsystems, which are in turn altered by social and environmental factors, the feeling of vulnerability should come as no surprise. It could be argued that participants who noted that poor medical advice led to feelings of vulnerability were a direct result of socioeconomic conditions within social systems.

While SST provides the context for which to interpret these feelings of vulnerability, the vulnerability theme also relates to CRT. With the inclusion of the CRT lens, SST can be directly applied to racial discrepancies, as the differences in systems grow from racial disparities. CRT illuminates connections among economic, political, social and cultural dimensions of contemporary society (Kellner, 1993). When used in conjunction, both of these frameworks describe how a connection between feelings of vulnerabilities and socioeconomic, cultural and racial disparities.

Inadequate medical guidance

The second theme was insufficient medical advice. Five out of the six participants felt that they made medical decisions based upon inadequate information. Poor information limited their ability to make decisions, leading to negative consequences. Inadequate communication manifested through negative interactions, behavior and relationships with their medical provider. The husband of Participant 1 implicitly stated that they were often given information about their pregnancy that went against their intuition, due to a lack of communication and understanding.

The dichotomy between what parents feel is right and the instructions the doctors gave grew from the parents being unable to adequately express their opinions due to an absence of medical knowledge. Participant 1 still feels that she and her husband had no idea whether delivering their baby early was the right decision. Additionally, they place blame on their medical provider's recommendation to switch from breast milk to formula, as that may have contributed to their infant's death.

Participant 2 felt that her doctor's indifference led to her child's death. While the doctor wanted a C-section and the participant wanted a vaginal delivery, the physician merely replied, "Let me know what you wanna do." This laissez-faire attitude made the participant feel that her decision was subjective. Yet when her baby passed away due to the umbilical cord being wrapped around the infant's neck, the participant felt that the doctor's blasé attitude contributed to a poor decision.

Lastly, Participant 3 noted that she was unable to make adequate choices due to medical advice. Her physical health was affected by depression, anxiety and trauma from being raped. However, at no point did the doctor inform her that these symptoms could affect her pregnancy, which is especially disconcerting considering she was about 13 years of age. The multiple health concerns that Participant 3 faced that were overlooked by her doctor demonstrated the dearth of insufficient medical advice that was offered.

Jackson (2007) stated that various health scientists indicated that IM should be explored within the broad context of human relationships, such as one's relationship to one's society, as well as the medical service they are provided. Each of these relationships can have positive or negative influences on the mother and child's health. Chen et al. (2014) argued that IM, socioeconomic groups, and demographic characteristics sometimes mirror existing social inequalities, leading to poor medical advice and health care inequality. The National Research Council (2013) mirrored these positions by stating that income and socioeconomic inequality lead to a disproportionate amount of deficient medical treatment and health services, thereby furthering the IM rate differences between IM between races and economic groups.

Jackson (2007) focused on the social relationships between those involved, regarding pregnancy and mortality rates. The scholar asserted that social relationships could diminish or improve birth outcomes. Williams and Jackson (2005) stressed that despite a more diverse ethnic and racial makeup in America's cities, there remains a gap of medical treatment options. Mays, Cochran, and Barnes (2007) stated that these differences determine who lives or dies. This assertion lines up with the study's findings that poor medical advice given along socioeconomic and racial lines contributed to the children's deaths. Feelings of inferiority and denial of economic and medical opportunities accompanied biased medical care, and sub-par advice and treatment. This assertion aligns with statements that participants made within the study.

Participants often come to their doctors with their own vulnerabilities, stating afterward that they do not feel that they were receiving proper medical advice. Participants 2, 3 and 4 all felt that the insufficient information the women received may have contributed to the babies' deaths, having led the mothers to think that their concerns were not urgent. Participant 5, whose baby passed from SIDS, felt that the death could have been avoided if the caregiver simply had let the baby sleep in a car seat instead of on a regular chair. SIDS and low birth weight can be reduced through proper medical advice (Chen et al. 2014). Additionally, Chen et al. (2014) felt that these post-neonatal deaths can be explained through regional data.

The theme of poor medical advice also aligns with both frameworks. As SST examines how multiple systems and subsystems interact with human behavior, it is easy to comprehend that parents' decisions are a product of their environment and the advice that they receive. In this case, poor or inadequate medical advice, potentially dictated by the socioeconomic conditions, created the environment in which their child died. As SST contends that individual, familial, communal, organizational, cultural, political and socioeconomic systems can all alter human behavior, medical professionals who failed to offer the much-needed medical advice indicate flaws within the systems.

While SST may not directly relate to racial disparities, applying CRT aids in making that connection, by asserting that the poor medical advice offered comes from differences in economic, political social and cultural dimensions. In the context of this study, CRT asserts that good medical care favors those in better socioeconomic conditions than the participants within this study, and that these differences are directly attributed to race. While the doctors may not outwardly project racism, they remained indifferent regarding the medical advice they offered, indicating different social system mechanisms may be in play. While poor treatment alone may not indicate racism, geographic and disparate socioeconomic conditions can link racial differences to medical advice.

The second research question (RQ2) asked participants to delve into sociocultural topics, which may aid in reducing IM rates for African American women. The three follow-up sub-questions consisted of: What are these health determinants? In what particular order or sequence do these play out in real life? And, are these available to the majority of African American women?

Upon analysis, these questions yielded two themes: prenatal care and strong advocacy. Unlike the previous two themes, research question 2's themes were not as closely linked however, upon inspection, a connection between them could still be made. Prenatal care and strong advocacy do relate to the chosen frameworks, as access to both rests upon existing socioeconomic systems and how they are affected by race. These two themes will be further examined in the following sections.

Prenatal care

Four out of the six participants felt that better prenatal care could have prevented adverse birth conditions. These types of prenatal care could include diet, vaccinations, substance abuse status, and frequent prenatal checkups. It is important to note the correlation between these recommendations and insufficient medical advice. Without a medical professional imparting this medical knowledge, parents can be left feeling vulnerable and IM could be increased.

Participants 1, 2, 3 and 5 noted that they felt they followed the above-mentioned prenatal care. They ate healthy food, attended prenatal checkups, exercised, and followed the limited and sometimes inconsistent and unconcerned medical advice. Participant 3 emphasized that she even took the recommended prenatal pills. By following the prescribed steps, which still led to infant death, participants felt despondent and looked inward for why the tragedy occurred.

With participants strictly following prenatal care recommendations and still resulting in IM, it is simple to see how participants felt that the advice they received was simply inadequate. The participants wondered what more they could have done if they had followed every instruction healthcare professionals gave them. Previous feelings of vulnerability, and a lack of medical knowledge, made them dependent upon doctor recommendations. Normally, following medical instructions should lead to positive results. However, if the doctors were not fully involved, then important advice and information could have been overlooked or dismissed.

The literature strongly supports the participants' recommendations for prenatal care. The Institute of Medicine (1998) stated that early employment of prenatal care throughout the three trimesters results in reduced risk of low birth rate, and increased positive pregnancy outcomes for women with limited education and a lack of access to adequate medical care due to socioeconomic conditions. The scientific evidence dictates that mothers who remain complacent about their child's health, especially in the first trimester, results in poor birth outcomes.

However, prenatal care advice is not universal. Burris and Collins (2010) and Hauck, Tanabe, and Moon (2011) stated that socioeconomic conditions and race/ethnicity disparities limit access to health services, diminish the utilization of prenatal care, and increase stress throughout the process. These studies indicated that race/ethnicity does play a part in available prenatal care. Additionally, this corresponds to adequate medical advice, which the literature has shown to be disproportionate between races and socioeconomic conditions.

Yet, this is not a hopeless situation. Lu et al. (2003) created a 12-point plan to help address these social and health differences as they relate to African American women. Steps that could be taken include, but are not limited to: access to inter- and pre-conception and quality prenatal care over the life course; active father engagement; coordinated and integrated family and community support systems; closing the gaps in education, poverty; and, eliminating racism (Lu et al., 2003). The CDC (2013) supports these assumptions, and adds that education and assistance should be made available to women the instant they reach the child-rearing age.

This theme directly corresponds to both frameworks. SST explains these experiences and recommendations by examining them through the lens of existing social systems. Familial support, uneven medical access, and other variables are all influenced by social systems. Should any of these systems lack support, the parent may not be well equipped with proper prenatal care. Poor social systems lead to contributory, influential and associated risk factors.

CRT bridges SST and racial inequality. Using just SST, many other factors could come into play, such as geographic location, education or income. However, CRT explicitly links the phenomenon to one of race. Employing CRT reduces other explanations, and attributes poor social systems to racial inequality. Lu et al. (2003)

would agree with this assessment, as the scholars isolated and extrapolated issues and solutions specifically for African American women, and the systems and resources which would be available to them. Strong advocacy is required to improve access to prenatal care for mothers with limited resources.

Strong advocacy

Out of the six participants, half stated that strong advocacy would have been a potential buffer against negative birth outcomes. Stronger advocacy can relate to medical professionals, support systems, or even advocating for oneself. Participant 1 remarked that both she and her husband asked practitioners to maintain their child with breast milk instead of formula. Upon the infant's death, the parents wished that they had been stronger advocates for their stances. Having a strong advocate or medical professional who would have supported their view, or at least acknowledge their concerns, would also have been beneficial and may have prevented the tragedy.

In retrospect, Participant 2 felt she should have advocated for her baby's health by going to the hospital and insisting on immediate medical help the minute she felt that something was wrong with her pregnancy. Both of these participants felt that stronger advocacy and support within the system would have had positive results. Yet advocacy should not be strictly left to individual women; scholars have ascertained that outside variables limit advocacy for African American mothers for their personal health, and for prenatal care for their children.

Jackson (2007) advised that IM be examined in the context of systems, such as economic opportunism, support systems, and medical access, as each can have a negative-accelerating stimulus on a mother's health and the health of her child. Chen et al. (2014) supports this assertion, and goes on to elaborate that socioeconomic groups and demographic characteristics relate directly to medical care, a position that the National Research Council (2013) has linked to IM. However, these systems are not universal and vary with geographic location and demographics.

Williams and Jackson (2005) stated that America's diverse cities; demographics and socioeconomic conditions create gaps for medical access and economic opportunities. Krieger (2012) felt that within these systems, there is a growing concern that discrimination and uneven differential treatment may increase poor health, thus making race an issue in birth outcomes (Clark, 2003; Clark et al., 1999; Mays, Cochran, & Barnes, 2007). The disparity among economic classes and racial groups requires an advocate to speak for those who cannot speak for themselves. While this study's participants might have felt that they could have advocated more themselves, an outside advocate representing these underprivileged groups may have a substantial stimulus on IM rates within the U.S.

Williams et al. (2010) contend that race, ethnicity and socioeconomic conditions cause unneeded stress in pregnancy, and that within these conditions, racism can be found. Geographic segregation limits the medical options for African American women (Clark, Anderson, & Williams, 1999; Dominguez, 2008; Engeland et al., 2015; Giurgescu, Zenk, Templin, Johnstone, & Kanitsaki, 2008; Krieger, 2000). Social forces create structural racism, which affects all levels of society, including government, economic, educational, and housing, justice, and healthcare systems (Eyles & Woods, 1983; Jones & Moon, 1987; Smith, 1988). These racial barriers prevent African American mothers from receiving adequate medical advice, and limit their support system, forcing them to rely upon themselves as advocates, rather than having doctors, nurses or other healthcare or social services advocate for them.

The theme of advocacy perhaps relates the most strongly to the two chosen frameworks. SST would dictate that the systems themselves are sub-par, creating a need for outside forces to enact change for those who are unable to do so themselves. In this case the health systems, which may be unduly influenced by racism, need advocates to create equal care and education for prenatal mothers. CRT theory would strongly support this theme, as it challenges inherent contradictions due to racial disparity found within those systems. CRT places racism as the prime factor that results in African American women not having strong advocates within the health system. CRT would argue that mothers having to advocate for mothers demonstrates systemic racism, as other demographics may well have better options and support.

Limitations of the Study

This study was limited in major specific ways. First, the study was limited by the geographic location of participants. Second, the sample size was limited to six African American women. Third, the study did not focus on trends within IM. Fourth, the study was limited by the mode of death of the infants in the study. Fifth, and last, the study did not include the perspectives of male partners who have first-hand experience with IM.

The geographic location was able to produce a saturated sample of African American women aged from 18-45, yet by no means is this study indicative of the entire

United States. While Franklin County was an appropriate choice of site for the study, a change in geographic region might produce different results, especially in terms of racial disparities in healthcare. Urban and rural areas have differing access to healthcare, and geographic regions may manifest treatment of minorities inversely. It is important to consider each of these issues before applying the results to a larger population.

The second limitation, which limited the women by the type of healthcare provider, could also provide differing results. Access to medical treatment is often tied to the ability to afford private or public healthcare insurance coverage. Geography also plays into the second limitation, as some areas might have increased access to healthcare. Additionally, the advice of doctors may vary based on the type of facility and the geographic location. While the results indicated a blasé approach to medical advice for the participants, it would be extremely reckless to apply this to all doctors, as those with a more diverse demographic may be more aware of the plight of African American women.

The third and fourth limitations were similar, as they focused on the trends and types of fetal and prenatal mortality. SIDS, abortion, miscarriages and fetal deaths were not accounted for. The narrow scope of the study offered a preliminary understanding of this phenomenon. However, other types of fetal deaths should be accounted for in future studies. The themes indicated that advocacy, medical advice, vulnerability and prenatal care were all important to pregnant women. It would be wise to see if mothers who suffered infant deaths from one of the restricted trends also felt that these themes were relevant to them.

The final limitation was that there was limited male perspective in this study. While husbands may have accompanied their wives for emotional support, they were not the focus of the study. (There was one other limitation found upon completion of the study that was not mentioned. This study was limited to mothers only; no social workers or medical professionals were interviewed in this study. Focusing on the views of healthcare professionals in future research might help to clarify their level of self-awareness, given the stated concerns of the participants in this study.)

Recommendations

This study has shed ample light on the strengths, weaknesses and biases inherent in current literature (Creswell, 2013). It has also made multiple recommendations for future research. Changing the methodology, research design, sample population, scope of study, and the geographic location could alter the uncovered themes. The next step in the research would be to offer a quantitative study, to examine if a wider sample may align better with the uncovered themes. A quantitative study that would test the emergent theory might allow for increased transferability and make it easier to compare results between samples and geographic locations, while uncovering new trends and themes. The design type might also cause considerable changes in the results. GT provides a basis for future work; however, an interesting study for future research would be to conduct a phenomenological study, for a more holistic approach. A phenomenological study could include male parents of dead infants, social workers, and medical professionals, to flesh out whether the themes the sampled mothers spoke of would equally be acknowledged and sustained from these perspectives.

The chosen sample is a launching point for future research. In addition, including other minority ethnicities in a future study might help to determine if they too felt that race and socioeconomic conditions would be a factor in their own treatment outcomes. Additionally, being able to compare African American perspectives to Hispanics and Caucasians might further help to uncover more similarities and differences in perception and experience. Another sample choice in an expanded-race investigation could also include men, healthcare professionals and social workers to ascertain if they too agreed with study results. Medical professionals might not be previously aware of the themes uncovered by this study, hence the present study has created an opportunity for further social changes.

Last, this study should be conducted in different geographic regions of the United States. Treatment at urban facilities might differ significantly from that of rural settings. Additionally, the quality or efficiency of the hospital or healthcare delivery system might influence the way that physicians relate to and provide medical counseling to their patients. Nevertheless, it would be important to test if the cost of healthcare influences current themes. Future studies should also compare and contrast the differences between races and socioeconomic conditions. Losing a child, for whatever reason, is life–changing, and mothers may identify with the same themes regardless of their race, socioeconomic status or location. Vulnerability, advocacy and thoughts about prenatal care, might not be strictly limited to one race, hence uncovering if they transcend the sample could be significant.

Making recommendations for positive change, Adler and Newman (2002) suggested that eliminating death rate disparity would require policies that improve education, or equalize resources among all American sub-groups. Focusing merely on maternal health behavior changes, without major efforts in policy and healthcare practice changes, has been viewed by some experts as ‘blaming the victims’ of racial death disparity. Marmot (1999) insisted that interventions that prioritize *upstream* policy changes, as well as *mid-stream* healthcare system practices and *downstream* individual lifestyle and behavior changes, have greater chance for success in the U.S. Improvements in maternal health, pregnancy and birth outcomes will also require considerable modifications to social determinants of health factors (Freundenberg & Tsui, 2014), as well as having quality patient-provider experience, and relationship-centered interaction with other members of the healthcare team (May, 2015; Daniels et al., 2017). In effect, an integrated, ‘*whole-stream*’ strategy is more likely to deliver on the expected outcome—reduced infant deaths.

Implications

The themes of this study are largely intermingled. Vulnerability came from poor medical advice, causing participants to call for personal advocacy for their babies, notwithstanding that they had complied with the recommendation for early onset of prenatal care for their pregnancy. Yet, with each one of these themes, there were implications for positive social change. Healthcare providers should be aware and better instructed about the feelings of vulnerability that some mothers have. Whether it is bedside physician manner or opening of new lines of communication, doctors should be well aware that pregnant women, especially those of color, are in a precarious position. They are hyper-aware that they may not be receiving the best medical care, due to their lack of medical knowledge throughout their pregnancy. Therefore, physicians should look to overcompensate, so as to minimize these negative feelings, and perhaps overturn negative pregnancy outcomes.

Doctors, nurses, administrators and perhaps even social workers should be aware that African American mothers felt that their medical advice was lacking in substance. The participants were conscious of their own limitations, and were left with many questions that were not adequately addressed. At the very least, doctors should offer more materials and options for women throughout their pregnancy, to educate them if they have questions. Another solution would be to have nurses offer follow-up sessions to go over concerns, which can then be relayed to the doctor.

Doctors and nurses should also widen their recommendations for prenatal care. Participants noted that they followed instructions and still had terrible birth outcomes. Basic prenatal care should be replaced with a more thorough program. Nurses could be instructed to offer better advice, or parental classes could be presented throughout the hospital, so other social services could pick up where the doctors left off. Classes could also build support groups, something that some participants felt they were missing. Lastly, social workers and nurses should be aware that patients felt that they need an advocate to get through to the medical system. Participants wished that they had fought more on behalf of themselves and their babies. However, if there was a social worker or nurse-navigator who was aware of their plight, this person could act as their intermediary or advocate, and lead discussions to allay their concerns about their providers.

Hence, greater advocacy from healthcare professionals would serve the patients well, and reduce the feelings of vulnerability and inadequacy as they navigate a complex medical system.

The chosen theoretical frameworks were able to connect existing racial discrepancies to healthcare systems. While the participants did not outright say ‘racism,’ the theoretical framework attributed their responses to race and inequality. Without these frameworks, the connections to race and inequality would be much weaker. We should not discount the connection between race and participants’ perspectives about the healthcare system. Granted, these implications exist, but there might still be several other factors at play that we do not fully understand at the present time. Regardless, healthcare professionals and other social-service experts should be aware of how race might affect birth outcomes, and therefore should work to rectify this situation, both at personal and institutional levels.

Reflections on the Researcher Experience

This study used the GT approach within the qualitative tradition. As such, my personal values, philosophy, untested ideas, and preconceived biases, as well as those of my peer debriefer, may have tainted our interpretation and analysis of the collected data. To be more precise, there are several professional and personal experiences of mine that I suspect may have affected my interpretation of data. I once worked as executive director for an international not-for-profit organization dedicated to the education, resettlement, advocacy and protection of HIV positive children, and children who have been orphaned by AIDS. Similarly, I once was a pediatric chaplain. My experiences working in these settings certainly sparked my interest in this kind of research. They may have also made me aware that human bias could creep into the most ‘holy’ of places. Perhaps, it did help that my debriefer, though a nurse by profession, never worked with infants, and lived miles away from me in a different state. Consequently, she approached data from an entirely different perspective, and this appeared to have countered errors linked to my own bias and approach to data analysis. Equally noteworthy was that she was more conversant with quantitative methodology, and had processed data with those lenses. She asked different questions of me, and of the collected data. She postulated that descriptive statistics would be a *sine qua non* for this study, despite my choice of qualitative design.

I credit her with making some of the numbers more logical and consistent. In the end, our contrasting approaches helped depict seemingly unrelated realities, leading to a more balanced analysis of data, from a qualitative perspective with a quantitative mindset.

Additionally, this study had been influenced by my personal experience with the loss of my twin baby brothers, along with the death of my breast-feeding mother at age 24. Needless to say, these experiences have lingered on longer than I realize.

For the greater part of my growing years, I sought to understand exactly what happened to a sizeable portion of my family. One might even add that these incidents played a part in my choice of career. Yet, for a long time, it was difficult to describe what I was experiencing, let alone analyze it. However, the more I pursued my quest for knowledge, the more obvious it became to me that perhaps I have been ‘put on a mission’ first, to find out what happened to these individuals, and perhaps to stop this tragedy from continuing to happen. While I am not sure that I am achieving these goals, I am proud to have dedicated a significant amount of my time to investigate this issue.

In the early stages of this research, I came across colleagues and mentors who suggested that this study was an effort in futility. They communicated to me non-verbally that any worthwhile study on this subject matter must have already been published, and was more likely to have been a quantitative study. I have to admit that those kinds of denunciation only propelled my passion to do something radically new and untested. It was not long before I began to realize that although a massive proportion of research has been done on this issue, only a small percentage of U.S. health services researchers are people of color. Belonging to this subgroup as an African-born immigrant, I could not pass up an opportunity to investigate a phenomenon that had wrecked my family. In addition, given the expectedly long time investment in qualitative inquiries and the associated non-cost-effective tickets, the experience of African American mothers was either thin or completely absent in published literature.

Through completing this study I have come to understand that working with an elusive population can be extremely challenging, even for an insider. Nonetheless, being an insider gave me seemingly easier access to stakeholders who knew how, when and where to rally the troupes. Therefore, it is worth mentioning that Franklin County, Ohio was chosen as the site for this study after my efforts to conduct the same research in Santa Clara County, CA failed to produce a single study participant. What changed was my recourse to known resource persons in Franklin County. I do not think that the change of research location affected the findings in any major ways. After such a long time working on this project, I am inclined to think that the more we can approach the subjects of research not simply for their numbers but for their stories, we will be in a better situation to design solutions that are both responsive to the issues and sympathetic to the situation.

Conclusion

IM affects infants differently across demographics and socioeconomic conditions. Previous research focused on risk factors, however, it was this study that explicitly demonstrated how the myriad of risk factors interacts and actively gestates to persist in current crisis proportions. IM could be viewed as a microcosm of where the health industry fails minorities like African American women. This study focused on the root causes of IM for African American women, to better ascertain where the system has collapsed and how to rectify the situation. Therefore, the purpose of this qualitative GT research was to explore the complex network of systems (macro), subsystems (micro), events, actions, interactions, conditions, behaviors, relationships and processes that underlie racial and ethnic disparity in IM among African American women in their optimal (ages 18-45) child-bearing years (Love, David, Rankin, & Collins, 2010). This study provided data that could facilitate a better understating of IM among at-risk populations

Freudenberg and Tsui (2014) maintained that a meaningful change to healthcare to reduce IM among differing demographics was needed. Adequate medical care is vital to infant survival during the neonatal period, especially for those from lower socioeconomic backgrounds (Chen et al., 2014). Therefore, the health of the baby could be influenced by uneven treatment of minority mothers within the healthcare system. Education level, race, employment, income, healthcare access and support systems all influence how well both the mother and baby fare (Santa Clara County Public Health, 2012; Scott & Wilson, 2011). With an ever-expanding, diverse population within the U.S., it is imperative to understand the etiology, social anatomy and epidemiology, and form a theory behind infant death disparities in this specific community. By investigating the inequities in birth outcomes within a qualitative context, this study offered insights that could decrease IM proportions.

Two research questions were asked within this study: What specific risk factors (negative or exacerbating), and what sociocultural factors (positive or protective mechanisms), do African American women identify as potential buffers against adverse birth outcomes for themselves and other women? These two questions yielded 4 themes: vulnerability; insufficient advice and counsel to make an informed decision about the baby’s health; prenatal care; and strong advocacy. Despite two different research questions, these four themes are all interconnected. Poor medical advice and a lack of advocacy can make pregnant women feel vulnerable, while poor medical advice limits their ability to choose better care for their infants. The uncovered themes were supported by the literature, and the two frameworks indicated that IM could be greatly influenced by existing systems and racial disparities.

By identifying the themes and linking them to systemic and racial disparities, future research and practical transformations can occur. Future study could change the methodology, design, location and sample; to learn the extent that race affects birth outcomes. Additionally, in comparing and contrasting IM between races, it would be possible to discern systemic failures. This study provides insights for medical professionals and social workers to fix the existing system to better meet the needs of African American mothers. In addition, doctors need to improve their care of the patients, and social workers need to advocate for those who may not be able to advocate for themselves.

While IM remains a tragedy, this study provides a foundation to further examine this phenomenon. Future research can investigate the extent to which race is a major problem. In the meantime, fixes to the medical system could alleviate the themes found in this study. No parent should suffer with IM—this study is one of the first of a series of steps needed to rectify this appalling situation.

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Appendix A: IRB Approval Notices

From: IRB
Sent: Thursday, July 06, 2017 2:54 PM
To: Barry Eneh <barry.eneh@waldenu.edu>
Cc: IRB <irb@mail.waldenu.edu>; Patrick Tschida <Patrick.Tschida@waldenu.edu>
Subject: IRB Approval Granted, Conditional upon Partner Approval

Dear Mr. Eneh,

This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, "*Exploring the mechanisms of racial disparity in infant mortality: A grounded theory approach*" conditional upon the approval of the research partner, as documented in the partner's approval, which will need to be submitted to the Walden IRB when obtained. The researcher may not commence the study until the Walden IRB confirms receipt of that notification of approval.

Your **approval # is 07-06-17-0326679**. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail is the **IRB approved consent form.** Please note, if this is already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date.

Your IRB approval expires on July 5th, 2018. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date.

Please note that this letter indicates that the **IRB has approved your research.** You may **NOT** begin the research phase of your doctoral study, however, until you have received official notification from the IRB to do so. Once you have received this notification by email, you may begin your data collection. Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application materials that have been submitted as of this date. This includes maintaining your current status with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 1 week of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you a made commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

Both the Adverse Event Reporting form and Request for Change in Procedures form can be obtained at the IRB section of the Walden website:
http://academicguides.waldenu.edu/researchcenter/orec

Researchers are expected to keep detailed records of their research activities (i.e., participant log sheets, completed consent forms, etc.) for the same period of time they retain the original data. If, in the future, you require copies of the originally submitted IRB materials, you may request them from Institutional Review Board.

Both students and faculty are invited to provide feedback on this IRB experience at the link below:

Congratulations!
Bryn Saunders
Research Ethics Support Specialist
Office of Research Ethics and Compliance
Email: irb@mail.waldenu.edu
Phone: (612-) 312-1336
Fax: (626-) 605-0472

Walden University
100 Washington Ave. S, Suite 900
Minneapolis, MN 55401
http://www.surveymonkey.com/s.aspx?sm=qHBJzkJMUx43pZegKlmdiQ_3d_3d

Tuesday March 6, 2018

Dear Barry,

This e-mail serves to inform you that your request for a change in procedures, submitted on January 30 has been approved. You may implement the requested changes effective immediately. The approval number for this study will remain the same.

In addition, the email serves as your notification that Walden University has approved BOTH your doctoral study proposal and your application to the Institutional Review Board. As such, you are approved by Walden University to conduct research.

Also attached to this e-mail is the updated IRB approved consent form. Please note, if this is already in an on-line format, you will need to update that consent document to include any changes.

Both students and faculty are invited to provide feedback on this IRB experience at the link below:

http://www.surveymonkey.com/s.aspx?sm=qHBJzkJMUx43pZegKlmdiQ_3d_3d

Best,
Bryn Saunders
Research Ethics Support Specialist
Office of Research Ethics and Compliance
Email: irb@mail.waldenu.edu
Phone: (612-) 312-1336
Fax: (626-) 605-0472

Walden University
100 Washington Ave. S, Suite 900
Minneapolis, MN 55401

Information about the Walden University Institutional Review Board, including instructions for application, may be found at this link:http://academicguides.waldenu.edu/researchcenter/orec.

Appendix B: Informed Consent Form for Participation in Research Interview

Study Title: Exploring the mechanisms for racial disparity in infant mortality: A grounded theory approach.

Researcher: Barry Chu Eneh MS, MPH□Walden University - College of Health Sciences

Dear __________________________________ I am requesting your participation in a research study at Walden University's College of Health Sciences Minneapolis, MN.

The purpose of this study is to uncover the driving and restraining risk factors for infant death disparity among African American infants in **Franklin County, Ohio**. Study will uncover the complex forces behind the death of America's Black infants and potentially produce a mid- range theory of racial death disparity. Study is expected to last from **March 5 through March 12, 2018**. Each participant will be asked about their views and experiences with pregnancy, childbirth, motherhood and the death of their infant.

Your participation will involve completing a paper-based survey questionnaire and answering several research interview questions. These activities will take approximately 90 minutes to complete in a private room at the local library nearest to you. You will be one of 6 to 15 participants selected for this interview. Each participant will be asked to provide information about their race, city of residence, education, health insurance, job, income, health, marital and immigration status, age of their baby and size of their family,

There are foreseeable risks to you if you choose to participate in this study. The possible risks are related to reliving the sad experiences of your child's death. Other discomforts may include arousing sad memories of your loss, grief and all associated issues.

While there might be no personal benefits to you, the potential benefits of your participation in this research study are: better understanding of the processes, properties and pathways to racial death disparity among African American infants. Study may also contribute to existing body of knowledge about racial infant death and the social factors that shape and determine them. Perhaps, researcher will be able to incorporate findings in future public health and healthcare delivery services to women and infants in this population. In addition, the findings of this research may be published in scientific journals, but your identity will not be revealed. Researcher will keep your name confidential; he will secure all collected information and ensure that only persons working on this study have access to confidential information. Finally, researcher will manage all collected information and destroy all personal identifying information after codes have been assigned to them.

Should this interview provoke any emotional discomfort, grief- counseling support will be available to you at no cost to you. You will be paid $30.00 in cash (in full amount) for your participation in this interview and, $20.00 for any follow-up interview. ☐For questions about this study, please contact *Barry Eneh* at *614-668- 1752*. Walden University Office of Research Ethics and Compliance can also be reached by contacting Leliani Endicott at *612-312-1336* and by Email irb@mail.waldenu.edu. 100 Washington Ave. S. Suite 900 Minneapolis, MN 55401. Phone:

The approval number for this study is 07-06-17-0326679 and it expires on July 5th 2018.

Do you have any questions about your rights as a participant in this research? If you wish to participate in this study, please sign this form in the space provided below and return it to the researcher. ☐I have read and understand the explanation provided to me. I understand that I may withdraw my consent and discontinue participation at any time without penalty or the loss of benefits to which I may otherwise be entitled. I have had all my questions answered to my satisfaction and, I hereby voluntarily agree to participate in this study. ☐I have received a copy of this consent form.

Participant's Name: (Please Print) ____

Signature: ______________________________ Date: ___________

Appendix C: Research Participant Communications – Interviewer Flier

Research Study on Infant Mortality
Exploring the mechanisms for racial disparity in infant mortality: A grounded theory approach

Are you an African American woman who has lost an infant within the last five years?

Are you struggling to live with the loss of an infant?

Are you willing to share your unique pregnancy and child delivery experiences?

If yes, are you are between 18 and 49 years of age? I would like to hear from you.

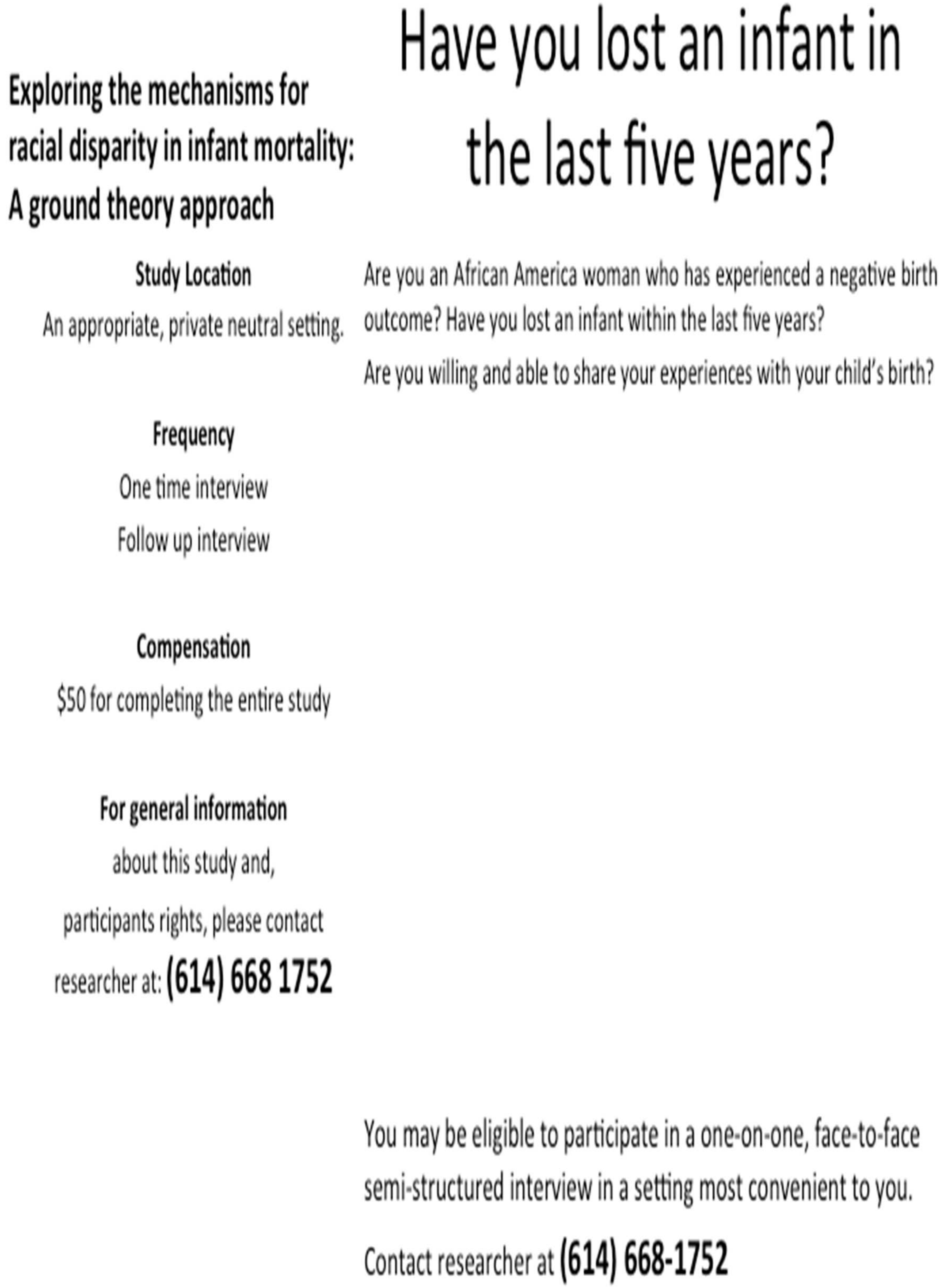
Consider participating in this research study to determine how known and unknown risk factors interact with one another to eventually sway the health of mother and infant.

You may be eligible to participate in this research study.
Participants will receive an honorarium of $50 cash, as travel reimbursement for completion of all study procedures and, a one-time completion of a questionnaire.
All information provided to the researcher will be handled carefully and confidentially.
For more information about this study, please contact:

Barry Eneh, MPH, MS
PHD Candidate in Health Services | Healthcare Administration
College of Health Sciences | Walden University
4609 Alum Rock Ave | Box 3098 San Jose CA 95156
C: 614-668-1752 | E: Barry.Eneh@Waldenu.edu

Reference

Bucks, Veronica. (2016). Newborn baby holding on to adult thumb. Getty Images. Retrieved March 9, 2016 from www.gettyimages.com.



Have you lost an infant in the last five years?

Exploring the mechanisms for racial disparity in infant mortality: A ground theory approach

Study Location

An appropriate, private neutral setting.

Frequency

One time interview

Follow up interview

Compensation

$50 for completing the entire study

For general information

about this study and,

participants rights, please contact

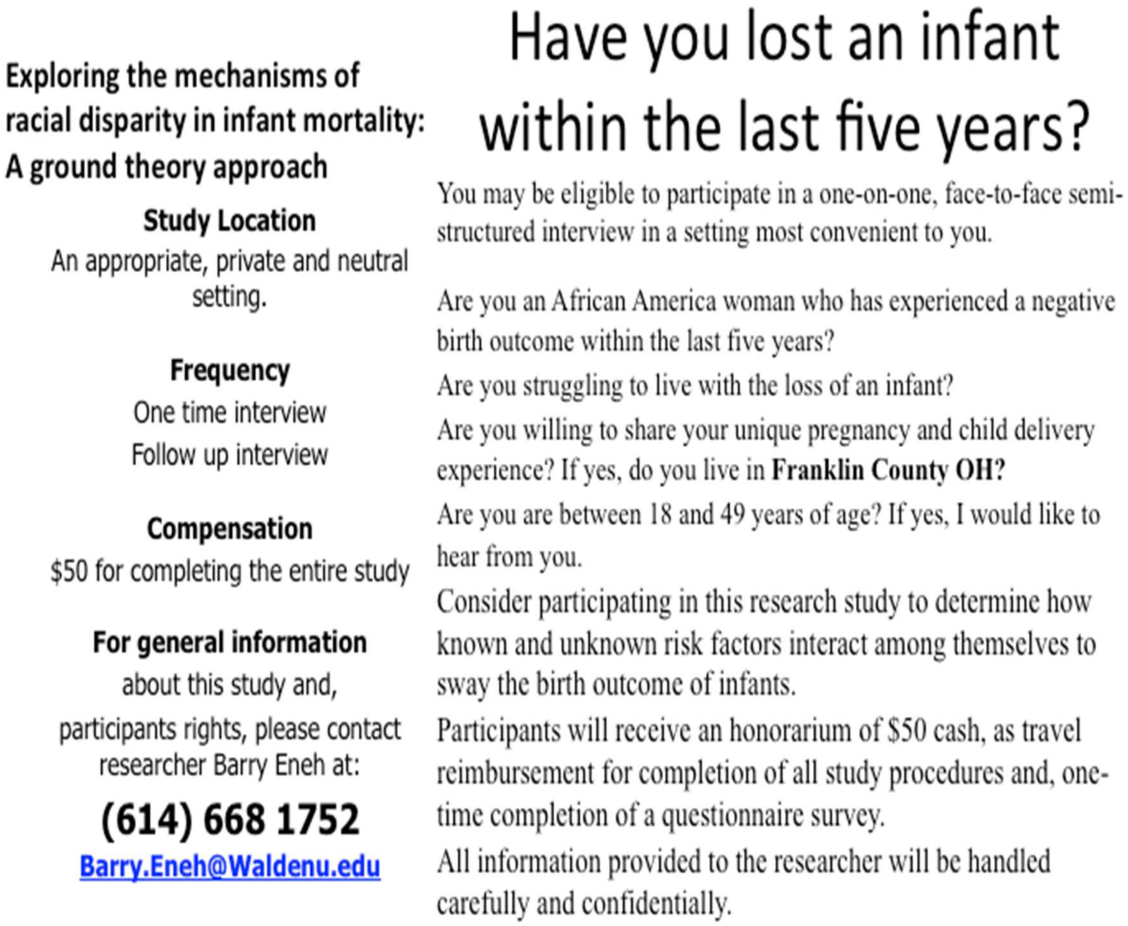
researcher at: **(614) 668 1752**

Are you an African America woman who has experienced a negative birth outcome? Have you lost an infant within the last five years?

Are you willing and able to share your experiences with your child's birth?

You may be eligible to participate in a one-on-one, face-to-face semi-structured interview in a setting most convenient to you.

Contact researcher at **(614) 668-1752**



Exploring the mechanisms of racial disparity in infant mortality: A ground theory approach

Study Location

An appropriate, private and neutral setting.

Frequency

One time interview

Follow up interview

Compensation

$50 for completing the entire study

For general information

about this study and,

participants rights, please contact researcher Barry Eneh at:

(614) 668 1752

Barry.Eneh@Waldenu.edu

Have you lost an infant within the last five years?

You may be eligible to participate in a one-on-one, face-to-face semi-structured interview in a setting most convenient to you.

Are you an African America woman who has experienced a negative birth outcome within the last five years?

Are you struggling to live with the loss of an infant?

Are you willing to share your unique pregnancy and child delivery experience? If yes, do you live in **Franklin County OH?**

Are you are between 18 and 49 years of age? If yes, I would like to hear from you.

Consider participating in this research study to determine how known and unknown risk factors interact among themselves to sway the birth outcome of infants.

Participants will receive an honorarium of $50 cash, as travel reimbursement for completion of all study procedures and, one-time completion of a questionnaire survey.

All information provided to the researcher will be handled carefully and confidentially.

Appendix D: Researcher Confidentiality Agreement

RESEARCHER CONFIDENTIALITY AGREEMENT

Name and Signature of Researcher: Barry C. Eneh

___________________________ 04-12-2017

> During the course of my activity in collecting data for this research: "Exploring the mechanisms of racial disparity in infant mortality: A grounded theory approach" I will have access to research participants and conduct data collection, which is confidential and should not be disclosed. I acknowledge that information so collected must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

By signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: Date:

Appendix E: Face-to-Face Survey Questionnaire

Name: ____________________________________Date: __________

Address: ____

City, State, Zip: ____

Telephone (optional):

1. Gender Identity:
   - Female
   - Male
   - Prefer Not to Answer
   - Other ____

Background Information

2. Ethnic origin (*Check **only one***):
   - Caucasian not Hispanic
   - African American not Hispanic
   - Hispanic
   - Asian or Pacific Islander
   - American Indian/Alaskan Native
   - African
   - Filipino
   - Mixed Race
   - Other: _______________________________

3. Please circle the ***highes**t* year of school completed:

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 23+
(Primary) *(High school)* *(College)* *(Graduate school)*

4. Are you currently (*Check **only one***):
   - Married
   - Single
   - Separated
   - Divorced
   - Widowed
   - In a Partnership

5. Are you currently employed (*check **all that apply***):
   - Always
   - Usually

- About half the time
- Seldom
- Never

- Full-time (40 hours or more per week)
- Part-time (Up to 39 hours a week)
- Student
- Retired
- Homemaker
- Self-employed
- Unable to work

6. How long during the past five years did you have health insurance coverage (*Check **only one***):
    - None of the time or never had insurance (0)
    - A short period of time or for less than 6 months (1)
    - Some of the time or for more than 6 months (2)
    - A good bit of the time or for more than one year (3)
    - Most of the time (4)
    - All of the time (5)

7. In general, would you say your health is (*check **only one***):
    - Very poor (0)
    - Poor (1)
    - Fair (2)
    - Good (3)
    - Very good (4)
    - Excellent (5)

8. In which city is your primary residence? (*Check **only one***):
    - Lancaster

    - Westerville,

    - Reynoldsburg

    - Grove City

    - Upper Arlington

    - Gahanna

    - Hilliard

  - Pickerington
  - Whitehall,
  - Dublin
  - Worthington
  - Bexley
  - Franklin
  - New Albany
  - Canal Winchester
  - Grandview Heights
  - Groveport Village
  - Columbus

9. How old was your baby when it passed away (*check **only one***):
   - 0 – 3 months
   - 4 – 7 months
   - 8 – 12 months
   - 13+ months

10. How large is your family (check **only *one***):
    - 0-3 months – small
    - 4-6 months – medium
    - 7 months and above – Large

11. How old are you at the present time (*check **only one***):
    - Less than 18 years old
    - 18 - 23 years
    - 24 – 29 years
    - 30 – 35 years
    - 36 – 41 years
    - 42 – 48 years
    - 49 – 55 years
    - 56+ years

12. Please indicate your average annual income (*check **only one***):

- No income
- Less than $9,999.00
- $10, 000- $20, 000
- $21, 000 - $40,000
- $41,000 - $49, 000
- $50,000 - $70,000
- $80, 000 - $100,000
- $101,000+

13. Please indicate your immigrant status (*check **only one**):*

- Foreign born
- Native born
- Not sure

Thank you very much for participating in this survey!

References

Stanford Patient Education Research Center. (2007). Sample Questionnaire: Chronic disease. Http://patienteducation.stanford.edu self-management@stanford.edu.

Brown, S. (2010). Lickert scale examples for surveys. Www.questionpro.com/liker-scale.

Appendix F: Interview Transcript

Semi-structured interview Questions and Protocols

Interview Number: #1____________________________________

Day of the Week, Date, Month, Year
Saturday March 3, 2018____________________________________

Start Time: From

End Time: To (No longer than 90 minutes–30 to 90 minutes)

Location of Interview: Home
432 Junction Crossing Drive

Interviewee (name and title):

Interview Phone Number:

Email Address:

Interviewee City of Residence:

Institution: Walden University College of Health Sciences

Study Interviewer: Barry Chu Eneh

Other Topics Discussed:

Documents Obtained:

Post Interview Comments or Leads:

Appendix G: Interview Guide

Semi-structured interview Questions and Protocols

Introduction (Semi-structured interview)
My name is Barry Eneh.

Research Topic:
Exploring the mechanisms for racial disparity in infant mortality: A grounded theory approach

Purpose of Study: General descriptive information about the study
I am conducting a study to find out the key experiences of African American women who have lost their infants.

I am doctoral student and I need the information that you would provide during this interview to complete my dissertation.
(Explain you are conducting a dissertation study and need the information from this interview to…).
Goal of the Research Interview:
There are three major questions for this study:

Research Question #1:
How do African American women prepare for childbirth in their community?

Research Question #2:
What factors are influential in birth outcomes for African American women?

Research Questions #3:
Are there social cultural protective mechanisms that might serve as buffers against adverse birth outcomes?

Specific Instructions
Ask participant **permission to record the conversation** for accuracy purposes and then, secure their personal endorsement of the **Informed Consent** Form (signature/audiotape).

Note taking: Do you mind if I take notes?
Now, here are the questions:

Interview Transcript – Semi-structured Interview Questions
Ask the same questions of all participants

1. **Basic Descriptive Questions - Experience of infant mortality**

   Can you talk to me about your life since your child passed?

What was the cause of death? What did your baby die?

Please, describe for me what happened on that day?

Describe for me an experience that stands out for you in this whole experience (During pregnancy, at birthing and death of your baby?).

What does it mean to you loosing your baby?

What did you like most about being a mother?

What has been the most difficult thing about this experience?

2. **Big Picture Questions - Definition of infant mortality**

In the light of your experience, what do you suppose is the underlying factor behind your infant's death?

Who or what specifically do you believe led to this unfortunate outcome?

What do you regret the most?

What keeps you going every day?

What does being a mother mean to you?
Talk to me about a typical day with. (your baby)?
What do you see as potential buffers that could protect African American women from having to experience this tragedy?

3. **Needs of mothers and infants:**

What has been the most difficult thing about this entire experience?

How could this tragedy been prevented?

What do you see as potential protective buffers for African American women?

What particular challenges exist within the African American community that is not currently being adequately addressed at the present time?

> In what particular order do these factors stack up against positive pregnancy outcome?
> What exactly can you tell me regarding these risk factors for birth outcomes?

Who or what exactly would you hold accountable for your child's death?

4. Follow up questions

You mentioned that you have not fully processed this event?
Can you share with me some of your feelings, thoughts and ideas?

Talk to me about your loss, grief and survival.

How have you learned to cope, since?

What would you like to tell other women?
Stemming from your experience of pregnancy.

Probe: **Structural Questions**

Did you have access to quality care?
Physical care?
Psychosocial care?
Emotional/spiritual?
Socioeconomic?
Sociocultural?
Information?

5. Specific example questions

When we talk about 'death determinants or risk factors' what specific example comes to your mind?

Describe to me the best you can, how these negative factors stack up.
In what particular order do these negative factors rank among themselves?

Clarification questions –Comparison and Contrast Questions

You have used the term … today. Can you clarify that for me?
Would you like to elaborate on that? Can you clarify what you mean by…?
What exactly can you tell me regarding the *factors* that led to your baby's death?
In your view what part have the following factors played in your baby's death? (Environmental exposures, socioeconomics, genetics, life style, stress, racism or discrimination, lack of healthcare access, lack of cultural support, political forces and epigenetics?)
Describe to me in more detail how this is a key factor?
How has this event shaped your life, belief and practice, going forward?
You talked about… Please, explain.
You said that there was a big difference between … and ….
What are some of these differences and similarities?
Can you describe a few for me?

6. **Changes that might help women and families:**

    <u>What do you see as potential protective factor for infants?</u>

    <u>How exactly could this tragedy been prevented or eliminated?</u>

    What type of interventions will be most effective on this matter?

    What specifically can the County do to address this issue?

    Are you satisfied with the quality of prenatal and postnatal services available to African American women in Franklin County?

    In what specific ways might cultural support advance pregnancy outcomes?

    If we were to recommend a perfect solution to this problem
        What will that look like?
        In content?
        How will that be delivered?
        Who will be involved?

    What type of interventions will be most effective in assisting would-be African American mothers to deliver full term, age appropriate weight and healthy babies?

    What can the county do that would help you to meet these needs?
        What can your city do that would help you meet these needs?
        What can the African American community do that will be helpful?

7. **Changes that might help African American women and their infants:**

    How would you describe your relationship with your spouse/family?
        What would you do to improve these relationships?

    Do you think that there is a need for specific cultural services?
        In what ways might cultural support advance pregnancy outcomes?

        What would be the main features of such a services?

        Have you witnessed any such program anywhere?

8. **Wrap up questions:**
        Is there anything else you wish to tell me at this time?

        Do you have any questions that you would like to ask of me?

Is there anything else that you would like to add at this time?

Will it be ok to contact you later if I have additional questions?

9. **Closing Remarks – Participant Referral** (snowball effect):

Thank you for your time, efforts and helpful information today.

Is it likely that you know an African American woman who have been through a similar experience and, willing to talk with me about it?

After the Interview

Test your recorder to be sure that it recorded the whole interview
Fill in apparent gaps in your notes
Write down your impressions of the interview and fold up the session.

Key Demographic Information of Participant:
Name:
Age:
Title:
Education:
Salary range:

Appendix H: Interview Questions

Types of Interview Questions

8 Types of Interview Questions (Janesick, 2011. P. 100).

Basic questions

Can you talk to me about your life since your child passed?
Tell me what happened that day?

Descriptive questions

Please, describe how you felt that day? (Describe for me…)
Tell me what you liked about being Johnny's mother?
What has been the most difficult thing about this entire experience for you?
How would you describe…?

Big picture questions

What is the underlying factor behind your child's death?
What keeps you going every day?
What does being a mother mean to you?
Talk about a typical day with … (your baby)?
What do you see as potential buffers that could protect African American women from having to experience this tragedy?

Follow up questions

You mentioned that you have no one to talk to about your feelings and thoughts about this particular event?
Can you share with me some of your feelings and thoughts?
Talk to about your loss, grief and survival.
What hope to do next?

Clarification questions

You have used the term … today. Can you clarify that for me?
Would you like to elaborate on that? Can you clarify what you mean by…?
What exactly can you tell me regarding the *risk factors* for your baby's death?
What is your view about the quality of medical care that you or your baby received?
Who or what exactly do you blame for your baby's premature death?
How has this event shaped your life?
You talked about…
In what particular order do these positive factors rank among themselves?

Structural questions

Describe to me the best you can, how these factors stack up?
What do you blame primarily? Secondly? Lastly?

Comparison or contrast questions

You said that there was big difference between … and ….
What are some of these differences and similarities?
Can you describe a few for me?

Ask the same questions of all research participants.

Specific example questions

When you talk about … what specific example comes to mind?

Wrap up questions (created by Barry)

Is there anything else you wish to tell me at this time?
Is there anything else you would like to add at this time?
Is there any question you have about this interview project?
Anything else you would like to add?

Closing

Thank you for your efforts and helpful information today.

The goal of interview is to capture the memories of people who have had any number of experiences critical to understanding a given period of time (in history) in relation to a specific (key) event or series of events (Janesick, 2011. P.114). As an interviewer, my goal was to document their memories and interpretations of events in their lifetimes (Janesick, 2011. P. 115)

Note Well: Quality in Qualitative Research

Consider sending a transcript of the interview (Member Checking or informant feedback or respondent validation) so that the participant if needed can make corrections. This approach helps to improve the accuracy, credibility, validity and transferability of a study.

Appendix I: Interview and Questionnaire Analysis Tool

Participant Selection Matrix

- Average or typical
- Above average or outlier
- Below average or unusual

Participant Sampling Strategy

- Maximum variation heterogeneity sampling strategy
  - Maximum variations
  - Variations of homo and heterogeneous sampling
  - Matrix of diversity attributes
  - Small sample of great diversity

Sampling Methodology - purposively information rick participants

- Semi-structured interviews
- Field observations
- Demographic survey questionnaire
- Document reviews
- Convenient sampling method
  - For comprehensive view of the data
  - Articulations of the meanings participants give to their experience.

Inclusion and Exclusion Criteria

- SCC resident
- Has lost an infant in the last 5 years
- Has experience with pregnancy, birth and death of an infant
- Minimum of 3 months post-infant death
- 18 years of age

Socio-demographic variables

- Age
- Gender
- Ethnicity
- Geographic location

Heterogeneous Sampling Inclusion Criteria – Descriptive statistics

- Geographic location (urban, city, suburban areas)
- Study site (home, workplace etc.)
- Ethnicity (U.S. or foreign born)
- Pregnancy status (pre/post delivery, wanted and unwanted pregnancy)
- Family size (large, small, none)
- Language status
- Education status

Employment status
Income level (salary range)
Marriage status
Health insurance status
City of residence

Participant Recruitment Areas

Community health clinics
Public health clinics
Health centers
Privately managed HCOs
Not-for-profit hospitals
Department of public health
Serve predominantly African American women and infants
Roots Community Health Center 1898 The Alameda San Jose
www.rootsclinic.org P: 408-490-4710

Before the Interview

Pilot study – test questionnaire and interview questions with a comparable demographic.

During the Interview

Introduction of study
Purpose of study
Duration of interview
Use of Research findings
Confidentiality matters
Participant consent
Tape the interview

After the Interview

Transcribe and analyze the interview document

Infant Mortality

Low birth weight or under weight birth
Preterm birth
Infant mortality

Appendix J: Member Check Form

May 1, 2018

Dear ____

Thank you for the insight you had provided and for the powerful interview.

To ensure validity and reliability in this qualitative research particularly, researcher's accuracy in reporting your account of your personal experience with infant mortality, I have attached a draft of my research findings for your verification and validation of the findings (Rudestam & Newton, 2015).

To be more precise, please check for the accuracy of the answers you have provided and, be sure to point out any information you strongly believe does not fit within the body of this report. Feel free also to contact me at **614-668-1752** or by email **Barry.Eneh@Waldenu.edu** if you have any questions, concerns or new information.

Please, note that you have two full weeks to review this document and provide any feedback. However, if after 15 days I do not hear from you, I will proceed to take the next step in my research efforts.

Once again, thank you for your time and for the important information you have provided toward the success of this study.

Sincerely,

Barry Eneh
Principal Investigator

Reference

Rudestam, K.E. & Newton, R.R. (2015). Surviving your dissertation: A comprehensive guide to content and process, 4th Ed. Thousand Oaks, CA: Sage Publications, Inc.

Appendix K: Code List

Code List

Topic: Mechanisms of racial disparity in infant mortality

Quotes

Participant #1
“We were **blind sighted** to believe that she would eventually get use to baby formula.’
“I was **not able** to do what a mother should do.”
We were **not made aware** of the potential risks of HELLP syndrome for our pregnancy”

Participant #2
‘They will **not take my calls’**
“It was like, what do you wanna do?”
Well, **let me know what you want to do**.”
“I just **wanna wait it** out and see if am gonna be able to have her virginally.”

Participant #3
“I was **never aware** of my depression until after my baby was already gone.”
‘Hey, you are having a healthy baby, you are having a boy.”
“They **could have told me sooner** at the time about my **severe depression**.”
“They **didn’t tell me** that my not eating, that my depression was going to cause me to lose my baby.’
“I **want to be a mother** to the children that I have…
I want them to have a better life, better lifestyle and everything that in never had. That’s my biggest goal.”

Participant #4
Caused the baby to unplug itself and drop’

Participant #5
“This was a had case to crack.”
There were no external bruises or anything like that.”
She **was a healthy baby** all the way.”
‘I know **everything happens for a reason**.’

Participant #6
“It was both a **blessing** and a **curse** at the same time.”
“I **have lived it** and, I try not to relive it.”

Code List

Tried
Unaware

Medical complications

Access ok
Uninvolved
Medical condition
Ineffective patient/physician communication

Patient/doctor disconnect
timely

Non-supportive family
Unaware

No stress

Smooth pregnancy

Medical condition

Appendix L: Ground Rules for Conducting Qualitative Research Interviews

Preparing the Research Questions
Prepare 5 – 6 questions that can yield over an hour of interview data on tape. One hour of taped interview would yield 20 pages of interview transcript. Transcriptionists might charge anywhere between $100 to $120 per hour of taped interview.

You would learn to develop a sense of awareness about your participants in the study and rearrange accordingly. Be sure to tape your interview and take field notes (notepad and pens and pencils), observe nonverbal cues and behaviors. *Make sure that the questions you ask are appropriate and adequate for measuring and describing the phenomenon you are trying to understand.*

Always get permission for you interviews in writing. Prepare a consent form.
Make your research questions short and direction. Never give your opinions even when prompted. Be comfortable with occasional silence. During the interview, be a conscious and patient listener. Do not talk while your interviewee is speaking. Never argue. Pay attention to interviewee's body language. Be attentive to signals from the interviewee. Use of Transitions: *I would now like to introduce another topic.*

Preparing for the Research Interviews – The Rule of Thumb
Be prepared with digital tape recorder (perhaps, also digital video recorder), a back-up recorder, batteries and a notebook to take notes while interviewing. Always have a thumb drive attached to insert into your computer and upload your interview onto a CD.

Before interview check your digital voice recorder or video recorder to see that it is functional. Test your voice on the tape by noting the *date, time, place* and *name of the participant* on the tape.

You may also feel more comfortable to call up the participant, remind and verify the exact date, time and place of the interview, and arrive early. Be prepared to reschedule. Always have a back up plan – to replace the participant etc.

Establish Rapport with interviewees.
- A relaxed and open atmosphere and pace for the interview.
- Explain clearly why you are conducting the interview.
- Tell the interviewer about yourself.
- Show genuine interest in the interviewee with verbal and body language.
- Take notes
- Smile. Relax.
- Listen actively and empathically.