THE MOTHERS’ VOICES PROJECT: A PHENOMENOLOGICAL STUDY EXPLORING THE LIFE EXPERIENCES OF AFRICAN AMERICAN WOMEN WHO HAVE EXPERIENCED FETAL OR INFANT DEATH

A Dissertation by

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THE MOTHERS’ VOICES PROJECT: A PHENOMENOLOGICAL STUDY EXPLORING THE LIFE EXPERIENCES OF AFRICAN AMERICAN WOMEN WHO HAVE EXPERIENCED FETAL/INFANT DEATH

The following faculty members have examined the final copy of this dissertation for form and content, and recommend that it be accepted in partial fulfillment of the requirement for the degree of Doctor of Philosophy, with a major in Psychology.

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DEDICATION

This dissertation is dedicated to my mother and father, who have always instilled in me the importance of humility, discernment and diligence; to Anikae and Baby Isaac who continue to give me purpose and inspiration; to my family, friends and mentors who have always believed in me and supported me in more ways than one; and to Carl whose love and support has been unwavering.

Psalm 18:2
One truth we have already realised- if we would fit the man for his environment, we must begin with the child: The child is father of the man

– (Mackenzie, 1906, p. 50)
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ABSTRACT

The persistent Black-White disparity in perinatal outcomes is a serious public health issue. Infants born to Black women are two times more likely than white infants to die before the age of one. Prior research has focused primarily on Black women’s exposure to risk and protective factors during pregnancy. The life course perspective serves as a useful framework for understanding how Black women’s early life experiences influence later health and birth outcomes. Prevention efforts guided by the life course perspective will be key in addressing adverse perinatal outcomes among Black women. The present study is a community-based participatory research partnership with the Kansas Infant Death and SIDS Network, Inc. A transcendental phenomenological approach was used to describe the life experiences, preceding fetal or infant death, among Black women. Five Black women (ages 20-36) were interviewed about their experiences from early childhood through adulthood.

Results identified eight broad themes: early childhood context, personal relationships, exposure to multiple sources of stress, maintenance of mental wellness, sexual and reproductive health experiences, pregnancy experiences, health system experience and exposure to fetal/infant death. Life timelines were also generated for each participant to describe life course patterns. The essential, invariant structure described the essence of bereaved Black women’s lived experience and was validated through the process of member checking. The findings indicate that black women encounter multi-level risk and protective processes over the course of their life which may impact their own health and their reproductive health advantage. The present study is the only identifiable phenomenological, life course-informed study of black women who have experienced infant death. The results suggest that life course perspective is an appropriate framework for understanding the lived experience of Black women.
### TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
</tr>
<tr>
<td>1.1</td>
<td>Glossary of Terms</td>
</tr>
<tr>
<td>2.</td>
<td>LITERATURE REVIEW</td>
</tr>
<tr>
<td>2.1</td>
<td>Infant Mortality: A Public Health Priority</td>
</tr>
<tr>
<td>2.2</td>
<td>Implications of Infant Mortality</td>
</tr>
<tr>
<td>2.3</td>
<td>Black-White Disparities in Perinatal Outcomes</td>
</tr>
<tr>
<td>2.4</td>
<td>An Overview of Risk and Protective Factors</td>
</tr>
<tr>
<td>2.4.1</td>
<td>Risk Factors</td>
</tr>
<tr>
<td>2.4.1.1</td>
<td>Individual-Level Factors</td>
</tr>
<tr>
<td>2.4.1.1.1</td>
<td>Maternal Nutritional Deficiencies</td>
</tr>
<tr>
<td>2.4.1.1.2</td>
<td>Maternal Overweight/Obesity</td>
</tr>
<tr>
<td>2.4.1.1.3</td>
<td>Maternal Diabetes and Hypertension</td>
</tr>
<tr>
<td>2.4.1.1.4</td>
<td>Maternal Substance Use</td>
</tr>
<tr>
<td>2.4.1.1.5</td>
<td>Maternal Age</td>
</tr>
<tr>
<td>2.4.1.1.6</td>
<td>Individual Socioeconomic Status</td>
</tr>
<tr>
<td>2.4.1.1.7</td>
<td>Maternal Stress: General and Race-Related Stress</td>
</tr>
<tr>
<td>2.4.1.1.8</td>
<td>Inadequate Prenatal Care</td>
</tr>
<tr>
<td>2.4.1.2</td>
<td>Socio-Environmental Factors: Community Level</td>
</tr>
<tr>
<td>2.4.1.2.1</td>
<td>Neighborhood/Community Socioeconomic Status</td>
</tr>
<tr>
<td>2.4.1.2.2</td>
<td>Residential Segregation: Isolation</td>
</tr>
<tr>
<td>2.4.1.3</td>
<td>Socio-Environmental Factors: Institutional Level</td>
</tr>
<tr>
<td>2.4.1.3.1</td>
<td>Provider Bias</td>
</tr>
<tr>
<td>2.4.1.3.2</td>
<td>Institutional Discrimination</td>
</tr>
<tr>
<td>2.4.2</td>
<td>Protective Factors</td>
</tr>
<tr>
<td>2.4.2.1</td>
<td>Individual-Level Factors</td>
</tr>
<tr>
<td>2.4.2.1.1</td>
<td>Interpregnancy Intervals</td>
</tr>
<tr>
<td>2.4.2.1.2</td>
<td>Social Support</td>
</tr>
<tr>
<td>2.4.2.2</td>
<td>Socio-Environmental Factors: Community Level</td>
</tr>
<tr>
<td>2.4.2.1.1</td>
<td>Racial Segregation: Clustering</td>
</tr>
<tr>
<td>2.4.2.1.2</td>
<td>Healthy Neighborhood Environments</td>
</tr>
<tr>
<td>2.4.2.3</td>
<td>Socio-Environmental Factors: Institutional Level</td>
</tr>
<tr>
<td>2.4.2.3.1</td>
<td>Prenatal Care Coordination and Management</td>
</tr>
<tr>
<td>2.4.3</td>
<td>Summary</td>
</tr>
</tbody>
</table>
### TABLE OF CONTENTS (continued)

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.5</td>
<td>32</td>
</tr>
<tr>
<td>The Life Course Perspective: An Alternative Framework for Understanding Black-White Disparities in Perinatal Outcomes</td>
<td>32</td>
</tr>
<tr>
<td>2.5.1</td>
<td>33</td>
</tr>
<tr>
<td>The Life Course Perspective</td>
<td>33</td>
</tr>
<tr>
<td>2.5.2</td>
<td>35</td>
</tr>
<tr>
<td>Life Course Determinants of Perinatal Outcomes</td>
<td>35</td>
</tr>
<tr>
<td>2.5.3</td>
<td>39</td>
</tr>
<tr>
<td>The Life Course Perspective: Moving Forward</td>
<td>39</td>
</tr>
<tr>
<td>2.6</td>
<td>41</td>
</tr>
<tr>
<td>The Present Study</td>
<td>41</td>
</tr>
<tr>
<td>2.6.1</td>
<td>41</td>
</tr>
<tr>
<td>Phenomenology</td>
<td>41</td>
</tr>
<tr>
<td>2.6.2</td>
<td>43</td>
</tr>
<tr>
<td>Purpose and Significance</td>
<td>43</td>
</tr>
<tr>
<td>2.6.3</td>
<td>43</td>
</tr>
<tr>
<td>Research Questions</td>
<td>43</td>
</tr>
<tr>
<td>3.</td>
<td>45</td>
</tr>
<tr>
<td>METHODOLOGY</td>
<td>45</td>
</tr>
<tr>
<td>3.1</td>
<td>45</td>
</tr>
<tr>
<td>Setting</td>
<td>45</td>
</tr>
<tr>
<td>3.2</td>
<td>46</td>
</tr>
<tr>
<td>Participants</td>
<td>46</td>
</tr>
<tr>
<td>3.3</td>
<td>46</td>
</tr>
<tr>
<td>Procedure</td>
<td>46</td>
</tr>
<tr>
<td>3.3.1</td>
<td>46</td>
</tr>
<tr>
<td>Institutional Review Process</td>
<td>46</td>
</tr>
<tr>
<td>3.3.2</td>
<td>48</td>
</tr>
<tr>
<td>Recruitment Process</td>
<td>48</td>
</tr>
<tr>
<td>3.3.2.1</td>
<td>48</td>
</tr>
<tr>
<td>Description of Research Team and Training</td>
<td>48</td>
</tr>
<tr>
<td>3.3.3</td>
<td>49</td>
</tr>
<tr>
<td>Data Collection</td>
<td>49</td>
</tr>
<tr>
<td>3.4</td>
<td>49</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>49</td>
</tr>
<tr>
<td>3.4.1</td>
<td>50</td>
</tr>
<tr>
<td>Phase I: Analysis of Interview Data</td>
<td>50</td>
</tr>
<tr>
<td>3.4.2</td>
<td>51</td>
</tr>
<tr>
<td>Phase II: Analysis of Life Timelines</td>
<td>51</td>
</tr>
<tr>
<td>3.5</td>
<td>52</td>
</tr>
<tr>
<td>Quality and Trustworthiness</td>
<td>52</td>
</tr>
<tr>
<td>3.5.1</td>
<td>53</td>
</tr>
<tr>
<td>Bracketing</td>
<td>53</td>
</tr>
<tr>
<td>3.5.2</td>
<td>54</td>
</tr>
<tr>
<td>Intercoder Agreement</td>
<td>54</td>
</tr>
<tr>
<td>3.5.3</td>
<td>54</td>
</tr>
<tr>
<td>Member Checking</td>
<td>54</td>
</tr>
<tr>
<td>4.</td>
<td>55</td>
</tr>
<tr>
<td>RESULTS</td>
<td>55</td>
</tr>
<tr>
<td>4.1</td>
<td>55</td>
</tr>
<tr>
<td>Qualitative Interviews</td>
<td>55</td>
</tr>
<tr>
<td>4.1.1</td>
<td>55</td>
</tr>
<tr>
<td>Theme 1: Early Childhood Context</td>
<td>55</td>
</tr>
<tr>
<td>4.1.1.1</td>
<td>56</td>
</tr>
<tr>
<td>Family Characteristics</td>
<td>56</td>
</tr>
<tr>
<td>4.1.1.2</td>
<td>58</td>
</tr>
<tr>
<td>Neighborhood Characteristics</td>
<td>58</td>
</tr>
<tr>
<td>4.1.2</td>
<td>58</td>
</tr>
<tr>
<td>Theme 2: Personal Relationships</td>
<td>58</td>
</tr>
<tr>
<td>4.1.2.1</td>
<td>59</td>
</tr>
<tr>
<td>Intimate Partner Relationships</td>
<td>59</td>
</tr>
<tr>
<td>4.1.2.2</td>
<td>59</td>
</tr>
<tr>
<td>Familial Relationships</td>
<td>59</td>
</tr>
<tr>
<td>4.1.3</td>
<td>62</td>
</tr>
<tr>
<td>Theme 3: Exposure to Multiple Sources of Stress</td>
<td>62</td>
</tr>
<tr>
<td>4.1.3.1</td>
<td>62</td>
</tr>
<tr>
<td>Familial Stressors</td>
<td>62</td>
</tr>
<tr>
<td>4.1.3.2</td>
<td>64</td>
</tr>
<tr>
<td>Financial Stressors</td>
<td>64</td>
</tr>
<tr>
<td>4.1.3.3</td>
<td>65</td>
</tr>
<tr>
<td>Partner-Related Stressors</td>
<td>65</td>
</tr>
<tr>
<td>4.1.3.4</td>
<td>67</td>
</tr>
<tr>
<td>Trauma-Related Stressors</td>
<td>67</td>
</tr>
<tr>
<td>4.1.4</td>
<td>70</td>
</tr>
<tr>
<td>Theme 4: Maintenance of Mental Wellness</td>
<td>70</td>
</tr>
<tr>
<td>4.1.4.1</td>
<td>70</td>
</tr>
<tr>
<td>Faith/Spirituality</td>
<td>70</td>
</tr>
<tr>
<td>4.1.4.2</td>
<td>70</td>
</tr>
<tr>
<td>Mental Wellness Strategies</td>
<td>70</td>
</tr>
</tbody>
</table>
TABLE OF CONTENTS (continued)

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1.5 Theme 5: Sexual and Reproductive Health Experiences</td>
<td>71</td>
</tr>
<tr>
<td>4.1.5.1 Sexual Health Experience and Behavior</td>
<td>71</td>
</tr>
<tr>
<td>4.1.5.2 Reproductive Health Experiences</td>
<td>74</td>
</tr>
<tr>
<td>4.1.6 Theme 6: Experience of Pregnancy</td>
<td>77</td>
</tr>
<tr>
<td>4.1.6.1 Pregnancy Attitudes and Intentionality</td>
<td>77</td>
</tr>
<tr>
<td>4.1.6.2 Maternal Health Status</td>
<td>78</td>
</tr>
<tr>
<td>4.1.6.3 Availability of Support and Resources</td>
<td>78</td>
</tr>
<tr>
<td>4.1.7 Theme 7: Health System Experiences</td>
<td>80</td>
</tr>
<tr>
<td>4.1.7.1 Provider Interactions</td>
<td>80</td>
</tr>
<tr>
<td>4.1.7.2 Continuity, Coordination and Access to Prenatal Care</td>
<td>84</td>
</tr>
<tr>
<td>4.1.7.3 Concerns and Recommendations</td>
<td>86</td>
</tr>
<tr>
<td>4.1.8 Theme 8: Exposure to Fetal or Infant Death</td>
<td>87</td>
</tr>
<tr>
<td>4.1.8.1 Occurrence of Fetal or Infant Death among Family</td>
<td>88</td>
</tr>
<tr>
<td>4.1.8.2 Personal History of Recurrent Fetal or Infant Death</td>
<td>88</td>
</tr>
<tr>
<td>4.1.9 Essential Invariant Structure</td>
<td>89</td>
</tr>
<tr>
<td>4.2 Summary of Life Timelines</td>
<td>91</td>
</tr>
<tr>
<td>4.2.1 Description of Life Timelines</td>
<td>91</td>
</tr>
<tr>
<td>4.2.2 Limitations of Life Timelines</td>
<td>92</td>
</tr>
<tr>
<td>4.2.3 Implications of Life Timelines</td>
<td>93</td>
</tr>
<tr>
<td>5. DISCUSSION</td>
<td>95</td>
</tr>
<tr>
<td>5.1 Life Course Perspective</td>
<td>95</td>
</tr>
<tr>
<td>5.2 Discussion of Emergent Themes</td>
<td>98</td>
</tr>
<tr>
<td>5.1.1 Early Childhood Context</td>
<td>98</td>
</tr>
<tr>
<td>5.1.2 Personal Relationships</td>
<td>99</td>
</tr>
<tr>
<td>5.1.3 Exposure to Multiple Sources of Stress</td>
<td>101</td>
</tr>
<tr>
<td>5.1.4 Maintenance of Mental Wellness</td>
<td>102</td>
</tr>
<tr>
<td>5.1.5 Sexual and Reproductive Health Experiences</td>
<td>103</td>
</tr>
<tr>
<td>5.1.6 Experience of Pregnancy</td>
<td>106</td>
</tr>
<tr>
<td>5.1.7 Health System Experiences</td>
<td>108</td>
</tr>
<tr>
<td>5.1.8 Exposure to Fetal or Infant Death</td>
<td>109</td>
</tr>
<tr>
<td>5.3 Strengths of the Study</td>
<td>110</td>
</tr>
<tr>
<td>5.4 Limitations of the Study</td>
<td>111</td>
</tr>
<tr>
<td>5.5 Future Research</td>
<td>112</td>
</tr>
<tr>
<td>5.6 Implications for Practice and Policy</td>
<td>114</td>
</tr>
<tr>
<td>5.7 Conclusion</td>
<td>117</td>
</tr>
</tbody>
</table>
TABLE OF CONTENTS (continued)

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>REFERENCES</td>
<td>119</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>143</td>
</tr>
<tr>
<td>A. Memorandum of Understanding</td>
<td>144</td>
</tr>
<tr>
<td>B. Letter of Cooperation</td>
<td>147</td>
</tr>
<tr>
<td>C. IRB Approved Informed Consent Form</td>
<td>149</td>
</tr>
<tr>
<td>D. Recruitment Flyer</td>
<td>154</td>
</tr>
<tr>
<td>E. Demographic Questionnaire</td>
<td>155</td>
</tr>
<tr>
<td>F. Interview and Script</td>
<td>156</td>
</tr>
<tr>
<td>G. Individual Timelines</td>
<td>159</td>
</tr>
</tbody>
</table>
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Risk and Protective Factors Associated with Perinatal Outcomes among Black Women</td>
<td>13</td>
</tr>
<tr>
<td>2. Demographic Characteristics of Study Participants</td>
<td>48</td>
</tr>
<tr>
<td>3. Demographic Characteristics of Research Team</td>
<td>50</td>
</tr>
<tr>
<td>4. Summary of Eight Broad Themes</td>
<td>55</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>U.S. Infant Mortality Rate by Race and Type of Infant Death, 2007</td>
<td>10</td>
</tr>
<tr>
<td>2.</td>
<td>Leading Cause of U.S. Infant Death by Race, 2007</td>
<td>10</td>
</tr>
<tr>
<td>3.</td>
<td>Ecological Framework for Perinatal Mortality among African Americans</td>
<td>12</td>
</tr>
<tr>
<td>4.</td>
<td>Exposure to Risk and Protective Factors over the Life Course, by Race</td>
<td>35</td>
</tr>
<tr>
<td>5.</td>
<td>Comparison of Life Course-Informed Approach and Existing Maternal and Child Health</td>
<td>40</td>
</tr>
<tr>
<td>6.</td>
<td>Phase I: Analysis of Interview Data</td>
<td>51</td>
</tr>
<tr>
<td>7.</td>
<td>Phase II: Analysis of the Life Timeline</td>
<td>53</td>
</tr>
<tr>
<td>8.</td>
<td>Summary of Life Timelines</td>
<td>91</td>
</tr>
</tbody>
</table>
CHAPTER 1

INTRODUCTION

In the United States, infants born to non-Hispanic Black women (hereafter referred to as ‘Black’) are two times more likely than White infants to die before their first birthday (Mathews & MacDorman, 2011). Moreover, rates of preterm birth and low birth weight deliveries are more than two-fold among Black women (Mathews & MacDorman, 2011). The Black-White disparity in perinatal outcomes poses a serious public health problem. Not only does infant mortality affect the psychosocial well-being of bereaved families (Boyden, Kavanaugh, Issel, Eldeirawi, & Meert, 2014; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008) it also significantly impacts the nation’s health care spending (Behrman & Butler, 2006). For example, the cost of poor birth outcomes is estimated at $26 million (Behrman & Butler, 2006). It is estimated that about $144 to $214 million of Medicaid costs could be saved per year by eliminating racial disparities in adverse perinatal outcomes1 (Zhang et al., 2013). In addition, the persistent Black-White disparities in perinatal outcomes pose a serious threat to health equity for African Americans. Considering the significant amount of money spent on health care in the U.S., public health researchers argue that there is more that should be done to ameliorate racial/ethnic health disparities (Braveman et al., 2011; Jones, 2010). Thus, it would behoove researchers, public health officials, health professionals and elected officials to ensure that interventions focused on preventing adverse perinatal outcomes continue.

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1 This figure does not count infant costs and is based on estimates from 14 states: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Maryland, Missouri, Mississippi, North Carolina, South Carolina, Tennessee, Texas, and Virginia.
Current research has drawn on the biological, psychological and social influences which may contribute to the Black-White disparity in perinatal outcomes. It is also acknowledged that these factors occur within multiple contexts beyond the individual. For example, many studies have focused on both maternal health behaviors as well as the environments in which Black women may live or work. The majority of this research, however, has focused on Black women’s exposure to multi-level risk and protective factors during pregnancy. Unfortunately, investigations within this purview overlook the contribution of (a) early life experiences which may impact reproductive health and (b) Black women’s cumulative exposure to risk and protective factors over time. The life course perspective, which focuses on examining the extent to which early life experiences and exposures to biological, social and environmental factors shape health across the lifespan, serves as a useful framework for gaining a deeper understanding of how Black women’s social context—early in life and over time—may influence their birth outcomes. There is accumulating evidence linking preconception factors (i.e., health status prior to pregnancy) and lifelong factors (i.e., lifetime exposure to socioeconomic disadvantage) to adverse perinatal outcomes in Black women (Love, David, Rankin, & Collins, 2010; Orr, Reiter, James, & Orr, 2012). The present study aims to contribute to the growing literature which implicates the influence of life course determinants on Black birth outcomes. Using a phenomenological approach, the present study provides a retrospective account of the life experiences of African American women who have experienced fetal/infant death.
Glossary of Terms

This paper includes a number of technical terms that are commonly used in maternal and child health research literature. The following glossary of terms is provided for the reader’s convenience.

*Allostatic Load:* The cumulative ‘wear and tear’ on the body’s major biological regulatory and response systems as a result of chronic stress

*Congenital Anomaly/Malformation:* A birth defect that is developed in utero and present at birth.

*Fetus:* A fetus is defined as an infant in the womb that is eight weeks post-conception.

*Fetal Death:* Fetal death refers to death before the complete removal from the mother (regardless of the length of pregnancy) that is not an induced termination of pregnancy (i.e. abortion). There are four categories of fetal death: early fetal death (death occurring between 20-27 weeks gestation), late fetal death (death occurring more than weeks gestation), stillbirth (death at 20 weeks gestation or more), and miscarriage (death in utero before 20 weeks gestation).

*Gestation Period:* The period of development in the uterus from conception until birth.

*Gestational Age:* The age of the fetus or pregnancy counting from the time of conception.

*Infant Death:* Infant death is synonymous to infant mortality and is often used interchangeably in the literature.

*Infant Mortality:* A live birth that results in death within the first year of life. There are four categories of infant death: early neonatal death (death in less than 7 days), late neonatal death (death after 7-27 days of life), neonatal death (death after 28 days of life), and postneonatal death (death after 28-364 days of life).

*Infant Mortality Rate (IMR):* The number of infant deaths per 1,000 live births in a given population. This rate is calculated using the following formula:

\[
\text{Infant Mortality Rate} = \frac{\text{Number of infant deaths during time period}}{\text{Number of live births during time period}} \times 1000
\]

*Intrauterine Growth Restriction (IUGR):* Fetal weight that is below the 10\textsuperscript{th} percentile for gestational age

*Life Course Patterns:* The sequence of life events and transitions that an individual experiences over time. These patterns represent “the course of life”, or life trajectory.
**Live Birth:** An infant that has been completely extracted from the mother, and whose heartbeat and respiratory system indicates normal functioning

**Low Birth Weight (LBW):** A live born infant that weighs less than 2500 grams (5 pounds, 8 ounces) at birth regardless of gestational age is considered low birth weight. The average birth weight of a newborn is 3,400 grams (7 pounds, 8 ounces). Very low birth weight (VLBW) is less than 1500 grams and moderately low birth weight (MLBW) is between 1500-2499 grams.

**Maternal Complications of Pregnancy:** Women may experience health conditions or problems during pregnancy, such as, anemia, urinary tract infections, mental health conditions, hypertension, gestational diabetes, obesity/weight gain or loss, or infections.

**Periconceptional Period:** The period of time during and immediately following conception

**Perinatal Death (Perinatal Infant Mortality):** The death of a fetus or infant that has survived for a brief amount of time either less than 28 days of age or 20 weeks gestation or older.

**Preconception Period:** The period of time prior to conception

**Preterm Birth (PTB):** The birth of a live infant that is less than 36 weeks gestational age (full term pregnancy is 40 weeks. An infant born earlier than 36 weeks gestation is often referred to as premature.

**Small for Gestational Age (SGA):** Infants who are born smaller in size than normal for their gestational age—weight below the 10th percentile for the gestational age.

**Sudden Infant Death Syndrome (SIDS):** The sudden, unexplained death of an infant less than one year of age.

**The Adequacy of Prenatal Care Utilization (APCU) Index:** An index, based on recommendations from the American College of Obstetricians and Gynecologists, that characterizes prenatal care utilization on two dimensions: adequacy of imitation of prenatal care and adequacy of received services. The index includes four categories: inadequate, intermediate, adequate and adequate plus.
Infant Mortality: A Public Health Priority

Infant mortality is a key indicator of population health and well-being (MacDorman, Hoyert, & Mathews, 2013; Merrill, 2010; Organization for Economic Cooperation and Development, 2010). Infant mortality has been linked to other adverse health outcomes at the population level. Reidpath and Allotey (2003) found that countries with higher infant mortality rates tended to have lower disability adjusted life expectancies (DALEs). The authors explained that the causes of infant mortality may be related to the same structural factors (i.e., economic development, general living conditions, social well-being) that affect the health of an entire population (Reidpath & Allotey, 2003). Furthermore, the United States spends more money on health care than any other industrialized country (Cockerham, 2012), yet has one of the worst rankings for infant mortality when compared to peer countries such as the United Kingdom or Japan (Cockerham, 2012; Organization for Economic Cooperation and Development, 2010, 2011). Preterm birth (PTB) is one of the strongest predictors of infant death. In the United States, one in eight infants are born premature each year (Centers for Disease Control and Prevention, 2013), thus making the U.S. one of the top ten industrialized countries with the highest rates of PTBs (Blencowe et al., 2012).

Implications of Infant Mortality

Despite years of widespread public health interventions, infant mortality continues to be an issue that has serious implications. There are three major concerns which underscore the significance and necessity for continued public health interventions. First, the cost of adverse birth outcomes associated with infant mortality is expensive. Although there are no known
comprehensive economic reports estimating the actual cost of infant deaths, researchers have been able to measure the economic impact of PTB and low birth weight (LBW) deliveries on the U.S. health care system. The latest national estimate of economic impact, indicated that PTB/LBW deliveries cost the health care system more than $26 million dollars (Behrman & Butler, 2006). For every PTB/ LBW infant, it costs the U.S. roughly $51,600 per infant (Behrman & Butler, 2006); whereas the average cost of a full-term newborn without complications is estimated at $4,551 (March of Dimes, 2008). One reason for the higher costs is that health care utilization is greater among PTB/LBW infants (March of Dimes, 2008). Among these infants, the average in-patient stay for delivery and 12 months following delivery was 12 days longer than for full-term infants born without complications (March of Dimes, 2008). In total, complicated births can cost insurance companies, on average, $14,667; whereas the average cost of uncomplicated births is about $10,652 (March of Dimes, 2008). Overall, it is evident that the adverse perinatal outcomes that are linked to infant death are costly. Thus, it is in the best interest of health care professionals as well as elected government officials to be involved in efforts to reduce adverse birth outcomes and infant death.

A second concern is the psychosocial impact on bereaved families. Prior research indicates that parents who experience infant death are at risk for experiencing diminished health and well-being (Boyden, Kavanaugh, Issel, Eldeirawi, & Meert, 2014; Christiansen, Elklit, & Olff, in press; Murphy, Shevlin, & Elklit, in press; Sanders, 1979). Further, the experience of infant death has been associated with development of depressive symptoms (Boyden et al., 2014; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008), poorer overall psychological well-being and adjustment (Rogers et al., 2008), increased post-traumatic stress symptomology (Christiansen et al., in press; Murphy et al., in press), divorce (Lyngstad, 2013), increased number of days on sick
leave (loss of work productivity), increased use of health services (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008), and even parental mortality (Li, Precht, Mortensen, & Olsen, 2003). Two recent studies have demonstrated the long-term impact of infant death on parents. Murphy et al. (in press) presented evidence of elevated trauma related symptoms among parents who were up to five years bereaved; and chronic post-traumatic stress disorder symptoms were found to be present in parents who were up to 18 years bereaved (Christiansen et al., in press). Altogether, infant death has long-lasting effects on the health and psychosocial well-being of bereaved families.

Finally, infant mortality is a serious issue because it poses a threat to health equity among populations of color. Although there have been noticeable declines in the national infant mortality rate over the last 40 years, there are still persistent racial and ethnic disparities that exist, particularly among Black Americans (Alio et al., 2011; Lu & Chen, 2004; MacDorman & Mathews, 2011; Mathews & MacDorman, 2011; Rosenthal & Lobel, 2011). For example, the rate of infant death is highest for infants born to Black women, followed by infants born to American Indian/Alaskan Native women and Puerto Rican women (MacDorman & Mathews, 2011). In comparison, the mortality rate for infants born to non-Hispanic White women is significantly lower than that of infants born to women of color (MacDorman & Mathews, 2011). As will be discussed later, it is of great concern that for some racial/ethnic groups, such as African Americans, disparities in birth outcomes continue to persist even after controlling for factors such as age, socioeconomic status, education level and smoking status.

Recently, the Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020 proposed that health disparities are “systematic, plausibly avoidable health differences adversely affecting socially disadvantaged groups”
(Braveman et al., 2011, p. S149). To that end, health professionals have contended that there is a moral and ethical basis for eliminating health disparities, especially those that exist along the lines of race and ethnicity (Braveman et al., 2011; Jones, 2010). Jones (2010) argued that the existence of health disparities (and their consequences) in the U.S. is both “embarrassing” and morally wrong considering that it spends more than any other country on health care and it is expected to be able to ensure that the most basic health needs of its citizens are met. Therefore, it is important for health practitioners and researchers to continue to address racial and ethnic disparities in infant mortality in an effort to promote progress toward health equity and social justice for all citizens.

**Black-White Disparities in Perinatal Outcomes**

According to the most recent comprehensive national report on infant mortality, Black women have the worst birth outcomes than any other racial/ethnic group (MacDorman & Mathews, 2011). Overall, Black infants die at over twice the rate as White infants (see Figure 1) (Mathews & MacDorman, 2011). The Black stillbirth rate of 11.1 per 1,000 deliveries is two times higher than the national stillbirth rate (Spong, Iams, Goldenberg, Hauck, & Willinger, 2011). Moreover, infants born to Black women also have the highest rates of death caused by congenital anomalies (birth defects), disorders related to PTB/LBW, sudden infant death syndrome (SIDS), and pregnancy complications (Mathews & MacDorman, 2011). As shown in Figure 2, the Black infant mortality rates for each of the leading causes of infant death are twice as high as those for White infants.

Despite nearly 50 years of research (Singh & van Dyck, 2010), the cause of the persisting Black-White disparity in perinatal outcomes remains largely unknown. A significant portion of
the Black-White disparity, however, has been attributed to the two-fold increase in LBW and PTB deliveries among Blacks. For example, according to national data, 44% of Black infant deaths were due to prematurity-related causes alone (MacDorman & Mathews, 2011; Mathews & MacDorman, 2011). Furthermore, investigations into a number of biological, socio-demographic and behavioral factors have yet to provide a complete explanation for the Black-White disparities. For example, the Black infant mortality rate remains more than two times higher than that of Whites after adjusting for maternal age, parity status, educational attainment and socioeconomic status (Bell, Zimmerman, Almgren, Mayer, & Huebner, 2006; J W Collins Jr & Butler, 1997; Love et al., 2010; Mathews, MacDorman, & Menacker, 2002; Schoendorf, Hogue, Kleinman, & Rowley, 1992; Tong et al., 2011).

Studies focusing on maternal risky health behaviors have also been unable to fully explain the Black-White disparity in perinatal outcomes. For instance, smoking during pregnancy has been linked to poor birth outcomes; and research indicates that Black women are less likely than White women to report smoking cigarettes during pregnancy (Bell et al., 2006; Tong et al., 2011). Although, Black women who do smoke during pregnancy are at increased risk of adverse perinatal outcomes, cigarette smoking does not fully explain the Black-White disparity. For example, the Black infant mortality rate among Black pregnant women who reported being a nonsmoker was still two times higher than that of White women who did report smoking during pregnancy (Mathews et al., 2002). To add, even when Black women begin prenatal care in the first trimester, their infants are still two times more likely to die than White infants (Mathews et al., 2002).
**Figure 1.** U.S. Infant mortality rate by race and type of infant death, 2007 (Mathews & MacDorman, 2011)

**Figure 2.** Leading cause of U.S. infant death by race, 2007 (Mathews & MacDorman, 2011)
Several risk factors such as smoking and prenatal care utilization can be directly linked to poor perinatal outcomes in Black women. The problem, however, is that after controlling for risk factors; Black women continue to have higher rates of poor birth outcomes than White women. Unrelenting investigation into adverse perinatal outcomes among Black women is necessary to understand how a combination of risk and protective factors may explain the Black-White disparity.

An Overview of Risk and Protective Factors

As mentioned earlier, a significant portion of the Black-White disparity in infant death is attributable to PTB and LBW. The existing body of literature has also pointed to various biological, psychosocial, socio-demographic and environmental factors that Black women are exposed to during pregnancy which has explained some of the variance in the Black-White disparity. These factors can be described in terms of the multiple socio-ecologic contexts in which Black women live. Alio and her colleagues (2009) offered a theoretical framework (see in Figure 3) for understanding the contribution of multiple contextual factors to the Black-White disparity in perinatal outcomes. The authors’ model suggests that there is a confluence of contextual factors that co-occur, at multiple levels, which may influence poor birth outcomes among Black women (Alio et al., 2009). Accordingly, to demonstrate that Black birth outcomes are influenced by varying contexts, this overview of risk and protective factors will be organized into two categories: individual-level factors and socio-environmental factors (see Table 1).

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2 As the two strongest predictors of infant death, there tends to be slightly more studies investigating the association between other risk factors and PTB/LBW, rather than infant death. Although, there are a number of studies investigating the direct relationship between infant death and other risk variables.
Figure 3. Ecological framework for perinatal mortality among African Americans (Alio et al., 2009)

Risk Factors

There are a number of risk factors associated with poor perinatal outcomes among Black women. A risk factor is defined as an attribute, behavior or exposure—either immutable or modifiable—which is in some way related to adverse perinatal outcomes (Burt, 2001). There has been considerable attention devoted to understanding the impact of individual and interpersonal risk factors associated with adverse perinatal outcomes in Black women. More recently, studies have begun to demonstrated the importance of considering women’s social and physical environment as well. It should be noted that although many risk factors have been linked to poor birth outcomes, no single factor or set of factors have fully explained the Black-White disparity.
<table>
<thead>
<tr>
<th>Individual Factors</th>
<th>Risk Factors</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Age</td>
<td>Maternal Ages &gt;20-25</td>
<td>Maternal Ages &lt;20</td>
</tr>
<tr>
<td>Socioeconomic Status</td>
<td>Lower Socioeconomic Status</td>
<td>Higher Socioeconomic Status Higher Educational Attainment</td>
</tr>
<tr>
<td>Maternal Health Status</td>
<td>Chronic health conditions (obesity/overweight, diabetes, hypertension)</td>
<td>Absence of chronic health conditions or comorbidity</td>
</tr>
<tr>
<td>Maternal Health Behaviors</td>
<td>Cigarette Smoking, Tobacco Use, Marijuana Use, Cocaine Use, Alcohol Consumption</td>
<td>Absence and/or Cessation of substance use</td>
</tr>
<tr>
<td>Maternal Health Behaviors</td>
<td>Inadequate prenatal care Close birth intervals</td>
<td>Early/Adequate Prenatal Care Adequate birth intervals</td>
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<tr>
<td>Maternal Health Behaviors</td>
<td>Inadequate nutritional intake</td>
<td>Adequate nutritional intake</td>
</tr>
<tr>
<td>Interpersonal Stressors</td>
<td>Exposure to chronic stressors (e.g., financial, partner-related, trauma)</td>
<td>Greater coping and support resources</td>
</tr>
<tr>
<td>Interpersonal Stressors</td>
<td>Exposure to racial discrimination</td>
<td>Active coping responses to racial discrimination</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Socio-Environmental Factors</th>
<th>Risk Factors</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Factors</td>
<td>Lower Neighborhood SES/Income Greater structural deterioration</td>
<td>Higher Neighborhood SES/Income</td>
</tr>
<tr>
<td>Residential Racial Segregation</td>
<td>Greater degree of isolation of Black neighborhoods</td>
<td>Greater degree of clustering of Black neighborhoods</td>
</tr>
<tr>
<td>Neighborhood Characteristics</td>
<td>Greater exposure to environmental hazards or toxins</td>
<td>Less degree of exposure to environmental hazards or toxins</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Institutional Factors</th>
<th>Risk Factors</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspects of Provider Provider Prejudice/Bias</td>
<td>Quality Provider-Patient Communication</td>
<td></td>
</tr>
<tr>
<td>Aspects of Provider</td>
<td>Minimal Adherence to PNC Content</td>
<td>Sufficient Adherence to PNC Content</td>
</tr>
<tr>
<td>Aspects of Health Systems</td>
<td>Institutional Discrimination based on Insurance Status/ Lack of Preconception Insurance Clinical Bureaucracies</td>
<td>Prenatal Support Services</td>
</tr>
</tbody>
</table>
IndiVidual-Level Factors

Maternal Nutritional Deficiencies

Maternal health status during pregnancy has a significant impact on birth outcomes. Black Americans, particularly Black women, tend to experience a greater burden of chronic health conditions and disease; and there is varying evidence demonstrating the effect of health status on Black birth outcomes. Maternal nutritional deficiencies have been implicated as a risk factor for poor birth outcomes. Animal models have provided strong support for the role of infection and inflammation in PTB (Vadillo-Ortega et al., 2002); and it is believed that nutritional deficiencies in humans may be a mediator in this relationship by causing dysregulation of these pathways (Abu-Saad & Fraser, 2010; Dunlop, Taylor, Tangpricha, Fortunato, & Menon, 2012). Vitamin D deficiency, for example, has been linked to several adverse perinatal outcomes such as preeclampsia, LBW, and neonatal hypocalcemia (a metabolic condition in which there is too little calcium in neonates’ blood) (Mulligan, Felton, Riek, & Bernal-Mizrachi, 2010). Several studies have suggested that deficiencies in vitamin D are associated with increased vulnerability to infection and inflammation during pregnancy, and thereby increases the risk of PTB (Dunlop et al., 2012) and fetal growth restriction (Bodnar & Simhan, 2010). Additionally, essential fatty acids, such as omega-3, are believed to contribute to the regulation of inflammatory mediators in utero (Dunlop et al., 2012).

Black women in the United States are more likely than White women to have deficiencies of iron, folate/folic acid, zinc, vitamin D, calcium and imbalance of omega-3/omega-6 fatty acids (Bodnar, Siega-Riz, Simhan, Himes, & Abrams, 2010; Dunlop, Kramer, Hogue, Menon, & Ramakrishan, 2011; Lee et al., 2007; Looker et al., 2008). Given the Black-White disparities in
nutritional deficiencies, some researchers believe that maternal nutritional status may offer some explanation for poor perinatal outcomes in Black women. The extant literature, however, on the role of nutritional deficiencies in the Black-White disparity in perinatal outcomes has been largely inconclusive. Aside from the difficulties in investigating nutritional deficiencies in humans (e.g., lack of experimental control) (Abu-Saad & Fraser, 2010), Black women are largely underrepresented in clinical studies on maternal nutrition and birth outcomes (Bodnar & Simhan, 2010). Only a few studies have investigated the differential impact of nutrition on birth outcomes in a large multiracial sample (Bodnar & Simhan, 2010; Cohen et al., 2001; Dunlop et al., 2012, p. 20). Nevertheless, researchers argue that maternal nutrition is an important factor to consider with regard to the prevention of poor perinatal outcomes, especially among Black women (Abu-Saad & Fraser, 2010; Bodnar & Simhan, 2010)

*Maternal Overweight/Obesity*

Overweight and obesity are important risk factors for poor perinatal outcomes that are well established in the literature. According to Ogden and colleagues (2006), overweight and obesity rates among Black women of childbearing age have been on a steady incline. Moreover, Black women tend to be more likely to be overweight or obese before pregnancy (Rosenberg, Garbers, Lipkind, & Chiasson, 2005), and tend to be more likely to gain more weight during pregnancy than other women (Chen, Feresu, Fernandez, & Rogan, 2009; Rosenberg et al., 2005). Maternal obesity places Black women at increased for preeclampsia (Rosenberg et al., 2005), birth defects (Stothard, Tennant, Bell, & Rankin, 2009), small for gestational age (SGA), LBW (Bodnar et al., 2010; McDonald, Han, Mulla, Beyene, & on behalf of the Knowledge Synthesis Group, 2010; Wise, Palmer, Heffner, & Rosenberg, 2010), infant death (Chen et al., 2009) and stillbirth (Salihu, 2011). Although obesity is typically associated with risk of large-for-
gestational age infants (Hunt et al., 2012), women who are obese tend to have increased risk of hypertensive disorders and heart disease which have been linked to LBW and PTB as well (Graham, Zhang, & Schwalberg, 2007; Rosenberg et al., 2005).

**Maternal Diabetes and Hypertension**

Maternal obesity is a contributing factor to diabetes and hypertension, which are the two most common medical risks during pregnancy (Rosenberg et al., 2005). Diabetes and hypertension both pose a serious health risk for pregnant Black women. In a retrospective cohort study, Graham and colleagues (2007) analyzed the linked birth/death certificates and medical data from 202,931 singleton births to Black and White women in Mississippi. The authors reported that, for Black mothers, maternal chronic diabetes was significantly associated with PTB; whereas maternal chronic hypertension was associated with LBW and infant mortality. In addition, maternal heart disease was associated with PTB and LBW among Black women only (Graham et al., 2007). Another study conducted in New York examined the association between obesity, diabetes and poor birth outcomes and revealed that Black women with chronic diabetes and hypertension showed an increased risk of PTB. Taken together obesity and obesity-related conditions are key risk factors for poor birth outcomes in Black women.

**Maternal Substance Use**

The association between maternal substance use and adverse perinatal outcomes is well understood in the literature (Henriksen et al., 2004; Long, Waterson, MacRae, & Murray Lyon, 1994; Pollack, Lantz, & Frohna, 2000; Wilcox, 1993; Windham, Von Behren, Fenster, Schaefer, & Swan, 1997). Cigarette smoking during pregnancy is one of the most preventable risk factors associated with poor perinatal outcomes. Although White pregnant women are more likely than
Black women to report smoking cigarettes during pregnancy (Bell et al., 2006; Tong et al., 2011), Black women who do smoke during pregnancy are at increased risk for experiencing poor perinatal outcomes. Smoking during pregnancy has been shown to account for as much as 14% of the racial variation in poor perinatal outcomes (Barnett, 1995). Furthermore, studies have consistently shown that cigarette smoking is associated with increased risk of PTB delivery (Ahern, Pickett, Selvin, & Abrams, 2003), LBW delivery (El-Mohandes, Kiely, Blake, Gantz, & El-Khorazaty, 2010), intrauterine growth restriction (IUGR) (Behnke, Smith, Committee on Susbtance Abuse, & Committee on Fetus and Newborn, 2013), and infant mortality (Paul, Mackley, Locke, Stefano, & Kroelinger, 2008). Prior research has also indicated that Black women are much less likely to report moderate to heavy alcohol consumption during pregnancy than their White counterparts (Day, Cottreau, & Richardson, 1993; Flowers, 1999). Black women who do exhibit heavy consumption of alcohol during pregnancy (i.e. 5 drinks per week), however, are at risk of experiencing placental abruption, preeclampsia, and delivering infants that are SGA, premature or stillbirth (Salihu et al., 2011).

Regarding illicit drug use, studies have shown that Black women tend to be more likely to report cannabis or cocaine use during pregnancy (Day et al., 1993; Flowers, 1999; van Gelder et al., 2010). In general, there is evidence that cannabis use, especially during the second and third trimester, is associated with risk for PTB (van Gelder et al., 2010) and LBW (Bailey, McCook, Hodge, & McGrady, 2012; Hayatbakhsh et al., 2012). Cannabis use during pregnancy has also been linked to excessive maternal weight gain during pregnancy (van Gelder et al., 2010); which has been associated with poor birth outcomes (Wise et al., 2010). Illicit drug use (e.g., cocaine use, can cause congenital anomalies that interfere with fetal development (Behnke
et al., 2013). Overall, it is clear in the literature that substance use during pregnancy is significant risk factor for adverse perinatal outcomes.

**Maternal Age**

Advanced maternal age is another important risk factor. Prior research has demonstrated that age-related declines in reproductive advantage is steeper and occurs much earlier in Black women compared to White women (Khoshnood, Lee, & Wall, 2005). For example, among White women the risk for poor birth outcomes is lowest between maternal ages 25 and 34 years (Love et al., 2010; Mathews & MacDorman, 2011; Reichman & Pagnini, 1997), which from a developmental perspective, is considered optimal child-bearing years. In contrast, the risk for poor perinatal outcomes among Black women tends to be lowest between ages 15 and 24 years (Geronimus, 1992, 1996; Love et al., 2010; Rauh, Andrews, & Garfinkel, 2001; Rich-Edwards, Buka, Brennan, & Earls, 2003). Essentially, Black women’s risk of adverse birth outcomes increases steadily before the age of 30 (Rauh et al., 2001). As will be discussed later, the association of advanced maternal age and adverse birth outcomes may be mediated by individual- and neighborhood-level socioeconomic indicators (Colen, Geronimus, Bound, & James, 2006; Geronimus, 1992; Love et al., 2010).

**Individual Socioeconomic Status**

Socioeconomic status (SES), which refers to an individual’s social standing in society based on income, occupational prestige and educational level, has been implicated as a ‘fundamental cause’ of illness and mortality (Cockerham, 2012). Several studies have examined the effect of individual-level socioeconomic indicators, such as insurance status, education level and occupational prestige, on birth outcomes in Black women. For instance, lower maternal and
paternal educational attainment has been linked to higher rates of prematurity (Kruger, Munsell, & French-Turner, 2011). Moreover, higher rates of PTB have been associated with lower levels of access to private insurance (Kruger et al., 2011) and lower income among Blacks with twelve or more years of education (Savitz et al., 2004). Overall, Black women who have lower levels of educational attainment tend to have slightly higher rates of infant mortality than Black women with more education (Mathews et al., 2002). One study examined the associations between maternal education, work substantive complexity (degree to which work involves complex problem solving, making decisions, critical thinking, low task repetition) and LBW among Black and White women (Meyer, Warren, & Reisine, 2010). For Black women, employment and working in a job with greater substantive complexity was associated with a reduced risk for LBW. In contrast, LBW was associated with having higher education while working in a job with less substantive complexity. Essentially, these findings suggest that Black women are at increased risk of poor perinatal outcomes when occupational prestige is incongruent with maternal educational attainment level (Meyer et al., 2010).

There is evidence in the literature which suggests that the relationship between advanced maternal age and poor birth outcomes is exacerbated by individual indicators of lower socioeconomic status (Buescher & Mittal, 2006; Geronimus, 1992, 1996; Rauh et al., 2001; Rich-Edwards et al., 2003). Rauh et al (2001) used a sample of 158, 171 singleton births to Black and White women in New York to assess the effects of maternal age and other risk factors on LBW. In using ‘receipt of Medicaid during pregnancy’ as a proxy for ‘income’, the authors reported that the age-effect—as seen in prior studies—was significantly more pronounced among Black women who had Medicaid status, but not among women who did not have Medicaid status (Rauh et al., 2001). In addition, an earlier study by Reichman and Pagnini (1997) reported that
after adjusting for socioeconomic variables (i.e., maternal education, insurance status, marital status), the odds of delivering a LBW baby were lower among Black women ages 15-19 years than for Black women ages 25-29 years. Overall, it appears that individual-level socioeconomic disadvantage is an important risk factor that shapes the association between maternal age and poor birth outcomes.

*Maternal Stress: General and Race-Related Stress*

Stress is an important contributor to poor perinatal outcomes, namely PTB (Giurgescu, Engeland, Zenk, & Kavanaugh, 2013; Hogue & Bremner, 2005; Schetter, 2009; Tegethoff, Greene, Olsen, Meyer, & Meinschmidt, 2010). Stress is defined as “external demands that tax or exceed the adaptive capacity of an organism” (Schetter, 2009, p. 205). Exposure to chronic stress significantly impacts immunological, cardiovascular and neuroendocrine pathways which shape fetal development and subsequent birth outcomes (Christian, Glaser, Porter, & Iams, 2013; Rosenthal & Lobel, 2011; Schetter, 2009, 2011; Wadhwa, Entringer, Buss, & Lu, 2011). It has been postulated that stress can activate changes in the maternal hypothalamic-pituitary-adrenal (HPA) axis during pregnancy, which is believed to play a role in the onset of labor and corticotrophin-releasing hormones (which are involved in the synthesis of cortisol and other hormones) (Duthie & Reynolds, 2013; Giurgescu et al., 2013; Schetter, 2009). Essentially, the chronic release of corticotropin hormones indicates a dyregulation of the stress system which may adversely affect fetal development and increase susceptibility to inflammation and infection in intrauterine pathways during pregnancy (Duthie & Reynolds, 2013; Giurgescu et al., 2013; Schetter, 2009; Wadhwa et al., 2011).
Stress during pregnancy is common among most women (Braveman et al., 2008; Woods, Melville, Guo, Fan, & Gavin, 2010). In fact, women may experience at least one major stressful hardship during their pregnancy (Braveman et al., 2008). Black women, however, tend to report experiencing greater exposure to chronic stressors than White women (Hatch & Dohrenwend, 2007; Lu & Chen, 2004; Turner & Avison, 2003). Reports of psychological distress, anxiety, depressive symptoms, financial stressors, partner related stressors and trauma-related stressors tend to be higher among pregnant Black women (Giurgescu et al., 2013; Lu & Chen, 2004). Greater self-reported exposure to such stressors among Black women has been associated with LBW (Holland, Kitzman, & Veazie, 2009) and PTB deliveries (Schetter, 2009). Moreover, several studies have assessed stress biomarkers among Black women. In 2013, Christian and associates investigated stress-induced inflammatory responses in a sample of Black (n=19) and White (n=20) women in their second trimester of pregnancy and in control subjects. Serum interleukin (IL)-6 samples were obtained from participants to measure stress-induced inflammatory responses at baseline, 45 minutes and 120 minutes after administering a stress test. The results demonstrated that IL-6 responses were significantly higher in Black women than in White women (Christian et al., 2013). Another recent study reported that minority women tended to have higher cortisol levels and lower levels of anti-inflammatory cytokines, which may compromise pregnant women’s ability to regulate inflammation (Corwin et al., 2013).

Black women also tend to have unique sources of stress, such as race-related stress, which are believed to play a role in their birth outcomes (Mendez, Hogan, & Culhane, 2013; Rosenthal & Lobel, 2011; Schetter, 2009). Interpersonal racism, which is typically operationalized as perceived racial discrimination, is considered a unique and potent source of stress. Perceived racial discrimination can take form as an acute stressor (i.e., isolated
experiences of unfair treatment based on race) or as a chronic stress (Earnshaw et al., 2013). Several studies have suggested that perceived racial discrimination may contribute to poor health and risky health behaviors (Carty et al., 2011; Gee, 2002; Schetter, 2009). There is also growing support which links perceived racial discrimination to poor birth outcomes (Earnshaw et al., 2013; Mustillo et al., 2004; Rankin, David, & Collins Jr, 2011). Rankin and associates (2011) conducted a case control study of 163 Black mothers and 121 controls in Illinois. Black women who delivered PTB/LBW infants were more likely than women who delivered full-term infants to report experiencing racial discrimination in the past year. Similarly, another study of Black and White women in Illinois, California, Minnesota and Alabama found that a greater proportion of Black women who had experienced PTB or LBW deliveries also reported having experienced racial discrimination in a least three situations (Mustillo et al., 2004). In this study, after adjusting for experiences of racial discrimination, the odds ratio for preterm delivery among Black versus White women decreased from 2.54 (95% CI= 1.33, 4.85) to 1.88 (95% CI=0.51, 2.41). It can therefore be concluded that stress as well as race-related stress may contribute to adverse perinatal outcomes in Black women.

Inadequate Prenatal Care

Prenatal care plays a crucial role in early detection and intervention of potential pregnancy complications which could result in infant morbidity or mortality (Centers for Disease Control and Prevention, 2000). Inadequate prenatal care, which refers to prenatal that begins after the second trimester (after 4th month) and/or prenatal care that consists of less than 50% of the recommended visits received during pregnancy, may be at increased risk for poor perinatal outcomes (Cox, Zhang, Zotti, & Graham, 2011; Partridge, Balayla, Holcroft, & Abenhaim, 2012). There is overwhelming empirical evidence demonstrating that Black women are two
times more likely than White women to have received inadequate prenatal care during pregnancy (Cox et al., 2011; Frisbie, Echevarria, & Hummer, 2001; Kotelchuck, 1994; Partridge et al., 2012). Furthermore, Black women appear to carry the burden of inadequate prenatal care. For example, the infant mortality rate for infants born to Black women who received no prenatal care is more than double that of infants to White mothers who also received no prenatal care (Mathews et al., 2002). A study in Mississippi found that among those who had received no prenatal care during pregnancy, there was a threefold increase for infant death among White mothers and over a five-fold increased risk for infant death among Black mothers (Cox et al., 2011). Several studies exploring barriers to prenatal care have pointed to several factors: unplanned/unwanted pregnancy, negative attitudes towards prenatal care, psychological stress, and insurance/finance-related constraints, no regular provider before pregnancy and lower education levels (Braveman, Marchi, Egerter, Pearl, & Neuhaus, 2000; Johnson et al., 2007). Overall, it is clear that inadequate or no prenatal care is a major risk factor associated with adverse perinatal outcomes among Black women. It should be noted that among White and Black women who do begin prenatal care during their first trimester, the infant mortality rate remains two times higher among Black women (Mathews et al., 2002).

**Socio-Environmental Factors: Community Level**

**Neighborhood/Community Socioeconomic Status**

The socioeconomic gradient in health is well established in the literature. The effect of neighborhood socioeconomic disadvantage on birth outcomes has also been extensively studied\(^3\) (Ahern et al., 2003; Paula Braveman, Cubbin, Marchi, Egerter, & Chavez, 2001; Colen et al.,

\(^3\) In the literature, researchers typically measure SES using a combination of indicators (e.g., income, education, insurance status) and explicit specifications such as income quartiles or income as a percentage of the poverty level at the population level (Braveman et al., 2001).
Black Americans compared with Whites are more likely to be socially and economically disadvantaged, especially in terms of employment rates, income level and median value of assets per household (Harris, 2010). What is more, a greater proportion of Black pregnant women tend to reside in impoverished neighborhoods (Collins, Rankin et al., 2011; Kruger et al., 2011; Rich-Edwards et al., 2003). Prior studies have concluded that risk of PTB is increased when Black women live in neighborhoods with low median incomes and high levels of unemployment (Ahern et al., 2003; Messer et al., 2008; Pickett et al., 2002); with the exception of one prospective cohort study (Phillips et al., 2012). Kruger and his colleagues (2011) examined the relationship between physical deterioration of residential environments and the rates of PTB/LBW deliveries. The authors argued that physical deterioration as well as social disorganization and crime are symptoms of low neighborhood income and efficacy (Kruger et al., 2011). The geographic concentration of rundown residential structures was strongly associated with greater concentration of PTB/LBW deliveries from the area. Yet, this association was most robust among Blacks (Kruger et al., 2011).

As discussed earlier, there is consistent evidence that individual-level indicators of lower SES appear to exacerbate the age-effect on birth outcomes in Black women. Low neighborhood SES appears to have the same influence. Collins and associates (2011b; 2006) examined how neighborhood poverty (four neighborhood-level indicators: low median family income, high rates of unemployment, homicide and lead poisoning) modifies the relationship between maternal age and infant birth weight. The findings revealed that neighborhood poverty did modify the association of advanced maternal age and the risk of moderate LBW. In addition, the
age-effect was slightly more pronounced in impoverished neighborhoods than in non-
impoverished neighborhoods, with the likelihood of moderate LBW higher among 30-34 year old women than 20-24 year old women (Collins et al., 2011, 2006).

Residential Segregation: Isolation

Black Americans tend to be the most racially segregated minority group in the United States (Bell et al., 2006; Iceland, Weinberg, & Steinmetz, 2002; Williams & Collins, 2001). Moreover, the spatial segregation of Blacks and Whites across residential neighborhoods has been investigated to explain the Black-White disparities in perinatal outcomes (Grady, 2006; Kramer, Cooper, Drews-Botsch, Waller, & Hogue, 2010). Residential segregation, a form of institutional racism, it is believed to be a fundamental cause of racial disparities in health (Gaskin, Dinwiddie, Chan, & McCleary, 2011; Williams & Collins, 2001). As an institutional mechanism, residential segregation has served to not only separate racial groups into different neighborhoods (through policies), it also determines the quality and type of resources available in those neighborhoods (Gaskin et al., 2011).

Residential isolation, or the degree to which minority residents are exposed only to one another within their neighborhood or metropolitan area, has emerged as a potential risk factor. Isolation may reflect a distinct aspect of institutional segregation which results in poor neighborhood quality, economic disenfranchisement, diffusion of harmful health behaviors and limited economic mobility (Bell et al., 2006; Kramer et al., 2010; Kramer & Hogue, 2009) within a given neighborhood. A number of studies have investigated the association between residential isolation and adverse birth outcomes. Overall, findings suggest that living in racially isolated neighborhoods appears to be associated with very PTB and moderately PTB (Britton & Shin,
2013; Kramer et al., 2010), risk for infant mortality (Sparks, Sparks, & Campbell, 2013) and IUGR (Grady, 2010) among Black women.

**Socio-Environmental Factors: Institutional Level**

Historically, there have been persisting racial disparities in access to and utilization of medical services (Mayberry, Mili, & Ofili, 2000). These racial differences in access and utilization of care also extend to prenatal care. Aside from individual characteristics and community-level factors, there is data suggesting that health providers and health institutions may, to some extent, contribute to racial/ethnic disparities in health (Muldoon et al., 2011; National Research Council, 2003; Peek, Odoms-Young, Gorawara-Bhat, Wilson, & Chin, 2010; Shavers et al., 2012; van Ryn & Fu, 2003; van Ryn, 2002). Institutional racial discrimination, is believed to play a major role in these racial disparities (National Research Council, 2003) which occurs through provider-level and institutional-level interactions.

**Provider Bias**

It is clear that discrimination can be detrimental to health and impact use of preventive services (Bird & Bogart, 2001; Mays, Cochran, & Barnes, 2007). Blacks tend to report higher levels of perceived racial discrimination in health care settings (Benjamins & Whitman, 2013; Hausmann, Kwoh, Hannon, & Ibrahim, 2013) and particularly with health care providers (Bird & Bogart, 2001; Penner et al., 2010). Furthermore, health care providers—as well as all other individuals—are likely influenced by any racial prejudices that they may have, which may carry over in their care practices (National Research Council, 2003). It is believed that, in these situations, providers may be operating on biases against persons (or women) of color, clinical uncertainty about interacting with Blacks and stereotypes about expected health behaviors of
Black patients. All of these factors paired with having to make medical decisions within limited time constraints (Penner et al., 2010) may be what leads to differential medical interactions. Prior research has demonstrated that lower provider adherence to prenatal care content (which is related to adverse birth outcomes) was evident among low-income women of color (Handler, Rankin, Rosenberg, & Sinha, 2012). Other studies have found that Black women are more likely to report not receiving advice about smoking cessation and alcohol use (Kogan, Kotelchuck, Alexander, & Johnson, 1994) and were less likely than White women to receive prenatal steroids (which help in fetal development) and tocolytic medications during pregnancy (Paul et al., 2006).

Institutional Discrimination

Certain aspects of the way in which health care systems are organized may interfere with the ease of accessing services for racial minority groups (National Research Council, 2003). In addition, populations of color may experience differences in quality of care and in rates at which they receive certain services. One institutional mechanism that dictates access to care is insurance coverage. There is data that suggests Blacks are two times more likely than Whites to be uninsured (National Research Council, 2003). For example, 8 in 10 Black Americans are a part of working families, they are more likely than Whites to work in jobs that provide no health insurance coverage (National Research Council, 2003). This has important implications for Black women in that many may not have insurance coverage prior to pregnancy. It is argued that health system changes currently do not fully ensure that women—who go through major life transitions such as pregnancy, marriage, moving, graduating from school—have continuous access to insurance (Dennis et al., 2013). Further, Medicaid expansions for automatic prenatal coverage to low-income, women has been associated with greater probability of Medicaid enrollment during pregnancy among women who were uninsured prior to pregnancy (Jarlen...
Bennett, Barry, & Bleich, 2014). Thus, it is reasonable to suggest that some institutional-level processes and policies can significantly impact Black women’s access and quality of care. Arguably, many of these institutional mechanisms are rooted in broader historical contexts of racism and classism.

**Protective Factors**

Relatively little is known about the conditions and attributes that mitigate or eliminate Black women’s risk for adverse perinatal outcomes. It is reasonable to assume that the reverse of some risk factors (i.e., lower socioeconomic status, poor physical health, substance use during pregnancy, inadequate prenatal care) may play a protective role in birth outcomes. Although the majority of the literature tends to focus on risks associated with perinatal outcomes, there is some empirical support for several factors which may mitigate Black women’s risk for adverse perinatal outcomes.

**Individual-Level Factors**

**Interpregnancy Intervals**

The association between the time interval between births and perinatal outcomes is clear in the literature (Blackmore-Prince et al., 2000; Conde-Agudelo, Rosas-Bermúdez, & Kafury-Goeta, 2006; Hussaini, Ritenour, & Coonrod, 2013; James, Bracken, Cohen, Saftlas, & Lieberman, 1999; Kozuki et al., 2013; Rawlings, Rawlings, & Read, 1995; Teitler, Das, Kruse, & Reichman, 2012; Zhu, Haines, Le, McGrath-Miller, & Boulton, 2001). According to the nutrition depletion hypothesis, adverse perinatal outcomes are a result of closely spaced births (less than 18 months) which allow limited time for recovery from the physiological stress of pregnancy (Hussaini et al., 2013). In general, data suggests that interpregnancy intervals of 18-23
months are strongly associated with decreased risk for PTB (Conde-Agudelo et al., 2006; Zhu et al., 2001), LBW (Blackmore-Prince et al., 2000; Conde-Agudelo et al., 2006; Zhu et al., 2001), SGA (Conde-Agudelo et al., 2006; James et al., 1999; Kozuki et al., 2013; Zhu et al., 2001), IUGR (Blackmore-Prince et al., 2000), and infant death (Hussaini et al., 2013). Despite the protective effects of appropriately spaced births for Black women, however, their rates of adverse perinatal outcomes remain higher when compared with White women (James et al., 1999; Zhu et al., 2001).

**Social Support**

Social support among pregnant women has also been widely studied. Some data suggests that social support may have direct protective effects against pregnancy complications (Zachariah, 2009), low birth weight (Almeida, Mulready-Ward, Bettegowda, & Ahuluwalia, 2014; Feldman, Dunkel-Schett, Sandman, & Wadhwa, 2000; Shah, Gee, & Theall, 2014) and may mitigate the negative effects of anxiety and depression (Nkansah-Amankra, Dhawain, Hussey, & Luchok, 2010; Nylen, O’Hara, & Engeldinger, 2013). This is especially important considering that Black women tend to be more likely to experience greater exposure to stressors during pregnancy.

**Socio-Environmental Factors: Community Level**

**Racial Segregation: Clustering**

Several studies have indicated that some dimensions of residential racial segregation may protect against Black women’s risk for adverse perinatal outcomes. Clustering refers to the degree to which Blacks live in contiguous neighborhoods within a metropolitan area (Bell, Zimmerman, Mayer, Almgren, & Huebner, 2007; Massey & Denton, 1988). Essentially,
clustering is characterized by a widespread distribution of predominately Black residents beyond individual neighborhoods; and is believed to reflect community attributes such as protection of discrimination, greater political and economic empowerment, and increased social cohesion or capital (Bell et al., 2006).

*Healthy Neighborhood Environments.*

The built environment in which individuals live, grow and work can significantly impact their general health and well-being in part through physical activity and promotion of healthy diet and behaviors (Berrigan & McKinno, 2008; Marshall, Brauer, & Frank, 2009). It also impacts one’s access to resources (i.e., grocery stores, community gardens, bike paths) and exposure to environmental agents (i.e., low/high air pollution). Dadvand and colleagues have investigated the association between environmental greenness and birth outcomes among pregnant women in Europe (Dadvand, de Nazelle, Figueras, et al., 2012; Dadvand, de Nazelle, Triguero-Mas, et al., 2012; Dadvand, Sunyer, et al., 2012). Their findings reveal that pregnant women living in ‘greener’ areas tended to have lower levels of exposure to air pollution (Dadvand, de Nazelle, Triguero-Mas, et al., 2012); and that the effect of prenatal exposure to green spaces on increased birth weight were robust among infants of socioeconomically disadvantaged women (Dadvand, de Nazelle, Figueras, et al., 2012; Dadvand, Sunyer, et al., 2012). These findings have important implications for the health of Black women in that Black women are more likely to live in socioeconomically disadvantaged neighborhoods, which are more likely to have higher concentrations air pollution (Marshall et al., 2009; Ponce, Hoggatt, Wilhelm, & Ritz, 2005). Thus, greater exposure to environmental toxins and pollution may be a risk factor associated with Black birth outcomes.
Socio-Environmental Factors: Institutional-Level

Prenatal Care Coordination and Management

Quality prenatal care coordination and management has an important impact on birth outcomes. Prenatal care coordination and management typically consist of services such as outreach, assessment, care plan development, health education and nutrition counseling. It serves the purpose of increasing families access to medical, social and educational services related to participants’ pregnancy. Other support services such as the Women, Infants, and Children (WIC) nutritional program, home visiting programs, family planning have also been shown to play an important role in improving birth outcomes in Black women (Issel, Forrestal, Slaughter, Wiencrot, & Handler, 2011; Schlenker, Dresang, Ndiaye, Buckingham, & Leavitt, 2012; Shah et al., 2014). Overall, women who received prenatal care coordination services are more likely to have better birth outcomes (Baldwin et al., 1998; Van Dijk, Anderko, & Stetzer, 2011).

Summary

Overall, there is a constellation of key risk and protective factors that Black women are exposed to during pregnancy. The socio-ecologic contexts in which Black women are exposed to these variables offer a more complete understanding of poor birth outcomes. Further, all of these variables should be understood as contributing to an integrated and co-occurring processes, rather than isolated exposures (Kiely et al., 2011). Yet, all of these points considered, researchers have still been unable to fully explain the Black-White disparities in perinatal outcomes. One issue is that many explanations are often based on analyses which measure select risk factors (i.e., socioeconomic status, stress) at the time of pregnancy (Lu & Halfon, 2003). Empirical investigations within this purview, although notable, have left gaps in knowledge.
regarding perinatal outcomes in Black women. Consequently, it has been necessary to seek out alternative explanatory frameworks for understanding the Black-White disparity in birth outcomes (Dominguez, 2010; Lu & Halfon, 2003). In the last few years, an emerging line of research has focused on Black women’s exposure to known risk and protective factors across the lifespan and its subsequent impact on birth outcomes (Fine & Kotelchuck, 2010; Ford et al., 2005; Halfon, Larson, Lu, Tullis, & Russ, 2013; Love et al., 2010; Lu & Halfon, 2003; Lu et al., 2010). Several empirical studies have demonstrated the relationship between adverse birth outcomes and pre-pregnancy risk factors (Love et al., 2010; Orr et al., 2012; Ramakrishnan, Grant, Goldenberg, Zongrone, & Martorell, 2012; Wise et al., 2010) among Black women. In addition, a recent study reported that pre-conceptional factors, such as diabetes, body mass index (maternal weight), and intimate partner violence, were the strongest predictors of adverse perinatal outcomes in Black women (Kiely et al., 2011). In conclusion, an examination of factors, within a life course context, will be needed to come closer to understanding the causes of the Black-White disparities in perinatal outcomes.

The Life Course Perspective: An Alternative Framework for Understanding Black-White Disparities in Perinatal Outcomes

Over the years, researchers and practitioners have worked to address the Black-White disparity in perinatal outcomes by focusing primarily on women during pregnancy. Although prior research has contributed to advances in understanding of the disparities in perinatal outcomes, there has been very little progress in eliminating those disparities (Hogan, Rowley, Bennett, & Taylor, 2012; Lu & Halfon, 2003). In the last 15 years, a growing number of researchers have proposed the life course perspective as an alternative conceptual framework for examining the Black-White disparities in perinatal outcomes (Fine & Kotelchuck, 2010; Ford et
al., 2005; Halfon et al., 2013; Hogan et al., 2012; Jackson et al., 2011; Kotelchuck, 2003; Lu & Halfon, 2003; Lu et al., 2010; Myers, 2008; Russ, Larson, Tullis, & Halfon, 2013; Shuey & Willson, 2008; White & Borrell, 2011). This line of research essentially suggests that women’s cumulative exposure to various factors may influence their birth outcomes. Furthermore, the following discussion will introduce the life course perspective, its emergence in the maternal and infant health research and highlight the growing evidence which supports the influence of ‘life course determinants’ of perinatal outcomes in Black women.

The Life Course Perspective

The Life Course Health Development Model, or commonly the life course perspective, builds on research from biological, behavioral and social science disciplines. It is a framework that draws from developmental models which conceptualized health as “a dynamic process that begins before conception and continues throughout the lifespan” and across generations (Braveman & Barclay, 2009; Elder, 1998; Halfon, Larson, Lu, Tullis, & Russ, 2014, p. 1). In contrast to classical biomedical models, individual’s health—within the life course framework—is shaped by a dynamic series of genetic, biological, social and environmental interactions. The life course perspective is employed in an effort to understand how early life experiences and exposures may influence health outcomes in later life. Key concepts in the life course literature include the notions of critical/sensitive periods, early fetal programming/epigenetics, and cumulative pathways/trajectories (Braveman & Barclay, 2009; Fine & Kotelchuck, 2010; Kotelchuck, 2003; Lu et al., 2010). It is hypothesized that exposure to adverse events during the critical periods of development (i.e., fetal exposure to cigarette smoking) may alter biological processes which subsequently ‘program’ one’s future health. Further, it is suggested that fetal programming (i.e., exposure to biologic events in utero) and intergenerational programming (i.e.,
parental health prior to conception) may impact the future health of offspring. In addition to internal biological influences, exposure to socio-environmental experiences (i.e., poverty, stress) can also have an effect on health. Moreover, the cumulative impact of multiple stressors or exposures may also ‘program’ health development. In total, individuals are believed to have health trajectories which are built or diminished over time based on one’s exposures to biological, social and environmental factors (Fine & Kotelchuck, 2010; Lu et al., 2010).

Earlier studies have examined life course health development as it relates to health disparities and health morbidity (Braveman & Barclay, 2009; Chittleborough, Taylor, Baum, & Hiller, 2009; Shuey & Willson, 2008). Over the years, the field of maternal and child health has oriented itself towards integrating the life-course perspective in efforts to address the persistent Black-White disparities in birth outcomes (Fine & Kotelchuck, 2010; Kotelchuck, 2003; Lu et al., 2010). Guided by the fundamental concepts in life-course theory, Lu and Halfon (2003) provide a model that describes the process by which the health trajectories of Black and White women may develop (see Figure 3). As shown, the model suggests women’s health trajectories are shaped, in part, by major risk (downward arrows) and protective (upward arrows) factors which dictate reproductive potential. Further, Black women have a greater burden of risk factors (which may include biological, social and environmental factors) which negatively impact their reproductive advantage. It can also be observed that—as indicated in the literature—while White women experience greater reproductive advantage during typical childbearing years, reproductive advantage among Black women begins much earlier and is less robust. Furthermore, continued investigation into how various factors shape Black women’s health and birth outcomes over the life-course and across generations will provide more insight into the underlying causes of the Black-White disparities.
Figure 4. Exposure to risk and protective factors over the life course, by race (Lu & Halfon, 2003)

**Life Course Determinants of Perinatal Outcomes**

Prior research suggests that Black women’s exposure to chronic stress and socioeconomic disadvantage may carry substantial weight in explaining the Black-White disparity in perinatal outcomes. Most studies have focused on these factors only during pregnancy. In the last several years, however, there has been an outpouring of studies that focus on the effects of known risk factors across Black women’s life course. Extant literature has pointed to several potential ‘life course determinants’ of Black perinatal outcomes: cumulative socioeconomic disadvantage, cumulative stress/allostatic load, preconception health status and maternal low birth weight.
The early work of Geronimus (1992, 1996) was focused on understanding the Black-White differences in maternal age patterns and infant birth weights. This line of research revealed that the association of maternal age and birth outcomes was noticeably different between Black and White women. In contrast to the patterns seen in White women, there appeared to be a greater survival advantage for infants born to teenage Black women than Black women older in age. Geronimus proposed the “weathering hypothesis” which postulated that Black women’s health may begin to deteriorate in early adulthood—much earlier than their White counterparts—as a result of cumulative socioeconomic disadvantage. Numerous subsequent studies reported findings that were consistent with the weathering phenomenon. That is, the association of advanced maternal age and poor birth outcomes among Black women appears to be exacerbated by socioeconomic disadvantage. Several studies have contributed to a greater understanding of how socioeconomic disadvantage over the life course impact Black women’s birth outcomes (Colen et al., 2006; Collins, Rankin, & David, 2011a; Collins et al., 2011b; Foster et al., 2000; Holzman et al., 2009; Love et al., 2010). Two studies linked neighborhood income data to a state transgenerational birth file to assess the effect of economic environment over women’s life course. Among Black women who were born in poorer neighborhoods and remained poor as adults, had a greater risk of LBW or SGA delivery than Black women who lived in upper income neighborhoods throughout their lifetime (Collins et al., 2011; Love et al., 2010). Most surprising, however, is that despite the protective effects of socioeconomic advantage, Black women’s rates of PTB and LBW were still significantly higher than those of White women (Love et al., 2010). Another study examined the extent to which the infants of second generation high-SES Black women experience improved birth weights (Foster et al., 2000). The authors reported that the proportion of LBW births decreased from 11.4% in
the second generation to 6.9% in the third generation. Yet, remarkably, third generation infants remained at higher risk for LBW than White infants (Foster et al., 2000). Thus, similar to other studies on health (Shuey & Willson, 2008), it is clear that the effects of cumulative socioeconomic disadvantage on Black women’s birth outcomes are robust. Moreover, it also appears that Black women who experience greater socioeconomic advantage or upward economic mobility—either in their life course or transgenerationally—have better birth outcomes. Yet, there remains a persistent residual of the Black-White disparity.

It is clear in the literature that the physiologic impact of stress can have deleterious effects on Black women’s perinatal outcomes (Christian et al., 2013; Corwin et al., 2013; Duthie & Reynolds, 2013; Giurgescu et al., 2013; Hogue & Bremner, 2005; Schetter, 2011). The number of studies examining the effect of cumulative stress on Black birth outcomes is extensive; and this line of research is often interconnected with work focusing on the weathering hypothesis and cumulative socioeconomic disadvantage. Further, it is suggested that cumulative stress (as caused by persistent socioeconomic disadvantage, chronic racial discrimination or chronic trauma) may lead to biological risk for disease morbidity and mortality (Duru, Harawa, Kermah, & Norris, 2012). The early work of McEwen, Seeman and colleagues advanced the concept of allostatic load (McEwen & Seeman, 1999; Seeman, Epel, Gruenewald, Karlamangla, & McEwen, 2010; Seeman, Singer, Rowe, Horwitz, & McEwen, 1997). Allostatic load, which is conceptually similar to weathering, refers to the cumulative ‘wear and tear’ on the body’s major biological regulatory and response systems as a result of chronic stress (McEwen & Seeman, 1999; Seeman et al., 1997). Current research indicates that Black Americans, particularly women, tend to have higher allostatic loads than Whites regardless of SES and health behaviors (E. d. Carlson & Chamberlain, 2005; Chyu & Upchurch, 2011; Colen et al., 2006; Duru et al.,
2012; Geronimus et al., 2010; Hickson et al., 2012). One study found that Black women had significantly shorter telomeres (a biomarker in which length is inversely associated with aging) than White women (Geronimus et al., 2010). The authors also reported that stressors associated with perceived stress and poverty contributed to the Black-White differences in telomere length. Overall, the authors estimated that Black women at ages 49-55 were 7.5 years biologically ‘older’ than their White counterparts, which further suggests the occurrence of accelerated stress-induced aging among Black women (Geronimus et al., 2010). To date, very few studies have investigated the impact of allostatic load (using an index of multiple biomarkers) on birth outcomes. Currently, there is no evidence of racial differences with regard to the relationship between allostatic load and poor birth outcomes (Wallace & Harville, 2012; M. Wallace et al., 2013).

Furthermore, there is growing evidence of the role that preconceptual health status plays in perinatal outcomes (Class, Khashan, Lichtenstein, Långström, & D’Onofrio, 2013; Kiely et al., 2011; Kramer, Hogue, Dunlop, & Menon, 2011; Wise et al., 2010). For instance preconception stress, as well as race-related stress prior to pregnancy, has been associated with increased risk of preterm birth and infant mortality (Class et al., 2013; Kramer et al., 2011; Mustillo et al., 2004; Rankin et al., 2011). Other studies have reported strong associations between pre-pregnancy morbidities (e.g., excessive BMI/obesity, diabetes) and adverse birth outcomes, in contrast to conditions that develop as a result of pregnancy (e.g., gestational diabetes, gestational weight gain). In addition, two transgenerational studies have linked low maternal birth weight to adverse perinatal outcomes in Black women (Collins et al., 2011a, 2011b). Findings indicate that the risk of LBW, PTB and IUGR infants were more likely among women who had been born LBW (LBW mothers) compared with women who were born with
normal birth weights (non-LBW mothers). Findings also suggest that maternal upward economic mobility is associated with decreased risk of PTB; but, interestingly, LBW mothers do not experience the same advantage (Collins et al., 2011a). These findings suggest that there may be underlying epigenetic mechanisms which contribute to adverse birth outcomes independent of social factors.

Overall, there is growing empirical support for the notion that continued exposure to various factors over the life course may shape women’s health in such a way that makes them vulnerable to poor health outcomes. The association of these life course determinants of health and birth outcomes are still not well understood, but existing knowledge has important implications for social and health policies regarding the health of children and women across the lifespan.

**Life Course Perspective: Moving Forward**

Although there is much more to be known, the shift in focus from women’s exposure to risk factors during pregnancy towards cumulative exposure has helped to fill some significant gaps in knowledge with regard to the Black-White disparity in perinatal outcomes. The life course perspective will be an important item on the maternal and child health research agenda (Kotelchuck, 2003; Lu & Halfon, 2003), largely because it allows for a more contextual and long-term understanding of women’s health development. In Figure 4, Russ and colleagues contrast a life course-informed approach with existing approaches in maternal and child health. Overall, life course-informed inquiry in maternal and child health research allows for a long-term investigation of multiple factors that may impact the health of women and their children (Russ et al., 2013).
In sum, it is clear that exposure to a variety of risk and protective factors—both during pregnancy and across the life-course—significantly and differentially impact Black women’s birth outcomes. Unfortunately, researchers have been unable to fully explain the residual racial differences in birth outcomes even after controlling for a multitude of variables. Despite pronounced gaps in knowledge, life course-informed research, however, appears to be a move in the right direction.

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<td>Study design</td>
<td>Cross-sectional</td>
<td>Longitudinal</td>
</tr>
<tr>
<td>Time frame</td>
<td>Single point in time/short-term</td>
<td>Long-term</td>
</tr>
<tr>
<td>Investigators</td>
<td>Single/related disciplines</td>
<td>Multiple disciplines</td>
</tr>
<tr>
<td>Focus</td>
<td>Single exposure - single outcome</td>
<td>Multiple exposures - multiple outcomes</td>
</tr>
<tr>
<td>Scope</td>
<td>Socio-demographic or biological or genetic data</td>
<td>Socio-demographic, biologic and genetic data all collected on same subjects</td>
</tr>
<tr>
<td>Subjects</td>
<td>One generation</td>
<td>Multi-generational</td>
</tr>
<tr>
<td>Risk factors</td>
<td>Descriptions of associations with health outcomes</td>
<td>Determine mechanisms accounting for association of risk factor with health outcome</td>
</tr>
<tr>
<td>Timing</td>
<td>Temporal association between risk factor and outcome</td>
<td>Risk factor may be separated from health outcome by years or even decades, identification of latent risks, cumulative risks and risk pathways</td>
</tr>
<tr>
<td>Critical and sensitive periods</td>
<td>Conception-3 years.</td>
<td>May include pre-conception, peri-conception. Within the 0-3 sensitive period, may be critical windows for biological embedding of short duration</td>
</tr>
<tr>
<td>Investigator training</td>
<td>Basic research methodology and data analysis</td>
<td>Advanced research methodology and higher-level statistical modeling</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Disease states, morbidity and mortality</td>
<td>Positive health</td>
</tr>
<tr>
<td>Study type</td>
<td>Observational, short-term intervention</td>
<td>Observational, long-term interventional, computer simulations</td>
</tr>
<tr>
<td>Health impacts of changes in maternal and child health policy</td>
<td>Descriptive, conjectural</td>
<td>Priority for study</td>
</tr>
<tr>
<td>Importance of MCH Research</td>
<td>Specialty area, low national priority</td>
<td>Foundation of nation’s health, research priority</td>
</tr>
</tbody>
</table>

*Figure 5. Comparison of life course-informed approach and existing MCH research (Russ et al., 2013)*
The Present Study

**Phenomenology**

The present research will be guided by a transcendental, phenomenological approach. The purpose of phenomenology is to describe the lived experience and discover the meaning of a phenomenon. This approach is both a philosophical perspective and set of methodologies (Moustakas, 1984). It focuses on groups of people with a shared lived experience of a phenomenon and describes the meaning that is tied to that experience (Creswell, 2008). The objective of phenomenology is to reduce individual experiences with a phenomenon to a description of the *essential invariant structure*, or the overall ‘essence’ of the phenomenon (Creswell, 2008; Moustakas, 1984). Transcendental phenomenology is one of two approaches within phenomenology. It is concerned with examining the textual description of participants’ lived experiences holistically by examining them from “many sides, angles and perspectives” until the essence of the phenomenon is captured (Moustakas, 1984, p. 58). Moustakus (1984) also argues that the focus of the phenomenological researcher should be on the actual descriptions of experiences rather than explanations or interpretations (p. 58). Moreover, the researcher should always be “intentionally conscious” of his or her own thoughts, biases and perceptions as well as be intentional about “clearing space within ourselves so that we can actually see what is before us and in us” (Moustakas, 1984, p. 60). Although the overall data analysis process (referred to as phenomenological reduction) will be described in detail in the Methodology section, the first and most crucial step in phenomenological reduction is the *Epoche* will be discussed here. The Epoche, or commonly referred to as bracketing, is the process by which the phenomenological researcher “sets aside [his or her] prejudgments, biases, and preconceived ideas about things [the phenomenon]” (p. 85). Moustakas (1984) viewed the
process of bracketing as a systematic way to allow descriptions to enter into the researcher’s consciousness as if for the first time (p. 85). Bracketing usually involves several ‘meditative sessions’ and time for memoing (taking reflective notes) to prepare the researcher to come to the data with a clear and “presuppositionless” mind (p. 90). During the analysis process it is also important that the researcher constantly remind himself or herself to focus on the textual description of the phenomenon and the meaning of those descriptions ‘as seen through the eyes of the participant’ rather than attempt to draw conclusions that are not explicitly described in the textual descriptions (Moustakas, 1984).

This approach, unlike quantitative research, relies on rich, thick textual descriptions. The research questions are designed to be open-ended and typically begin with words such as “what” or how” rather than “why” (Creswell, 2008). In quantitative research, sample size plays an important role in type of statistical analyses conducted and generalizability. This is not necessarily the case in phenomenological research. Rather than focusing on how many have experienced a phenomenon, this approach focuses on the content of the experience (Englander, 2012). Thus, a large sample size is not required for the purposes of this approach. There is no standard sample size cut-off for phenomenological research, but scholars recommend a minimum of three to ten participants (Creswell, 2008; Englander, 2012). Moreover, generalizability as it is understood in the postpositivist paradigm is an inappropriate concept within phenomenology (Creswell, 2008). Although, researchers may oftentimes frame, for example, the ‘essence’ of the lived experience of perinatal bereavement as something that may be applicable to other people who have experienced that phenomenon, the intent is not to generalize the findings to a larger population.
Purpose and Significance

The purpose of this research is to describe the lived experience of African American women who have experienced the phenomenon of infant death. This study has significant implications because in using a life course perspective, it will provide a contextual and longitudinal account of Black women’s life experience prior to infant death. This research also has significant implications for both research and practice addressing racial disparities in maternal and child health. The present study is, to my knowledge, the first qualitative, life course-informed empirical study of Black women who have experienced infant death. Second, this study does not merely describe African American mothers’ experience of infant death; it also describes their lived experience, using a life course perspective, to understand the meaning of their shared experiences as it may relate to their birth outcomes. By understanding the ‘essence’ of African American women’s experience, informed steps can be taken to promote Black infant health.

Research Questions

The two central research questions for the present study are presented:

1. **What are the factors that have shaped the lived experience of African American mothers who have experienced the phenomenon of infant death?**

The second central research question allows for a description of the participants’ lived experience from a socio-ecological perspective. Essentially, this means that the researcher will not only focus on describing experiences, she will also examine the ecological level (i.e., individual-level, family-level, community-level, health systems-level, macro-level) at which these experiences occur (as described by the participants).
To describe participants’ experience in this manner is useful in ‘discovering’ the social context of the lived experience of the phenomenon.

2. **What are the shared life-course patterns among African American mothers who have experienced the phenomenon of infant death?**

This question allows for an in-depth exploration of African American women’s life experiences and how these experiences may be related to infant health outcomes. This research is a deliberate step away from the notion that women and infant health begins with conception. Instead, it is important to understand women’s experiences across the life span and the degree to which these experiences (and exposures) shape health outcomes later in life. Further, this research question will allow for an examination of potential similarities in women’s overall life experiences which may point to underlying risk or protective factors associated with birth outcomes.
METHODOLOGY

Setting

A description of the setting from which participants were recruited is necessary in that it allows the reader to make sense of the data against a contextual backdrop. Participants were recruited from Sedgwick County, Kansas. According to the United States Census Bureau, the county’s 2012 population estimate was 503,889 (U.S. Census Bureau, 2013). African Americans account for about 9.5% of this population (U.S. Census Bureau, 2013). According to the latest published county data, in 2010, the Black IMR was 13.8 infant deaths per 1,000 live births (Sedgwick County Health Department, 2012). The overall IMR for the county and state was 7.4 and 6.3 infant deaths per 1,000 live births, respectively (Sedgwick County Health Department, 2012).

This county also has a Fetal and Infant Mortality Review (FIMR) which is comprised of several community and state organizations and agencies. In addition, there are also several coalitions, task forces and community-based organizations that regularly implement county and state wide programs and events. Although Kansas has been making progress towards meeting the target IMR of 6.2 infant deaths per 1,000 live births set forth by Healthy People 2020, there is still a considerable amount of work to be done to address the racial disparity in infant mortality.
Participants

A purposive sample\(^4\) of five African American women who had experienced perinatal or infant loss participated in this study. Participants’ ages ranged from twenty years to thirty-six years old. Most of the participants were married (N=3), received at least a high school diploma or GED (N=4), and had experienced an infant death in the last five years (N=4). Table 1 displays participant characteristics.

A set of inclusion criteria which were determined through conversations with the KIDS Network based on knowledge of Black infant death characteristics in Kansas. The inclusion criteria for participants was as follows: women who identify racially as Black/African American, women between the ages 18-40 years, and women who have experienced perinatal or infant death in the last 8 years. Further, perinatal death and infant death were defined. Perinatal death was defined as infant death that occurs at least less than 28 days of age, and including fetal deaths with a stated period of gestation of 20 or more weeks (Barfield & Committee on Fetus and Newborn [CFN], 2011, p. 3). Infant death was defined as the death of a newborn infant at least more than 7 days old and no more than 364 days old (Barfield & CFN, 2011, p. 3).

Procedure

**Institutional Review Process.** The present study was approved by the executive director of the Kansas Infant death and Sudden Infant Death Syndrome Network of Kansas, Inc. (KIDS Network Inc.). The KIDS Network, Inc. functioned as an expert community research partner on

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\(^4\) Purposeful sampling refers to a strategy for deliberately selecting ‘information-rich’ individuals who have experienced a particular phenomenon (Creswell, 2007; Onwuegbuzie & Leech, 2007; Patton, 1990).
this research. This study was also approved by the Wichita State University Institutional Review Board (see Appendix A-D).

Participants’ privacy and confidentiality were protected in three ways. First, only three personnel (two KIDS Network staff members and the author) were authorized to correspond with participants. These personnel had access to participants’ names, phone numbers and/or email addresses during and after recruitment. Potential participants and participants were contacted using secure telephones and/or computers located at the KIDS Network, Inc. office. Second, each participant was assigned an identification number that was used to keep track of completed interviews and other documents. This identification number was also linked to identifying information (e.g., participants’ name, contact information) in a password protected database and used only for appointment scheduling and follow-up calls for member-checking. All identifying information was destroyed immediately after the completion of the study. Third, all documents and materials were stored in a locked file cabinet at the KIDS Network, Inc. office.

It was acknowledged that participants might experience emotional or psychological discomfort while discussing their experiences concerning infant death and/or other significant life experiences. Thus, participants were informed that a licensed bereavement specialist would be present at each interview session to provide emotional support if needed. At the end of the interview, there was also time allotted for personal reflection and the sharing of words of encouragement for other bereaved mothers. Participants were also provided informational materials from the KIDS Network, Inc.
Table 2.

**Demographic Characteristics of Study Participants**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Occupation</th>
<th>Education Level</th>
<th>Marital Status</th>
<th>Cause of Death</th>
<th>Year (most recent)</th>
<th>Total Number of Infant Deaths</th>
<th>Family History of Infant Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>28</td>
<td>Student</td>
<td>GED/HS Diploma</td>
<td>Never Married</td>
<td>Birth Defect</td>
<td>2012</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>Ruth</td>
<td>20</td>
<td>Student</td>
<td>Some College</td>
<td>Never Married</td>
<td>Stillbirth</td>
<td>2012</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>Debbie</td>
<td>21</td>
<td>Fast Food Crew Member</td>
<td>Less than High School</td>
<td>Married</td>
<td>Stillbirth/Miscarriages</td>
<td>2013</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Lisa</td>
<td>31</td>
<td>Human Services Professional</td>
<td>Master's Degree</td>
<td>Married</td>
<td>Disorder related to PTB/LBW</td>
<td>2006</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Tonya</td>
<td>36</td>
<td>Homeworker</td>
<td>Some College</td>
<td>Married</td>
<td>Miscarriage</td>
<td>2013</td>
<td>7</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Note: Participant Tonya had significantly more fetal deaths than other participants. Details of her experience suggest that there might be underlying biological factors (i.e., incompetent cervix, infertility) at play. Her data may skew the data some.

**Recruitment Process.** All participants were recruited by the KIDS Network Inc. who began contacting women who they thought might be interested in participating in the study. Recruitment flyers were also posted on bulletin boards at the KIDS Network Inc. offices as well as other community-based health agencies. After a list of potential participants was generated, the researcher made individual calls to the prospective participants to further explain the nature of the study, ask screening questions and schedule an interview session. Participants were asked to share information about the present study with any women they knew who might be interested in participating in the study; thus, remaining participants were recruited through this snowball sampling technique. Women were recruited for interviews until saturation was reached. Saturation, or the point where no new information emerges from additional data collection (Jones, Kriflik, & Zanko, 2005), was reached after five interviews.

**Description of Research Team and Training.** A research team was formed which consisted of four undergraduate student and four graduate students from the Behavioral Community Research and Action Team. One staff member from the KIDS Network, Inc. was
also a member of the coding team. Demographic descriptors of the research team are listed in Table 2. The team members attended an hour training session led by the lead author on transcribing and phenomenological data analysis. Team members met bi-weekly for ten weeks at the KIDS Network, Inc. office to discuss and analyze the data.

**Data Collection.** Semi-structured interviews were conducted either at the KIDS Network, Inc. office (N=2) or at the home of the participant (N=3). The average length of interviews was two hours and sixteen minutes. All interviews were recorded using a digital voice recorder. After signing a consent form, participants completed a short demographic questionnaire (see Appendix E).

At the start of each interview, the researcher provided participants with a large sheet of paper displaying a horizontal line which represented a ‘life timeline’. The researcher explained to participants that the timeline was a creative way to record important events in their lives. Participants were asked to use a marker to mark any major life event or transition that came to mind during the interview session. The topics discussed during interviews included early childhood experiences; preconception health, experiences during pregnancy, and experiences as a bereaved mother (see Appendix F).

**Data Analysis**

Data analysis for this study was two-fold: the analysis of the interview data and the analysis of participants’ life timelines.
Table 3

Demographic Characteristics of Research Team (including lead researcher)

<table>
<thead>
<tr>
<th>Team Roles</th>
<th></th>
<th>Total</th>
<th>N=6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coders</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transcribers</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>European American</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undergraduate Student</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate Student</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Master’s Level</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>KIDS Network</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff Member</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Phase I: Analysis of Interview Data.** After each interview session, audio recordings were transcribed by a member of the research team. The plan for analysis for the interview data was adapted from Moustakas’ (1994) method of phenomenological data analysis (See Figure 6 for a data analysis schema). First, the researcher read through each interview transcript and set of interview memos two to three times. The second step was what Moustakas (1994) calls *horizonalization of the data*. The researcher separated all irrelevant information from relevant information in the interview transcript. The researcher then extracted significant statements which reflected single, specific thoughts from the interview transcript. Third, the researcher re-read each significant statement and eliminated any repetitive statements. After step 3, the coding team was provided with the interview transcript and significant statements and was encouraged to memo (i.e., take in-depth notes) during this process. Step 4 consisted of the coding team
grouping the significant statements into meanings that depict what participants described as their lived experience. The fifth step of analysis was initiated after steps 1-4 were completed for all interview data. In this step, the coding team organized the formulated meanings into clusters of themes which were common to all of the participants’ descriptions. The final step of analysis involved using the clusters of themes to develop an overall description, or the essential invariant structure. The essential invariant structure is the central underlying meaning of the experience (Creswell, 2007) as provided by the participants. After the data analysis, the research team created a codebook which listed each theme and associated formulated meanings.

**Figure 6. Phase I: Analysis of interview data**

**Phase II: Analysis of Life Timelines.** The life timelines were analyzed in an effort to describe the shared life-course patterns that emerged from participants’ experiences. The analysis of the life timelines consisted of identifying shared life events and creating a visual representation of these life events in the form of a timeline.
The analysis plan for the life timelines was adapted from the work of Maltz and Mullany (2000) which suggests using visual representations particularly for qualitative data and to illustrate life-course patterns (see Figure 7 for a data analysis schema). After each interview session, the researcher took the life timelines and created a table. The first column included the description of the life event (e.g., loss insurance coverage, began smoking) (and any other memo notes) and the second column included the age at which the life event occurred. A table was generated for each participant.

The first step of analysis consisted of coders receiving a table for two participants to review. Second, the research team created codes for the life event data. In the third step, the research team identified which codes were present among most of the participants, and disregarded all other codes. The final step consisted of creating an aggregated life timeline that illustrated the number and timing of key life events for participants. The age from birth ascending to the time of the interview was graphed on a horizontal line and the major life event codes were placed along the timeline with arrows to indicate the age of occurrence.

Quality and Trustworthiness

In an effort to stay true to phenomenology, the researcher took three major steps to guarantee the trustworthiness and quality of the present study: bracketing, intercoder agreement and member checking.
Bracketing

One of the key features of phenomenology is its emphasis on challenging the researcher to be aware of her own prior experiences and knowledge in the face of studying the meaning of phenomena. The researcher should be intentional about separating herself from her own biases and attempt to understand the phenomena and the meanings associated with it as described by the persons who have experienced the phenomenon (Moustakas, 1994). Accordingly, the research used several strategies by which she (and her research team) could intentionally set aside her own views, expectations and experiences to fully understand the lived experiences of bereaved African American women (Moustakas, 1994; Creswell, 2007). The researcher used memoing to keep track of her ideas and reflections during the data collection and data analysis process. These memos were reviewed and the researcher made a deliberate effort to separate her
own views. During the data analysis process, the research team was given a journal to memo and to keep notes and to bracket out their expectations and prior knowledge.

**Intercoder Agreement**

The research team met bi-weekly to discuss and analyze the data. At the start of each meeting, members were reminded to memo and try to put themselves in the place of the participant to see the described experiences through their eyes rather than generate assumptions or premature interpretations based on their own prior experiences. Themes and meanings were discussed; and any disagreements were resolved through consultation with an expert qualitative researcher.

**Member Checking**

After the analysis of the interview data, three participants were contacted individually to verify the truthfulness of the findings and interpretations (Creswell, 2007). Participants were provided a member checking packet which included (a) a description of what member checking means and an example of what it might look like, (b) a list of themes, and (c) the essential invariant structure (see Carlson, 2010).
CHAPTER 4

RESULTS

Qualitative Interviews

A total of six in-depth interviews were conducted. The data from one interview however was not included in the final analysis of interviews due to a data recorder malfunction. Thus, data from five interview transcripts were analyzed. From these data, eight broad themes and twenty subthemes were identified. A summary of the eight themes are provided in Table 4 below. Finally, the essential, invariant structure was derived.

To protect the identity and privacy of participants, all names (including the names of doctors, clinical settings, neighborhoods) have been changed. As an added measure of confidentiality, the authors changed the gender of several of the participants’ children who were mentioned. Participant demographics can be found in Table 2 (p. 48).

Table 4.
Summary of Eight Broad Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Theme Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Early Childhood Context</td>
</tr>
<tr>
<td>2</td>
<td>Personal Relationships</td>
</tr>
<tr>
<td>3</td>
<td>Exposure to Multiple Sources of Stress</td>
</tr>
<tr>
<td>4</td>
<td>Maintenance of Mental Wellness</td>
</tr>
<tr>
<td>5</td>
<td>Sexual and Reproductive Health Experiences</td>
</tr>
<tr>
<td>6</td>
<td>Pregnancy Experiences</td>
</tr>
<tr>
<td>7</td>
<td>Health System Experiences</td>
</tr>
<tr>
<td>8</td>
<td>Exposure to Fetal/Infant Death</td>
</tr>
</tbody>
</table>
Theme 1: Early Childhood Context

The first theme, *Early Childhood Context*, consisted of two subthemes: family characteristics and neighborhood characteristics. This theme reveals participants experiences during childhood and adolescence. These experiences, which held great significance, included participants’ perceptions about the quality of their overall childhood, family dynamics, and the significance of certain neighborhood characteristics.

**Family Characteristics (Theme 1.1)**

Participants’ perceptions of the overall quality of their childhood experience varied. Some participants mentioned that their early childhood experiences were mostly positive:

“I tried to experience everything, I had a good childhood.”— Sarah, 28

“It’s funny because in my early childhood I thought it was awesome. Nothing major [happened in my childhood] everything was really good.”— Lisa, 31

Further, one participant indicated that bonding was a key aspect of her experience growing up with her family:

“So moving back into town my dad was there. I remember him being there more often and he had actually got a job sometime at [company]. Somewhere he had got a job in town and still life was good…playing games together, family night, sitting around the fireplace, watching The Little Mermaid because that’s what I wanted to watch. I’m the baby so I was spoiled”—Lisa 31

For several women, however, early childhood was perceived to be a challenging experience. There were mentions of participants feeling as though they ‘didn’t get to have a childhood’. Although, there were some mentions of familial relationships, their experiences tended to be characterized by having to assume adult roles and responsibilities at an early age, experiencing parental domestic violence and substance abuse, or experiencing challenges
associated with the disability of a family member. Two participants described their experience of having to assume adult roles at an early age:

“I don’t have much positive about my childhood. I didn’t get to really have a childhood, honestly. There was a role switch at age nine. I started taking care of my mom. She was diagnosed with bipolar disorder officially and disabled because of [her disorder]. The medication she was on and she was a drug addict, [she] shook, she couldn’t do much for herself so I was doing breakfast, lunch and dinner. And you know that was hard. My dad [was] in and out of jail or always working. It was one or the other.”—Debbie, 21

“I really didn’t have a lot of childhood really…I could run the house by the age of seven. I basically raised my little brothers and sisters because my mom was either always working or you know she just—I feel like she kind of became detached when I was younger, with all of us. It was overwhelming. It was a lot, like I had to grow up fast. I would honestly say [the reason for her detachment was] the men in her life. She was wanting to be with one guy, but you know that didn’t work out so she was with, you, whoever she was with. For a while I was kind of upset, you know? Because it’s like I kind of felt like my childhood was stolen from me. My positive is that it just made me more mature for other things so…But, don’t me wrong. Like, I did have a good childhood”—Ruth, 20

The experience of parental domestic violence and substance abuse was also described in detail:

“They [my parents] were always a physically, emotionally, verbally abusive couple, [and] towards everybody. They fought their entire relationship and they were married for twenty years.”—Debbie, 21

“[When] my mom and dad fell into their addictions, I know my aunt had taken care of me a couple of different times when we were homeless. There were two periods where I was homeless and actually in a homeless shelter. It was around eight to eleven years old when the homeless shelter [situation came about].”—Debbie, 21

“I came from an abusive home. My father was an alcoholic and mom always had to protect us so it was a little difficult growing up as a child and I am the oldest. So it was a little difficult.”—Tonya, 36

. Next, the following describes participants’ experience dealing with the disability of a family members and/or single parenthood:

“I was raised in a single parent home, just me, [my siblings], and my mom. I see my father every now and then.”—Ruth, 20
“They [childhood years] were still kind of tough because she was a single mom and she was disabled. Right before she left she was involved in a hit and run accident that paralyzed her for a year and she was able to start walking again then shortly after that is when she left but it was still kind of difficult you know as far as her being a single mother and raising us, our life was…… our life was better. We might not have been rich but life was definitely better and she did take good care of us with what she had”—Tonya, 36

“My mom went blind [when I was] eight years old…I take care of my sister and my mom”—Sarah, 28

**Neighborhood Characteristics (1.2)**

Most participants shared vivid stories that described the neighborhoods in which they lived as youth—which included both rural and urban areas. Overall, most participants described their neighborhoods as safe, enjoyable environments:

“We had a real country childhood. Every summer we should go down there [to grandma’s house]. We rolled ourselves in big tractor wheels and rolled down hills, my little cousins, they swam in the sewer line and would come home smelling like…[laughs]”—Sarah, 28

“I lived on the [southeast side] of town growing up. And then I lived on [neighborhood] with my grandmother. And then we lived on [Parkland street]. So it’s always been like a suburb. Like, I never lived in a project or anything. Sometimes it does get out of hand, but it’s not like to the point where you know, we have to stay under our windows or something like that. I honestly—I loved where I grew up because… I knew people. You know, we weren’t always kept in the house. We were honestly kicked out of the house…the dynamic was always fun it’s always been families on our block so it was never like you didn’t have kids to play with. You didn’t have people not to grow up with because it was always families and kids everywhere.”—Ruth, 20

“It was fun. Now as far back as I can remember we stayed on [Park Avenue] and I did not like that neighborhood it was terrible (laughs) then we moved to [the west side], that was a fun neighborhood….We had a lot of kids in the neighborhood and had these biker guys that had this big huge ramp they would ride all day and we would go watch them and play on it…so that was a fun neighborhood and then we moved to [west avenue], we had a lot of friends over there [too]”—Tonya, 36

**Theme 2: Personal Relationships**

The second theme, *Personal Relationships*, consisted of two subthemes: intimate partner relationships and familial relationships. Within this theme, participants described how strong
relationships with family or intimate partners (e.g., spouse, boyfriend) served as a source of stability and social support.

**Intimate Partner Relationships (2.1)**

Every participant shared that their current intimate partner relationships were important to them. Significant others and spouses were essentially viewed as a key source of support and stability for participants:

“He is very humble and he is very caring. He is a great husband. He’s stubborn at times, don’t get me wrong but he’s really attentive and caring and so that’s the best way for me to describe it. He’s a good guy.. Yes and being married to a decent man, a good man, that was important to me, I had had so much bad stuff in my life whether it was seeing what my dad did to my mom or what I had been through as a teenager and as a child, I just wanted something different”—Tonya, 36

“I think he [current boyfriend] was the reason why I didn’t just sit an mope around [when my infant passed away]...Yeah, he kept me going and....”—Sarah, 28

“Now that I have a boyfriend I’m more stable than when I—before I had a boyfriend. I was kind of just like [more willing to be involved with different men]. I did everything. I was just like ‘forget it lets go!’ And now that I’m with him, he’s been my stability. Since he’s older than me [he is thirty years old], he’s just like it’s okay to have fun but it’s okay to just chill sometimes too.”—Ruth, 20

“I’ve been ready to settle down since I was like fourteen, and when I met him [my husband who is seventeen years older than me], it kind of scared me because he asked to marry me like the second day we were together [laughs]. It’s a relief to find someone who does love me for who I am. It’s nice that he can still sit there and deal with me, because I’m a lot to deal with at the age of twenty-one, sadly. But, it’s definitely a big relief. It kind of helped me find myself because finally I got something that really was important to me and made such a difference….yeah we make a great team. Family, or friends, otherwise, this is my best relationship.”—Debbie, 21

[My husband] is an awesome guy. It is very significant because he’s not my daddy but I put him on the level because like I said my father is a hard-working man. He knows what to do. He is all about security for his family.”—Lisa, 31

**Familial Relationships (2.2)**

Most participants indicated that they had close relationships with their family members.
In many cases, participants’ reported that their social life was spent primarily with their first cousins:

“It was only all family…my mom is my best friend. It was all cousins [we are all very close and they mean a lot to me].”—Sarah, 28

“I’m more of a family person, so I’m more around my family. So you know we’re a really tight knit family like we still get together on holidays or we still call each other on birthdays. You know there is never a year that goes by that I don’t hear from my all family. You know it might not be all of them at once but just sporadically throughout the year.”—Ruth, 20

“Family. I really, really enjoy family, friends--. I was talking to a friend earlier it’s like I really cherish and appreciate my friendships so I don’t have a lot and so if I let you into that little circle you are truly important to me. My husband has taught me even more about appreciating family and being there so--.”—Lisa, 31

“My family, my spiritual life, having balance in my life, those things are important to me.”—Tonya, 36

When asked what family means to her, one participant (Lisa, 31) said, “acceptance, I guess. That is the only word I can come up with…feeling like I had a family… [our family] did not have those kinds of issues. They had issues, of course, but not like that.” Among participants who did not have close relationships, it was mentioned that close familial relationships was something that they felt was important. One participant who mentioned that she “didn’t have much” of a family explained that:

“[Growing up with family dysfunction was] devastating. Even [with] all of the negative I can say about them. Family time was always…I was raised that it [family] was very important.”—Debbie, 21

In addition, relationships with prominent matriarchs within the family were significant and meaningful for most of the participants. Other participants mentioned briefly living with their grandmothers at some point. Grandmothers, in particular, represented family, warmth, and safety:
“She was a sweet old grandmamma that everybody wants. She fed a lot of fruit, that was my favorite pastime between her and I. She always included me in cooking and holidays and she liked to play with me. Just the aura she had, just made a big difference, how I felt about her compared to other people in the family… I mean compared to my other family members, she was just there for me.”—Debbie, 21

“I had a grandma and she was like old school…I got to live with her so I was really close with her.. She was like Madea for real with the pistol in her bag..nobody wanted to mess with her. She would curse the whole town out but still feed them. She was a real sweet lady. She was just a very up-front woman...and she was very family oriented. I called her mom as well. She was like always with me and my mom all the time. I always felt like I was the favorite grandchild”—Sarah, 28

“…..and I remember I think it was my grandmother that gave me the lesson when you walk in somebody’s house you always say ‘Hi”—Lisa, 31

Overall, the role of familial relationships was salient in participants’ lives. Further, for several participants, family members served as a trusted source of information. Family appraisals of physicians, for example, appeared to influence participants’ attitudes and decisions about health providers.

In describing her dissatisfaction with a physician during her first well-woman visit, one participant (Sarah, 28) followed up by saying, “but, she was a good doctor…everybody [referring to family members and elders] say she’s good.” In a later conversation about her concern for her current physicians’ competence, she added that “everybody says he’s good. All of the [elders] that I talk to…” Similarly, another participant (Lisa,31) discussed her physician and stated, “he’s seen my mom, my grandmother and all this kind of stuff, so we kind of grew up with him. [His] medical care, he was awesome. He was very wonderful.” A third participant (Tonya, 36) indicated that, “Most of the doctors that I found out about were through friends and family or people that had personal experiences with them.” She expressed some regret, however, with regard to her decision to change doctors based on advice from a trusted source:

“When I got pregnant with my first baby I was still seeing doctor [my first doctor] but I allowed somebody to convince me, “you need a woman doctor, you need a woman
doctor” because he was a male, but he was so good and he had been with me all that time so I sat him down in his office one day, he did my first exam and I told him I was going to switching doctors because I wanted a woman doctor and he put his head down like he was about to cry and I felt so bad but I was like I need a woman doctor. When I got with her, I did not like her, she was terrible to me.”—Tonya, 36

**Theme 3: Exposure to Multiple Sources of Stress**

*Exposure to Multiple Sources of Stress* was the third theme which consisted of four subthemes. Participants reported experiencing some or all of the four categories of stressors during early childhood, the pre-conceptional period, during pregnancy and during the post-partum period. For instance, one participant expressed her feelings about the presence of stress during her pregnancy and what that may have meant for her pregnancy outcome:

“A lot of stress played a big part and you know there was a—each of those websites for reasons for miscarriage and stress can be one of them. Now I asked my doctor but I don’t really trust it. He said it can play a part in it but it usually doesn’t actually cause a miscarriage unless it’s a significant amount. Which to me, I considered where I was at, a pretty significant amount. So you know that could have been [a factor in my pregnancy].”—Debbie, 21

**Familial Stressors (3.1)**

Within the first subtheme, participants described experiencing stress associated with conflict with or among family members. One participant (Debbie, 21) described her experiences with stress prior to her pregnancy and during her pregnancy. Prejudicial attitudes from her in-laws about her race, age and competence were sources of stress:

“You know, when my husband and I first got together, I was ‘too young’, [and] color was a big deal. That wasn’t blatantly said, but [he] never really brought any dark color in the home. Well his first wife was Mexican and White, but [she] looked more White than anything. But, color, and age difference—we are seventeen years apart… I’m only twenty-one and he’s thirty-eight. So, they thought I was stupid because of that.”—Debbie, 21

“I mean I can say there was lots of stress. His parents [definitely made my pregnancy difficult and stressful]. I think maybe if we still had the kids and his parents weren’t part of [our lives], it wouldn’t have been such a problem. [My husband ] told me that his mom badgered his first wife with his second child, and you know she came out with slight
disabilities that you can semi tell. So, you know we think that played a part into it. You badger a mom when she is pregnant with a child there are things that could happen. I mean if alcohol and smoking affects it, so can anything causing chemical [changes] in the brain. But, you know definitely stress is a big deal.”—Debbie, 21

Another participant (Tonya, 36) described the strained relationship with her alcoholic father. She shared that he has suffered with addiction over the course of her life, and that he continuously tries to re-enter her and her mother’s lives:

“Yes [he has tried to reenter my life], I want to say he is sober now but that wouldn’t be true. He has relapsed and is not how he used to be. He is back on doing medication which is not good and marijuana, which is not good and he is still drinking. He doesn’t do it every day but he does it periodically, which is not healthy for him at all because he has such a bad history of drugs and alcohol. So, I mean I tolerate him, I don’t go around him a lot. I call him to check on him and stuff like that and I love the mess out of my father but I don’t like to see him like that, it’s pretty painful….I’ve never really just said you know what I need to step away from you, I just did. When he was out there doing whatever I just didn’t tolerate him because he was violent. So, okay I’m just not going to talk to you. When he got sober he would call and apologize, the anger would be towards me too , he would really flip. I think it was some years ago, he really had a bad relapse and he would just curse me out. [He would] call me all kinds of names and I told him to not call me ever again. [I said to him] ‘I don’t want to talk to you, you need to get help.’ So, he was gone a good year, he called saying sorry and that he got help and this is what happened—same story”—Tonya, 36

A participant named Lisa (31) described a culmination of stressors (during her pregnancies) that she felt may be related to her ambivalent relationship with her father and her need to maintain a certain image in an effort to please him. She also alludes to her heavy work schedule and the stress associated with competing on the job (which she believes stems back to her father’s expectations):

“I think that I didn’t pay attention to it [stress] as much as I probably could have or should have, but, yes there was quite a bit of stress going on. I worked a lot. There were issues going on between me and my husband that I was not so much in tuned with. It was a lot of stress and then stress of still maintaining this good girl image or whatever. I remember the singer Brandy did a special delivery [television special] and then the story came out later that that was all a hoax because she wanted to keep this image. I can relate to that because even with my father making that statement of ‘Are you living your life right?’ [in response to my losing my first twin] and so I was kind of like ‘oh no, I’m not okay’ so that just—and then he is my dad—going back to values: ‘hard work you don’t get nothing for free’. You're going to work for it. So I [have] never had a blue color job
because I’m lazy-ish [laughter]. I can’t work that way but every job I had, I had a personal competition with everybody to be the best one there.”—Lisa, 31

**Financial Stressors (3.2)**

Within the second subtheme, financial stressors, participants shared that they experienced a significant amount of financial stress prior to pregnancy, during pregnancy and during the post-partum period. One participant articulated that financial struggles were ongoing, persistent and created disruptions in daily life:

“[During my first pregnancy], we were having financial difficulty, which in turn affected [my step-children]. Before I came into the picture [with my husband’s two children], they were eating microwave dinners, no complete meals or anything. So, when I got into the picture I started actually making meals…so that was more costly, so we needed more money. There wasn’t a lot of food going around. I was pregnant at the time and I didn’t eat any more than I was eating beforehand, and of course I was still gaining weight because the baby was obviously taking whatever. We actually had [social services] cases against us. We got pinned for ‘physical neglect’ as far as food and stuff like that. It was the fact that a bowl of cereal in the morning, easy mac in the afternoon and ramen noodles at night wasn’t sufficient (the cases were later dismissed). And you know [I’m thinking to myself] mentally, I’m not stable for this, with hormones from pregnancy, freaking out about finances, freaking out about [two step children] that I need to take care of, I couldn’t do it…and that was our point for the adoption… There was a lot of stress. Period. Financially. During all of my pregnancies, the girls were with us. I praise these women that have two and three kids and they’re pregnant again. I don’t know what they’re doing, but I salute you. I had issues. But, you know that was a lot of it.”—Debbie, 21

Participants also experienced stress associated with the affordability of medical services during and after pregnancy, and issues with general insurance coverage. Most participants reported having coverage during their pregnancy—regardless of private or public insurance. There were still concerns, however, about the affordability of co-payments during prenatal visits, the cost of preventative medical procedures, and the cost of securing medical insurance coverage. One participant describes her endless anxiety about the cost of medical services:

“[With my first pregnancy with the twins, I was thinking]… I have wonderful insurance but truly how am I going to pay these bills? So there were times that I wouldn’t set an appointment because I’m like I can’t afford it and so my doctor was like can you make
that appointment for her? So before I left to the office he was like I understand you can’t but I really need you because I need you to be well we need to make sure so he would make --. He would have someone make the appointment before I left.”—Lisa, 31

“[With my third pregnancy and the complications that arose, I thought to myself] ‘Who’s going to pay for this?’ because my insurance was even worse than before [through my employer]. They [the doctor’s office] had a new system where they call your insurance company and find out how much they’ll pay and your portion. And so, I was paying almost two hundred dollars every time I came to my doctor because that was what the arrangement was. [I remember] before each doctor’s appointment, [I asked my husband], ‘do we have the money? Can we pay this?’ This sucked and so it pissed me off… and the stress of us having to move this [money] around [for expenses].”—Lisa, 31

Debbie (21) mentioned that she doesn’t currently have health insurance through her job. She has worked as a restaurant server and currently works as a McDonalds crew member. She was worried about her financial struggles, the upcoming Affordable Care Act mandates and what that means for her:

“Yeah, I don’t [currently] have insurance. A lot of jobs won’t offer insurance…when I worked at [restaurant] as a server they were going to offer insurance until they realized what the actual premiums were and they were like, ‘no, that doesn’t work for use’. I mean we’re servers, [making] $2.13 an hour plus tips.”—Debbie, 21

“Then, you know come tax time, if you don’t have insurance by January 1st, they are taking thousands of dollars. I will not have insurance. Even [social service agency] doesn’t count as insurance-it’s just a donation. So, why should I have to be fined for something I can’t even afford in the first place! Even if you go to [insurance company] for a very simple insurance plan, it’s a five hundred dollar deal.. I know that someone who is over the maximum limit for state insurance can’t afford the actual insurance that you have to pay a premium for. You’re stuck in between making too much for state insurance and not enough for regular. [It’s a ] ‘you pay it out of your own pocket’ deal. People can’t afford six hundred dollar ER visits!”—Debbie, 21

**Partner-Related Stressors (3.3)**

In the third subtheme, partner-related stressors, participants identified a number of experiences with their husbands and intimate partners which caused a significant amount of stress prior to pregnancy and during pregnancy. The majority of participants mentioned that they had experienced intimate partner abuse or violence in the past. In these cases, the abusive
relationship occurred during participants preconception period, and tended to occur when
participants were younger in age:

“William was my first boyfriend—first love. He was older [twenty-three]. He was out of
high school. I was thirteen. My mom didn’t like the fact that he was older than me. No
one really liked the fact that he was older than me and then he already had a past. He was
[known for being] a womanizer. He, you know, he was an older guy that liked to date
younger girls. He was very mentally abusive. Like he would kind of play with words.
You know if there was something that I did that he didn’t like he would play with words
to kind of make me feel like I shouldn’t have done that. You know or I’m not going to do
that like; there were many things I missed my sophomore year because if he told me not
to go I wouldn’t go.” —Ruth, 20

“When I was] about twenty-three [or] twenty-four...that was my first time I moved out, so
then we [boyfriend at the time] moved in together… I want to say within the week I had
went to jail because we had got into it…you talk about domestic violence and it’s
happened so suddenly you don’t even know when you’re in it because I used to be one of
those ‘oh that would never happen to me blah blah blah’ yeah shut up Lisa’, so like I said
I went to jail. That [time] was hella stressful.”—Lisa, 31

Other partner related-stressors were related to concerns about paternity or conflict with
the father of the baby. This experience was most salient among participants who were not
married:

“[When I first found out that I was pregnant]….me and the dad—we weren’t really
together and he was already in a relationship. [Beforehand] we were like best friends and
then everything hit the fan. He wasn’t claiming that he messed with me. It was hard
because I had his baby mama calling me trying to be ‘friends’. She’s like ‘well, we’re
still together and yadda yadda this and that’. I said, ‘I do apologize but its late, I love him
and we’ve been messing around since I was eighteen and I was twenty-six at the time…
and you know it was just a whole bunch of stuff.”—Sarah, 28

“[At eighteen] there was a point when I got pregnant. Yeah, I was doing a lot [multiple
sexual partners]. At the time I had three runner-ups on who the daddy [of my child] could
be. And I was just like, ‘I don’t know’. William [old boyfriend] was one of them and he
was married. It was just like ‘argh, this is really bad’. [It was] very stressful. [Once I
received more information from the sonogram], eventually he [William] got X’ed out and
he was not the dad. And then the other guy was not the dad. [The father was her current
boyfriend/high school sweetheart and when he found out he was very upset and broke up
with her].” —Ruth, 20

“The person that stressed me out was my high school sweetheart David. [We] met my
junior year. He was also my fiancé. Yeah, he was my stressor throughout my whole
pregnancy, up to the point of the memorial and a little bit after. [We had broken up] but, I wanted to get back with him because, you know, the baby was going to be by him, maybe we could work it out, [maybe] the baby was going to bring us back together. Yeah, that didn’t work out but, he stressed me out to ‘what her name was going to be’ to where she was going to live. I was just like, she’s not even born yet!”

In addition, one participant shared her experiences with spousal infidelity which she described as a ‘hurtful’ and ‘stressful’ time:

“We [my husband and I] got together [when I was] twenty-five or twenty-six. In [2009], he told me he cheated on me. I knew something was wrong before then, however I couldn’t put anything together. I saw text messages he explained them away or got defensive and I didn’t want to get into an argument about it...we had actually just got to a good place probably after Josh [third child] was born... I was mad at him because it [the affair] was going on during the pregnancy with [first pregnancy, my twins, Peter and unnamed child who later died] and I was like ‘even with everything going on this is what you’re going to do!’ . I was angry, hurt, mad…and it was crazy because I felt like I reacted more to that than I did losing [my twins]...it was hard because I didn’t want to tell anybody about it.”—Lisa, 31

“When I was pregnant with Josh [third child], there was another incident where I had a little too much time on my hands so I started going through our phone records and I kept seeing this number pop up and so I called it…and it was a girl and I just hung up, and then I called him and I went off. At that point I didn’t care. So he explained what had happened and I was like ‘I don’t need you. I don’t need this. So if this is what you want to do take your mess and go. I’ve got a family that loves me. I don’t need you.’ I had this calming feeling over me like it’s going to be okay. I was like okay because I was upset, I was crying and I think I was four or five months pregnant… So that was another stress in there as well. [I was like] you are choosing the wrong time homie, you could have waited a year or two ago, so this is not the right time to deal with this!”—Lisa, 31

**Trauma-Related Stressors (3.4)**

The experience of trauma was significant for participants; particularly those who openly acknowledged the effects that trauma may have had on their well-being or health behaviors.

Although participants’ experience of trauma varied, those experiences significantly impacted their lives afterwards.

Participants described their experiences with the death or disability of a close member early in life. Tonya (36) shared that the disability of her mother (due to a hit and run accident) was a challenging experience as a young girl. She also shared an emotional memory of her
experience with the death of her younger cousin and the subsequent impact that it had on her and her family members:

“No [I never received any help] because I didn’t know at the time that’s [panic attacks] what it was. I didn’t know until I became an adult and started having my miscarriages, that’s what I was having as a child, was panic attacks and that was brought on when my cousin died. He and my brother were playing [near] the stove, and the hot grease fell over. I think they were trying to get a cup or something and the stove fell over, it missed my little brother but it fell on my little cousin….and he died in the hospital a few days later...I think i was seven or eight at the time…I saw all the after affects…yes, I remember that. [It was] terrible because we had the funeral, then my aunt tried to kill herself in our home…it was just terrible.”—Tonya, 36

Other participants, such as Sarah (28), did not articulate any connections that they felt linked their experience of trauma and current health outcomes. Their experience, however, did make a significant and memorable impact in their lives at the time.

“My mom [went] blind when I was eight years old, and then the death of my grandma [when I was seventeen]. At thirteen years old, [my] eleven year old cousin died [from complications related to lack of oxygen to brain]. It was shocking because she was the first death we had in our family, she passed before my grandmother”—Sarah, 28

The stressful impact of parental domestic violence and substance abuse on mental and physical well-being was noted by some participants:

“I really haven’t a good sleep pattern for years and that started way before all that happened, I mean even as a kid that was a problem. I used to be scared to go to sleep because I used to think my dad would come home and there was going to be a problem. So that was always an issue…I think I just dealt with it, you know I really didn’t understand what all of that meant back then and I did have panic attacks as a kid, real bad”—Tonya, 36

One participant, Debbie (21) described how her parents struggled with psychiatric disorders, substance abuse and domestic violence. At age eight, she had to move into a homeless shelter, and remained homeless until eleven years old. Her mother was also diagnosed with biopolar disorder:

“At the age of four I had several things happen. The age of four I actually remember very vividly because so much did happen. Let’s see first come around four or five. My mother had cut me with a meat cleaver or a butcher knife. [clears throat]. It left a pretty hefty scar on my fingers. It wasn't on purpose or anything but it was significant to me. It’s always been
significant to me. And then also in that same time frame she cut my dad’s eye right above, just right in here on that bone, above the eye socket. She cut him and it almost killed him. It almost made him go blind and things like that because they were fighting.”—Debbie, 21

“I disliked] him [my father] and my mom getting back together. My mom was doing so well without him. She'd been clean almost that entire time [that he was incarcerated], from drugs, from the age of fifteen to seventeen. She and I were [living] in a [halfway] house for women. And she had [been] released during that time. They kicked her out. And I had told her when she started if she was going to do this again then I was moving out and I was moving in with dad. Even though that was not something I wanted. I found out she relapsed and I said you just lost me ‘bye’. So, I had moved in with dad right after that and that did not work out.”—Debbie, 21

The experience of sexual assault was one of the most salient trauma-related stressors described by participants. Every woman indicated that their assailant was someone that they knew personally. Some women disclosed that they had been sexually assaulted on more than one occasion. As will be discussed in theme 5, one participant discussed her risky sexual behaviors and reproductive health experiences in the context of her sexual assault history. Within this subtheme, participants allude to the subsequent impacts that sexual assault had on their sexuality and health behaviors:

“My biggest traumatic thing is, I was molested in kindergarten or first grade. It didn’t really dawn on me…until I got to high school. My mom didn’t find out that I was molested until I was in the hospital checking up on my daughter.”—Ruth, 20

“[My junior year of high school], I got raped. We were interested in each other. So like you know we would hang out every now and then. And we had sex on one encounter, then I was kind of just like no, this is not really going anywhere this is a waste of time. Like I said his friends lived down the street from me. And I remember it. Like I went--. My mom sent me to go to the store. And at the time we had those. Oh shit. Oh man oh man....: I was getting ready to get out and he came through the back side of the door and I was in the front and he pulled me to the back of the van and he raped me in that van. And I remember I just went in [my home] and I just took like the most scorching shower.”—Ruth, 20

“Because I was molested by a girl and a boy… then…it was kind of a tug-of-war with my sexuality. I didn’t know if I liked girls or if I like boys—but to like girls was a sin. So you know it was just kind of back and forth.”—Ruth, 20

“I was pretty good and then once seven hit I started socializing with neighborhood kids and I got a hold of a teenager. At that time I was in the state [custody]. She was doing bad things like drugs and stuff like that and she and I like to play house. And I was always boyfriend
and she was always girlfriend. At that point there was sexual molestation and stuff like that. So, at that point I also found more feelings towards women. I was raped at the age of ten. I didn’t come out and say anything until I was fourteen.....And that was actually a man.”—Debbie, 21

“I think when I write a lot of things down there is a lot of negativity that I like to put down on paper. I’ve been positive. I tend to put down a lot of negative items. I just look at it like sexual molestation, sort of questioning myself, taking pills from mom, homeless, rape, I mean just yeah. I kind of see a fiery pit of life and I prefer it to be different.”—Debbie, 21

“Then there was a gentlemen [from my church] I went down to his home and.. he actually raped me because I didn’t want that and he forced himself upon me and i got another sexually transmitted disease and this was all within the same year. [I drank to cope] because again alcohol is in my home and I had been introduced to that at a young age…after that happened, that’s what I did, I just drank…”—Tonya, 36

Theme 4: Maintenance of Mental Wellness

The fourth theme, Maintenance of Personal Health and Wellness, consists of two subthemes: faith/spirituality and mental wellness practices. This theme describes participants’ desire for establishing and maintaining personal wellness in the midst of “stressful” social environments.

Faith/Spirituality (4.1)

Participants described how spiritual grounding was important for their overall wellbeing. Their spirituality or belief in God was essential for meaning-making in their lives:

“So I guess going back to what’s important to me values, my spirituality I do have a strong faith in God that everything happens for a reason.”—Lisa, 31

“I mean even though I don’t go to church, I still pray. I thank God for everything…the day…what happens throughout the day…what happens to my life. It [being a Christian] keeps a positive attitude and it keeps you strong, just knowing that there is someone [up] there to look over you, other than you know, your family members.”—Sarah, 28

Mental Wellness Strategies (4.2)

Participants described several strategies or practices that they employed to maintain balance and stability in their lives. Other women discussed the importance for having a certain mindset that is helpful for them in the face of adversity:
“Just having a stable life when I do have this baby…having a career [is all important to me]”—Sarah, 28

“I don’t want to be brought down. I’d rather raise myself up as much as possible. Just that little bit…I don’t care if it’s an eighth of an inch.”—Debbie, 21

“Yeah, right, well I've just recently started taking what I call a mommy day where I go get my nails done or I go to the movies. I go sit at Starbucks and grade papers. But just having some, truly some me time because really outside of that it is my family [laughter]”—Lisa, 31

“You know, I’m really big on keeping my life peaceful, for however long that lasts. And then there is you know, myself. I have been more focused lately on what makes me happy. I used to be a people pleaser. So I didn’t want to make anybody mad or upset and I didn’t want to start any confrontation even though it was either a burden on me or you know I didn’t really want to do it, but I did it anyways. So I have been more focused on just…you know…me. I’ve taken many mental health days. So if I go away for a day it’s because I’m focusing on just making sure that I’m okay before I make sure everybody else is okay.”—Ruth, 20

**Theme 5: Sexual and Reproductive Health Experiences**

The fifth theme, *Sexual and Reproductive Health Experiences*, consists of two subtheme: sexual health experience and behavior and reproductive health experiences. Some similarities and differences emerged with participants’ sexual and reproductive health experiences. Most of the experiences discussed occurred during early and middle adolescence.

**Sexual Health Experience and Behavior (5.1)**

The majority of participants shared that they had engaged in early sexual intercourse, and some expressed regrets about initiating sexual activity so young:

“I lost my virginity at twelve. So, that wasn’t good…because I was too young and had no business…so you know, it just wasn’t a good thing to do or experience either… and then I became very sexual active at fifteen”—Tonya, 36

“You know I had been in a relationship with someone else which you know I found out later was really more for the sexual aspect because we were both each other’s first partners. So we kinda just stuck together just because of that and we were afraid to venture off…I was sixteen when I met him. We met in the mental hospital.”—Debbie, 21

“I kind of wish I would have waited a little longer…I lost my virginity when I was sixteen.”—Sarah, 28
Parents and peers served as sources of information about sex and sexual health. Some participants described how they appreciated that their mothers discussed sexual health topics with them. Other women, whose parents did not engage in sex discussions with them, shared that they wished their parents would have engaged in those conversations. Some of them felt that perhaps they may not have begun having sex as early:

“My mom didn’t hide anything from me and she talked to me. I know a lot of girls that said their parents didn’t talk to them about their periods or you know, how a guy should treat you. My mom pretty much kept it real. This how it’s going to be, this how you got to be. So it means a lot now.”—Sarah, 28

“Yeah, like my mom talked…..about sex early [laughter] to the point where it’s just like, ‘I do not want to know that! Come on, couldn’t I just be a kid?’”—Ruth, 20

“I did start asking my mom, you know concerning sexual questions at the age of nine or ten.”—Debbie, 21

“Well like I said my father was into emitting fear. [He would say]’If you’re going to have sex you come have it in front of me and I’ll tell you if you're doing it right’. And so were like….My parents didn’t [have sex conversations] with me.”—Lisa, 31

“If somebody truly sat down with me and talked to me about why it would have been better to wait to have sex and all of the emotions that go with it and what I was giving of myself, I would have had a better understanding and probably would have waited, and it wouldn’t have happened in the sixth grade and all that.”—Lisa, 31

“My mom was the type of mom that didn’t like to talk about sex so I was getting all that bad advice from my friends at school, and I asked her questions and she would be like, “what are you doing, no you can’t do that”, and I’m just like, ‘mom, I just want to know, I’m having all of these weird feelings and I just want to know what to do!’”—Tonya, 36

Participants also appeared to learn vicariously through their peers. Some participants mentioned that seeing their peers’ experiences with unsafe sex and sexually transmitted diseases served as a motivator for safe sex practices:

“Sometimes…taking my friends to the doctor and they were having to get warts burned off or have herpes and all that, you know. And, I’m like I don’t want none of that!”—Sarah, 28
One participant shared that she did use some form of contraception as a method of protection from contracting sexually transmitted infections:

[Early sexual activity], at least I had condoms. I’m bad with pills. But, I never got pregnant so, something was working. [I used] condoms because I was very leery about people.”—Sarah

Other participants indicated that they engaged in high levels of risky sexual activity, and several described their experience with contracting sexually transmitted infections from their sexual partners:

“I became really sexually active at fifteen and that was what I considered my first boyfriend, and that was not a good situation at all because he was sexually active with a whole bunch of other females. So, I ended up getting a sexually transmitted disease. I found out…that was devastating because I had never had one before in my life—ever. I’m like “what?!”. So, of course my feelings were hurt, so once I got over that [the sexually transmitted infection], I started sleeping with multiple people just because…being stupid (and I don’t mind sharing because I’ve talked to people about it and tell them not to do what I did).”—Tonya, 36

“[When I contracted the sexually transmitted infection] my mom is the one that knew because of the disease I had. I’m like ‘mom, something doesn’t feel right down there’ and she’s like, ‘well do XYZ, this is what you have to do’. It was a bad experience.”—Tonya 36

“I guess there’s that double standard again. Going back to men can do one thing and women can do another thing. Amongst what I found out [about myself] was I enjoy sex so probably that’s what I was doing in high school. My friends were smoking weed, they didn’t know I was having sex [and] I didn’t know they were smoking weed. I would have probably --. Okay were going to do Sex in the City. I was probably Carrie of having sex. Samantha was extreme and I had some friends that were extreme. However I was not as prudish or conservative as Charlotte or Miranda so probably Carrie but also I was more relationship based too so it was a guy that we were dating even though it might not have been on the long term.”—Lisa, 31

“[I] never had an STD however I did get crabs [pubic lice] but I don’t think that was from the sex. I wasn’t having sex at the time so I was like, ‘what the hell is this about? I don’t appreciate it’ so that was the worst outside of getting pregnant. Because I remember one time trusting this guy taught me a valuable lesson. Don’t trust him because I knew he had condoms probably three out of five times he would not use it. I never ended up pregnant so that was a blessing all together. Didn’t end up pregnant didn’t end up with anything as well but he taught me don’t trust him because I saw it come out I knew it.”—Lisa, 31
“I contracted a sexually transmitted disease—herpes simplex virus II—at the age of seventeen or eighteen. I had several tests. My first blood test was when I noticed the break out, and it came back negative. [The] second test (I got regular testing when I was having different partners. You’re not supposed to do that anyways even though you’re not supposed to have different partners), anyways, I got tested in between times and-negative. I didn’t find out until my second pregnancy, [that I had herpes]. [I think] it was dormant since I was seventeen or eighteen, because they told me I was negative each time [although During my second pregnancy, one sore came up and I asked [my doctor], and he said, ‘well, that looks like herpes’ and they tested me and sure enough positive.”—Debbie, 21

“I did find out that when David [ex-fiancé, father of baby] was cheating on me he had developed herpes. And he gave me herpes…I went and got checked before I found out that I was pregnant. And I was clear, clean as a whistle.”—Ruth, 20

One participant described her high levels of risky sexual experiences in the context of prior sexual assault:

“I you know, I lost my virginity at a very early age thinking that is you know, that was connected with it [molestation]”—Ruth, 20

“I will say [that] I had a lot of boyfriends [that I was sexually active with]. So, I think that was another way to get past it [the experience of sexual assault] is being around guys. Because that was the only way that it made sense to me. So like, I censored sex with love. So that was the only way that I understood it, until, you know, as I got older [I realized] that love isn’t always about sex.”—Ruth, 20

**Reproductive Health Experiences (5.2)**

Participants described their reproductive health experiences and reproductive health care utilization. With regard to reproductive health, one participant described her experience of menstruation and how she feels it was connected to her history of sexual assault:

“Eight is when I started my cycle. I started my period early. And from research [I found out that], because I was molested at a very—at younger age. Like a lot of my friends didn’t start until they were twelve, and ten. I had one friend that didn’t start until she was sixteen. I started at eight.” Ruth, 20

Similar to other participants’ descriptions of parental involvement in discussing sexual health information, participants did mention parental involvement in topics about reproductive health:
“And so like she told me about, you know, everything that was going to happen and you were going to have cramps, and you know these are the utensils that you use when you start your period, you know everybody prefer--. You know somebody might prefer a pad over a tampon. At that age I was not using the tampon. She was just like, ‘No you use a pad’. So it was kind of just like when I started—I was thankful that I started at home.” – Ruth, 20

Other experiences included having reproductive health problems at an early age:

“I’ve had a lot of actual physical symptoms with my uterus. I’ve had three Dilation and Curettage (D&C) procedures. I have two separate issues with children: my birthing [and] my carrying of babies…and then the third one which is the incompetent cervix is what they think…and now that I have issues after the D&C its going to be hard.”—Debbie, 21

“I understood for the most part how everything works, I just didn’t really understand the whole abnormal cells situation [physician discovered abnormal cells on cervix at age fifteen] at the time and what it meant for me as an adult trying to carry a child. I had no idea, but i did understand how my reproductive organs worked and all that stuff.” — Tonya, 36

With regard to reproductive health care utilization, every participant mentioned that they received well-woman care at an early age and regularly. Well-woman care was also viewed as important for preventative reasons and as an important part of maintaining health:

“When I was sixteen [I got my first well-woman check-up]. [It’s important] and I mean it’s probably every women’s major [thing to do].”—Sarah, 28

“When I lost my virginity [at seventeen] I started getting them [well-woman visits]. Typically, I went in like twice a year, especially after I started switching partners. This year, I’ve had six [visits]. So, I’m good.”—Debbie, 21

“Yeah, I would always get my [well-woman] check-ups.”—Lisa, 31

“I was fifteen [when I had my first well-woman visit] and they discovered some abnormal cells on my cervix. So at age fifteen, I had to have them frozen off, so that was my first exam. It wasn’t a good [experience], it didn’t feel too good. I was happy they were able to do what they were able to do, you had your pain, and recover for a day or two, it was fine after that……[it] was recommended that I come back every year and that’s what I’ve done since then.”—Tonya, 36

Some participants described their experience and concerns with hormonal contraceptives. They explained that after educating themselves about certain contraceptives, they were more aware of the potential negative side effects and how they might potentially affect their health:
“When we start trying to have kids [after] we got married, I’m thinking [to myself] ‘okay now it should happen’ and it didn’t. I had the Depo-Provera shot and I went to the doctor and got off of it and it took almost a year to get pregnant. That was when I started having to face it. I didn’t know at the time that they were all connected.”—Tonya, 36

“I didn’t start gaining weight until after I got on birth control and I want to say that was high school the end of high school my senior year and it was literally I went from that ten to a twenty in a year. In a year two year time frame…Oh, evil birth control…And my doctor he was like ‘Oh no’ and then I’m like I’m not crazy. I’m not...”—Lisa, 31

“When I was twelve, I started birth control for acne. Then, when I hit sixteen or seventeen, I started Depo-Provera ….up until eighteen, and I didn’t get pregnant until a year later….which could have played a part in my miscarriage. Depo-Provera has a lot of side effects and it takes a while to get out of your system—the average [time] is up to a year.”—Debbie, 21

One participant shared her experience with having two abortions. She shared that she viewed abortion just as any other method of family planning. Her decision to get the abortions was a personal choice, which for her meant, a choice to be responsible. She mentions that the contexts in which she made her decisions are important to understand:

“I was seventeen. My senior year [of high school] it was me and [my now husband], and I ended up having an abortion. I was about nine weeks when I had that abortion. It was interesting because it was a relief after I had it done. There was a time when me and [my now husband] were making plans….but I leaned towards the more negative side of not having a life and not going to college, struggling and things of that nature, so I had the abortion and it was just kind of like- I didn’t feel bad [about it].”—Lisa, 31

“When I was twenty-three or twenty-four, [I had a boyfriend] and while we were together, I got pregnant again, and I had another abortion. It was my—it was a choice that I made. I was ready to live this life. My brother called me and said ‘I’m going to give you the money…Do you really want to be attached to this personal for the rest of your life?’ The reason why they asked that is because I had gone to jail, we had got into an argument and it was volatile—we were fighting. He bust my lip. I tried to stab him and somebody called the police because they saw me chasing him with a knife. So, he asked me that, and I was like ‘no’. I went ahead and took advantage of that.”—Lisa, 31

“Those people that come up there with those signs ‘pro-life’ and I was like are you even in the same argument? You’re pro-life, pro-choice is completely different. Having that choice didn’t make sense until I got older and started to really pay attention and I appreciate getting into social work because then you start to become aware of all the issues that are going on and you kind of want to know, ‘well how does this affect me and what is this about so having that choice, then it was just like this, is what I want to do having that choice now very grateful, thankful. I remember watching *If These Walls*
Could Talk… It’s still a choice that I have to this day, that I’m very happy I have the choice—grateful that I have that choice and that nobody can tell me otherwise, because it would get to the point where—I think it was the one [from the movie] where the woman did the back alley abortion… but I can see me going that far… yeah so having that choice like I said. I made a choice, this was my responsibility. I did it. I knew I could have done things to prevent it, but…”—Lisa, 31

Theme 6: Experience of Pregnancy

The Experience of Pregnancy is the sixth theme which consists of three subthemes: pregnancy attitudes and intentionality, maternal health status, and availability of support and resources.

Pregnancy Attitudes and Intentionality (6.1)

Participants who did not plan their pregnancies described experiencing initial shock (and sometimes fear) followed by a later acceptance of the pregnancy. This acceptance was influenced by factors such as learning the sex of the infant:

“I wasn’t planning to get pregnant, so it wasn’t something that crossed my mind. I think [for my first pregnancy] I wasn’t ready to be pregnant because I wanted to party still. So, me getting pregnant happened in the midst of all this partying. [When I found out] um, I was kind of shocked—but with this [current] pregnancy, I was just excited from the start—but with Luke [first child], I was kind of shocked, just because of how me and the dad were. We weren’t really together and he was already in a relationship. It didn’t really hit me until I found out what [the sex of Luke] was… that’s when I got attached… I was like, ‘okay, I’m pregnant, it’s a little boy’.”—Sarah, 28

“I found out I was pregnant two days before my [high school] graduation. I felt like my life was crumbling underneath me. I had just made the cheer team at [the university], I was going to be there on a cheer scholarship. [Later] I was actually pretty excited to be pregnant. I was just like, ‘I’m having a baby’.”—Ruth, 20

[When I went to the clinic for a pregnancy test], she [the nurse] knocked me into reality, hard. She was like, ‘Since you weren’t planning on getting pregnant, you know we have adoption, we have abortion, there are other ways you can—’ I was just like, I would never do that to my baby. She said, ‘So, you are planning on keeping it then?’ I was just like ‘Yeah’.—Ruth, 20

One participant in describing her experience with infertility mentioned that she and her husband knew that they wanted to be parents and have children. She mentioned, “We tried, we...
kept trying and trying” (Tonya, 36). After her seven miscarriages, she made a decision to adopt a little girl.

**Maternal Health Status (6.2)**

Some participants experienced significant health complications during their pregnancy:

“I already had really bad acid reflux before I got pregnant, so being pregnant made it worse. And I had preeclampsia. [Several days before she miscarried] my blood pressure was up, [it was] the reason why my legs and everything were so swollen and my face was going numb because my blood pressure was through the roof. I literally couldn’t walk, my feet were so swollen to the point it felt like needles were being stuck into my feet. For me to use the bathroom, I had to scoot out of bed and crawl……while I was pregnant. [When I was rushed to the hospital at eight months], I was withering away because my placenta [was] rupturing and [my baby] was straining all of the blood to my stomach to the point where I had a good sized blood clot in my stomach. I was withering away so fast [as I was sent into labor and delivery] that if I had to push, my heart would have failed.”—Ruth, 20

“Mhm yeah and it was a hard pregnancy going back because when it happened I knew something was wrong. I could no longer eat. Really all I did was to drink Ensure and so I hated Ensure. I mean people were trying to say hey try noodles with ranch dressing so they’re not dry just try all these things and I mean nothing. I hated hamburgers because they scratched my throat coming back up. Salads, I love salads they were the nastiest things coming back up so that is some of what I remember afterwards and then it was the fears that came in when I got pregnant again it’s like oh morning sickness. That was just nasty you know things like that.”—Lisa, 31 describing her third pregnancy

“At eighteen weeks and so I started going to the doctor every week and I saw my doctor and the maternal fetal specialist and I started seeing the lady about my kidneys because I had high levels of protein in my urine and like I said by this time I had --. I gained the weight in high school so being twenty-five or twenty-six I averaged about 280 5’9 and a lot of people are like oh yeah but I’m like yeah I’m almost 300lbs. Don’t talk about me. [laughter] so yeah doing all these appointments. I went and got my heart checked.”—Lisa, 31 describing her first pregnancy

One participant, Debbie (21) mentioned that she had several issues with her uterus and was diagnosed with an incompetent cervix. She continued by mentioning that she was a smoker (preconception) and believed that may have created some health problems that affected her birth outcomes. She also mentioned:
“[I’ve had to get] a colonoscopy and an endoscopy [at seventeen]. My transverse colon was backed up and too high and was causing severe pain...come to find out I had gastritis. They told me I would most likely be a lot gassier. I need to watch foods I eat, which I don’t. But I’m trying to lately.”—Debbie, 21

Others participants made brief mentions of their health, and described themselves as “healthy and never having been sick” or as one who has “never been health conscious.” After her sixth miscarriage, one participant described how she tried to improve her health:

“I felt like I was taking better care of myself because back then even with some of my other pregnancies, my nutrition wasn’t the best. I wasn’t very educated on what I needed to do to take care of myself and everything was different. I had prenatal [supplements], fruits, vegetables, smoothies, everything, I had the book “What to expect” and although I had that the first time. I didn’t eat certain foods, I didn’t do anything, it still didn’t happen.”—Tonya, 36

**Availability of Support and Resources (6.3)**

Several participants mentioned how valuable having prenatal educational resources available to them either at the hospital or on the internet:

“However like I said the hospital social worker came in, she hooked me up really well. But things that I did not know because this was a first time experience having a child being in the hospital even just dealing with that experience people coming in and saying—talking about breast feeding they said ‘You know you won’t be able to breastfeed however you can start pumping.’ and all these different kind of things so it helped so much to have so many people.”—Lisa, 31

“United Way okay they have a list of different maternity helping places. They sent me to them…..I don’t know it’s one of those places that offers maternity clothes or baby clothes and baby food and stuff like that. I loved having the mobile site. They have [website].com. They have a mobile app. You can look at your baby and all between the weeks and that kind of stuff. Those were big things. I guess I like to education myself, that’s more soothing than they think.”—Debbie, 21

One participant explained that her background knowledge was helpful during her time of pregnancy:

“I knew a little bit because being in social work by that time I had worked at [Social Service Agency], What I got from them is they do resources. You come here I’m going to help you with some resources so I know this is the list of places to go to. So I knew
resources. That wasn’t a big thing and maybe that’s why it wasn’t a huge thing for me I knew who to call if I needed something for this or whatever.”—Lisa, 31

The experience of having social support in and outside of the hospital setting was believed to be valuable:

“I had someone around me. [My husband] was definitely like ‘What’s going on? What are you doing?’ My dad (he’s just nosey by nature) so he was like, ‘I’m just being nosey, but what are you doing?’ So, even if I wasn’t aware, having people around me who were aware [was an important resource].”—Lisa, 31

“I didn’t have a whole lot of support when it comes to people…just my husband mainly. But, my third pregnancy, lots of people rubbing the belly which kind of helped me out. I don’t know why. Soothing I guess. This last pregnancy I actually went in to birth. I don’t know if I’m remembering things that might actually help you out. “—Debbie, 21

**Theme 7: Health System Experiences**

The seventh theme, *Health System Experiences*, consisted of three subthemes: provider interactions, continuity, coordination and access to prenatal care, and attitudes/recommendations about prenatal care.

**Provider Interactions (7.1)**

The first subtheme is “*Provider Interactions*” which consists of six meaning units. Participants described their experiences with health care providers across various medical settings. One participant described her first well-woman visit as a teenager, and the provider interaction was perceived as “judgmental”:

“She was like “If you are having sex this should not hurt” I’m like “I only had it one time and i don’t even think we did it right” [laughs]....: She was a good doctor. Everybody say she good. But, she is mean and she was just like basically, I was young and I was having sex and I should be able to handle this and take this .......She was judgmental, I think...Yeah, she was rough”—Sarah, 28

The majority of participants described their experiences with physicians during their pregnancies or shortly after their infant death. Some women described satisfactory experiences,
whereas others were displeased with certain aspects of their provider. Overall, participants mentioned a desire for provider honesty and openness:

“Yeah he would keep telling me I needed to lose weight this was my OBGYN he would constantly. He used to be a heavy man and then he lost weight and he [my doctor] is like, ‘you don’t understand.’ He probably didn’t use the word fat but that’s what I heard. It’s like you’re calling me fat. However during this time I appreciated [it] because he started having conversations about me like, ‘there are a lot of complications, I know you hear about the people who have twins and everything’s great but there are a lot of complications and so just wanted you to know and here are some things to read’ and just different things so just being aware. Every single time he would have this conversation”—Lisa, 31

Providers’ effort to learn about patients was highly valued among participants.

Participants perceived providers to be distant and uncompassionate when they were seemingly uninterested in participants’ background.

“He’s delivered all [of] my children. I’d say this man, ‘as busy [as he is], as many people [as he sees]… he sees me, my cousins, and my other friend. He’s very busy, so [I feel] he truly cares about his clients and patients to take this time out because I’m one of how many? It’s like even if he [in a roundabout way] called me ‘fat’… okay. You care. You’re doing it because you care and so I didn't take it [personal]. He’s telling me I’m fat because I’m unhealthy it’s [as if he is saying] ‘I’m truly caring about you’. I mean I always appreciate him because when he comes in its like, I don’t know if it’s my chart or your great memory, but he asked about me and he knew about me. So, I don’t know if [he remembers so much about me because its] in my chart. But [even if that’s the case, that means that] he took the time to study up on my chart before I got there so that just helped. Yeah, that meant a lot.”—Lisa, 31

Yeah, I did [have a lot of stress during my pregnancy.] Nope [doctor did not ask me about myself or any stress that I may have been dealing with]…that’s why I said they’re very distant.”—Debbie, 21

Experiencing assurance in provider’s knowledge and competence was also an important characteristic that participants found desirable during provider interactions:

“Yeah but my specialist is the one that tells me everything. My main doctor, I don’t feel like…[laughs] I just feel like….They say he’s a good doctor …He’s just like, fumbling the paper and can you give me one minute and I’m like?! [laughs] ....You’re supposed to have this stuff together. Or, [ he would ask me] did they fax the paper over here? [I’d say]
I don’t know! I don’t work here! Yeah everybody says he’s good. All of the [elders that] I talk to and I’m like I’m about ready to fire him.”—Sarah, 28

“[She was terrible because] she didn’t know anything, like she just didn’t know. I did a lot of spotting with that pregnancy and pretty much every pregnancy after, I did a lot of spotting and she would tell me to walk more or like when I kept asking about the different things that were going on down there, she could never give me an answer, just would tell me to take a Tylenol. So I did not like her and the doctors after that I wasn’t really too pleased with them, I think there were one or two that was as helpful as they could be for the situation but other than that I hated those doctors.”—Tonya, 36

Another important characteristic among participants was provider communication and rapport:

“I loved Dr. Tatum. Yes [I feel that I had a good health care experience]. She was kind of like me. We are very straight forward people so you know she would just tell me how it is and I would tell her what I wanted. She felt more like family….so it wasn’t a disconnect.”—Ruth, 20

“And I forgot what it’s called, but even the example of nurses coming in and just doing things [and] they’re really supposed to be talking to you, so I’m asking questions like, ‘Hey what’s going on here?’ But not everyone would do that, so that [increases] your stress level just a little bit when someone’s coming in and doing something to you or around you and you don’t really know.”—Lisa, 31

“He was great, Dr. Evans and I will never forget him because he was so sweet, he was the nicest doctor I ever had. He was real good. He was thorough and he would take you to his office and sit you down with all his notes and explain everything, I remember that at a very young age. Even at age fifteen he made sure he explained everything to me and if I didn’t understand something he would explain it. Well, this is what this means and this is what that means, so he was really good.”—Tonya, 36

“[My last doctor] I loved her because she’s just honest and very knowledgeable. She is going to sit there and explain to you and whatever she needs to do, if she doesn’t know she’s going to find a colleague. She is always making sure she is doing whatever she can to help me.”—Tonya, 36

Participants mentioned interactions in which they felt “dismissed” when they expressed concerns about their health. Thus, provider attentiveness and connectedness was highly desired among participants:

“[My last doctor] didn’t seem very connected. I don’t like doctors who are just like, ‘oh, it’ll be fine, you’ll be okay. This last pregnancy, I let him know that I had a friend who got on hormones, which is what I was on, had bed rest, and got to five months and had the same [cervix] issues. I told him, ‘I’m afraid of this happening.’ He says, ‘Oh it’s rare.’ At the time I was scared of it, but…I was also very happy that we were pregnant so
I kind of dismissed [his lack of concern] at the time. But, now thinking about it…[I feel] kind of angry about it. Yeah I understand it’s rare, but it could happen to me. It [interaction with doctor] was very distant.”—Debbie, 21

“Some [doctors] I felt like I didn’t have that connection with where I could say something because they knew everything, ‘you don’t know anything, I’m the doctor I know everything’ type situation. But, for the most part doctors were pretty open and we were able to communicate about what it was I wanted or what we needed to do.”—Tonya, 36

Another source of dissatisfaction mentioned was incomplete, inconsistent explanations for important health matters. Participants indicate that this experience was frustrating and created doubts about the quality of care that they were receiving:

“And I was always wondering, because now they tell me, “We see the umbilical cord connected to the placenta. You’re telling me you can see it now, but when I was pregnant with Luke, y’all did the same sonogram, the same tests, why couldn’t you see it then? Now, I’m asking more questions, you know wanting to see, paying attention to the sonogram, what’s that? because they don’t give you all of the information, and I feel like I wasn’t checked properly when I was pregnant with Luke, because they said that they couldn’t tell me until afterwards, but you see the umbilical cord right now. [For example], that the umbilical cord was crossed over and connected to the membrane. But I don’t understand that because they always check me, and the placenta, and well that’s connected there and so they tell me all of that stuff during this pregnancy, so.”—Sarah, 28

“It’s aggravating—it aggravates [my husband] more than anything—that you know the hospital wouldn’t give me the certain medications that help the progress of the baby. They would have done it! [They could have] injected the steroids and the magnesium…which help with lung developing, the heart development. So, she had a chance of living. Well, they didn’t do that because at 20 weeks it was too early. Essentially, they told us there was no chance of her living. [Later, I was asked] ‘why didn’t you get a curettage on this pregnancy?’ Even though you’ve had two miscarriages, someone should have recommended it to you. So, that puts more doubt and anger in my head. ‘You mean I should have had this before you even diagnosed me with an incompetent cervix? I was at high risk in the first place, and they should have been taking all of the necessary precautions to make sure it [miscarriage] didn’t happen again. With my doctor assuming it wouldn’t happen to me, just because it was supposedly rare. Well [since then], I’ve found many more cases—three different cases—in this area.” Debbie, 21

One participant expressed her displeasure with her provider ‘keeping her in the dark’ about pertinent health information:
[During one appointment], he just did a quick examination, ‘how are you doing?’, checking [my] blood pressure, checking the baby’s heart and he said, ‘How’s everything going?’. I said, ‘well, I’ve had some bleeding’. [He says] okay let me check’ and then he got quiet, and I was like ‘you can’t keep getting quiet on me!’ [He says] ‘no, no just want to check and make sure everything is fine, can you meet me at the hospital?’ I get there [and the staff says] he’s got you a room set up. [I’m thinking] why do I have a room? This was the one piece of him that I did not appreciate. I was [placed] on bed rest and did not know it until the maternal-fetal doctor go there to tell me, ‘Oh you’re not going anywhere. We’re going to monitor you for a few weeks. So you’re going to be here’. The first thing I thought of ‘I can’t afford this’. I was 24 weeks. I had dilated to 3 centimeters.

**Continuity, Coordination and Access to Prenatal Care (7.2)**

Participants’ experiences with provider continuity, or seeing the same health care provider over a period of time, varied. Some women expressed that their physician provided care to them for a number of years, whereas others experienced a lack of provider continuity:

“He’s delivered all [of] my children….”—Lisa, 31

“[During my last pregnancy], I had two different doctors in the hospital through the same office. And, I had someone call me and say, ‘Look, we’ve got to move you around since your doctor left the state. We’ll make you an appointment and they switched me to this last doctor. [I thought this was] stupid. It’s very aggravating too because you know, I had to re-fill our history right after the [previous miscarriage]. You know their files don’t exactly just go [snaps] over to the other doctor. You literally have to fill out everything over again.”—Debbie, 21

I honestly couldn’t count [the number of doctors that I have had] I can name a few, I know I had at least five [doctors], like I said I’ve had seven miscarriages over the last 16 years. I’ve had several doctors.—Tonya, 36

One participant discussed her prenatal experience which was characterized by poor prenatal care coordination and communication between health systems:

“When I was eight months…and I had preeclampsia. I went to a hospital [the emergency room, not home hospital] in Cloverdale. They told me, ‘Oh don’t fret. This is preeclampsia, just stay off your feet and [watch your] salt intake.’ So that’s what I did, I came back home, stayed in a neutral place, not too much light, not too much stimulation, didn’t really eat any salty foods. Felt good, drove back home. Got back home and I literally couldn’t walk, like my feet were so swollen to the point like it felt like needles were being stuck into my feet….So, I called my doctor on Monday and I told her,
‘Okay well you guys should be getting paperwork to let you know that I went to the hospital [emergency room] and they diagnosed me with preeclampsia’. My doctor was like, ‘we haven’t got any paperwork and you need to get down here right now because this is your first pregnancy, you’re already having complications with [the pregnancy]’”—Ruth, 20

“I have insurance with [my current] pregnancy, [but] I had a hard time getting medical insurance because they said I made too much [money]. Then, the hospital referred me to a place that was supposed to see me without insurance and they never—they still haven’t called me back. I gave them my number and I’m like, ‘my doctor from [Fargo hospital] referred me over here and they say that you all would see me without insurance’…and nobody would see me. Then, finally when I got to [my current doctor’s office], my doctor was like, ‘well they should have scheduled you an appointment because they know you were going to get insurance’”—Sarah, 28

Participants also described institutional barriers that interfered with their access to prenatal care. These issues usually were caused by delays in Medicaid coverage, and insurance lapses:

“Immediately I got to go in to [see] a doctor. As soon as I call them they were like, ‘okay we’ll send you a letter when you’re approved [for Medicaid]’. And I would wait like a week or so, you know because I already had prenatal vitamins. I had already been told at the child bearing age to go ahead and take vitamins. So I went ahead and bought prenatal vitamins that had a lot more to them. So I had already taken my prenatal vitamins every day, that wasn’t my concern. I didn’t really have to rush into the doctor especially the first two times. Even though the second time I did kind of rush into the [doctor’s office]. So, I called the state and they were like, ‘well you were approved like three days ago.’”—Debbie, 21

“[During my pregnancy with Luke] they [would say] we have places that will see you and I’m like ‘well every place that I go to they say that I have to wait on my insurance card. I’m like, I tried and called and tried to make an appointment and they say, well call us when you get your Medicaid card because we can’t see you. It [my insurance coverage] would stop. So, they wouldn’t see me. So, I would miss some months of being seen. Actually, I hadn’t even been seen until I lost Luke because my insurance had lapsed.”—Sarah, 28

Finally, participants discussed inconsistent insurance coverage throughout their life, particularly during major life transitions. In addition, one participant discussed the challenges that she faced trying to receive donated post-partum medical care because she did not have insurance coverage:
“So, at the age of seventeen, I had [health insurance] up until I hit nineteen, and then it ended. [I had] insurance through the state. I could get all of my mental deals taken care of—psychiatric issues, medications, all of that. That’s how I had insurance from the age of thirteen through the age of eighteen.”—Debbie, 21

 “[Up until eighteen I received insurance coverage] because I was on welfare. When I turned eighteen, [I stopped my well-woman visits because of] no insurance. But, there were times where I felt like I needed one and have to pay a little fee.”—Sarah, 28

“Actually no [my insurance] did not [lapse during my pregnancies], so that was nice. You know it was never an issue. But, it would be nice to have insurance without having to be pregnant. It [insurance] had just ended [when] I turned nineteen…then I lost it after my pregnancy [loss], and then gained it during my second pregnancy, lost it…and then gained it during my third pregnancy.”—Debbie, 21

“[I don’t have insurance, and I’ve been having issues with my uterus], I’ve contacted [local agency that coordinates access to donated medical care for uninsured, low-income individuals], and they said that I have to have a referral. So, I’ve asked my doctor’s office to possibly put that [referral] in. If not that then, I have to go to [one of two federally qualified health centers], which isn’t exactly something that I’m looking forward to. Especially since they don’t know [my] situation, and I don’t know if they have surgeons to do certain things. I can’t pay for a $30,000 surgery again. So hopefully, [I will be accepted] as a donated patient…I have a feeling she won’t since I have so many problems.”—Debbie, 21

**Concerns and Recommendations (7.3)**

Participants also shared some general concerns about their health care system experiences as well as some recommendations for providers. One participant described her frustration with her provider’s inability to provide her with a diagnosis that explained her difficulty carrying children:

“They [the specialists] couldn’t really give me an answer; they did all these tests and couldn’t really tell me what was going on. I didn’t really get diagnosis at all. [This felt] hopeless because you’re like, you want to have kids and you can’t get pregnant and they can’t tell you why. They really can’t offer you anything else, after all [of] those tests and all those needle pokes, ‘this is all we can do’”—Tonya, 36

Another participant (Debbie, 21) described her concerns with provider rapport and interactions with nurses within medical settings in great detail. She expressed her mistrust and lack of confidence in nurses within the health care system:

“I want more connection, more feeling. We understand a lot of doctors kind of fall off bandwagon after being in it [the profession] for a little bit. But it would be nice for, I
guess, [for them] to be more into what is going on, more in tuned with the listening. I appreciate the profession. That’s great, but you also have to be human. I don’t need a robot in front of me. You know one of these days we’ll probably have that but—I don’t want a robot for a medical provider.”—Debbie, 21

“As far as the actual system right now. At present, that’s a whole different subject. That’s a very long subject. I know we have good doctors. As far as insurance and facilities, I don’t think they’re well-kept or managed correctly. The people aspect—doctors, nurses—they are not in tuned. They have awful attitudes. I have a friend who is a CNA and HHA. I’ve heard nothing, but bad, how many nurses just don’t care and they just let go of so many things. And on top of that, I see it. Nurses have the worse attitudes and so many are going into the medical field right now. I know a lot of people going into [the nursing field] and honestly I wouldn’t want any of them as my nurse. I’ve been into the ER, I don’t know how many times. It just doesn’t work for me. They’re not with it. They like to assume things that it isn’t their place to assume. They take facts and they use it against you, you know, their knowledge that they’ve come up with for the college education that most of them have—that you would think they have.”—Debbie, 21

Another participant recommended that providers share explanations during prenatal visits, and felt that changes should be made to ensure that all women can have access to prenatal care regardless of their insurance status:

“And that’s something that they [doctors] need to do. Because when women are pregnant during that time, they need to see that person right then and there. Because early prevention is the best thing. I know they [babies] are little and they [doctors] probably can’t see too much of anything but, you need to check something. You know, and that’s one problem. They should see women as soon as they [become pregnant]- with or without insurance. Because either way it goes they are going to need to be looked at by somebody.”—Sarah, 28

“I just wish for first time moms they would—because we may not know all the questions to ask—I just wish they would explain stuff to us more in detail and make sure that we understood what was going on.”—Sarah, 28

**Theme 8: Exposure to Fetal/Infant Death**

The final theme, *Exposure to Fetal/Infant Death*, consisted of two subthemes: occurrence of fetal/infant death among family and personal history of recurrent fetal/infant death. Overall, most participants expressed that they had heard of infant mortality or infant death.
Occurrence of Fetal/Infant Death among Family/Friends (8.1)

Among participants who reported that there had been instances of fetal/infant death in their families, several mentioned that their first cousins had experienced the death of their infants:

“Yeah as crazy as it sounds, I have a cousin, my first cousin who’s had fifteen miscarriages, but she has two children and she was one of the ones that was telling me to keep trying and then I have another cousin that has had several miscarriages, she’s a first cousin and then another first cousin who’s had several miscarriages. So, there is like four of us total, and there tons of girls [in the family], but all of the first cousins were the ones that have been dealing with that. We’ve all been pretty much diagnosed with the same thing.”—Tonya, 36

“But she [one of my cousins] had a stillborn. But it was so long ago.”—Ruth, 20

“She [best friend] had prior had a baby at the age of fourteen. But, she lost him through pneumonia.”—Ruth, 20

Another participant (Sarah, 28) provided some insight into what the occurrence of infant death in her family meant to her:

“I mean yeah [I had heard of infant death], but I never thought that would happen to me…like [I thought] it was going to skip me.”—Sarah, 28

“We had just experienced it [infant death] with my other cousin. Because you had seen it just happen to your cousin so… She found out and then right after she found out, I found out. And I was looking at it like, okay because God is not—I thought I’d be okay—because God’s not going to you know, two children in our family, and he’s not going to take them both, but then…I’m like wow, its two babies from the same family. Like we’re blood cousins—my first cousin’s child and…… it was just shocking. But, our babies are cousins and they’re actually buried side-by-side.”—Sarah, 28

Personal History of Recurrent Fetal/Infant Death (8.2)

Three participants had a history of recurrent fetal or infant death:

“[I had] two miscarriages, early on, one was 6 weeks 3 days, [the] second one was 10 weeks exactly. Then, the birth was the last lost was at 20 weeks.”—Debbie, 21
“I’ve had seven miscarriages over the last 16 years. The longest time [I was pregnant] was the four and a half month, my first one was four and a half months and my last one here last year was four and a half months.”—Tonya, 36

Tonya (36) continued by saying that after her first miscarriage, she was ready to try again shortly after:

“For me it was immediate, and so we were told we shouldn’t have a problem, and that sometimes these things just happen, blah, blah, blah”—Tonya, 36

During her first pregnancy, one participant (Lisa, 31) was carrying twins. One of the twins died as a result of twin-to-twin transfusion syndrome. She had a preterm birth delivery with her second twin, who died several weeks later. Although, she did not experience any subsequent infant deaths after the first two infants, she described her anxiousness during her subsequent pregnancies. She remembered feeling uneasy when she began to experience complications during her third pregnancy that were similar to her first pregnancy:

“In the beginning [of my second pregnancy], Dr. Elders was kind of watchful but as time went on, I could kind of see him relax. With Josh [third pregnancy] he was the same way, he was like ‘hey third time around things should be pretty good however we’re going to lean towards caution’ and so I remember the first time I had protein in the urine “Oh you got to go to Dr. Williams.” I was like “Oh gosh”….with Josh [third pregnancy] all [of these] triggers were going off and the protein in the urine, high blood pressure… I remember going to the doctor one time, [they told me] ‘oh it was a protein in the urine’ and he was like ‘I’m going to need you to go to [hospital], we’re going to monitor you for 24 hours.”—Lisa, 31

**Essential, Invariant Structure**

Black women’s life experiences preceding fetal or infant death varies greatly. It appears that early childhood and adolescent contexts are shaped heavily by family characteristics such as family cohesiveness, parental domestic abuse, single parenthood or economic stability. Those characteristics, in turn, play an even greater role in women’s adult lives by either acting as an added source of stress or a buffer against it. This is especially important considering that Black
girls encounter a series of acute and chronic stressors, which oftentimes persist into adulthood. It is important to Black women to have the protective resources (i.e. strong relationships and social support) to cope with those stressors, which may later affect their physical, spiritual, mental and sexual health. Retrospectively, many women are aware of the ways in which stress may be manifested in their health behaviors, although many women are not yet fully aware of these ‘carry over’ effects from experiences greater amounts of stress.

Their engagement in positive health behaviors or health risk behaviors is always nested within a larger context, and it is important to understand the various contexts in which Black women live. Black women typically try to see the good in their interactions with the health care system, but are very clear about their expectations of the health provider as well as the system as a whole. Some Black women may have a strong supportive base that helps her navigate the health care system, while other women are at risk of getting lost in the clinical and system bureaucracies. In essence, the participants care about their health and the health of their infants, but it is imprudent to assume that all mothers have everything that they need to know about their health and health resources, especially during pregnancy. Most importantly, Black women express a strong desire to educate themselves about their own health, but they also want their providers to be an active participant in that educational process. Overall, it is critical for health professionals to understand that Black women’s lives are dynamic and shaped by a series of factors that impact their health trajectories in both positive and adverse ways. Moreover, not only is social support important, institutional support (e.g., access to adequate health care, positive provider-patient relationships) is just as essential for Black women’s health across the life span.
Life Timelines

A total of five life timelines were obtained from participants during the interview session. Individual life timelines can be found in Appendix G. Furthermore, Figure 8 is a summary of participants’ life timelines.

![Figure 8. Summary of life timelines](image)

**Description of life timelines**

The purpose of the life timelines was to understand participants’ life trajectories, and to understand if participants shared common life patterns. Figure 8 is a visual representation of the major life events reported by participants. Life event codes are listed along the Y-axis. It should be noted that ‘positive life events’ is comprised of life events such as marriage, educational achievement, first job and so on. The developmental stages are listed in ascending order along the X-axis. As noted by the legend, the shaded boxes represent the number of occurrences of a specific life event—the darker the shade the more occurrences.
Based on Figure 8, participants reported a greater amount of positive life events during adolescence and emerging adulthood. It is difficult to say whether or not the large amount of positive life events persist into young and middle adulthood because the oldest participant was thirty-six years old. It is clear, however, that participants do experience a number of life events that may serve as protective factors over the course of their lives. It appeared that traumatic or disruptive life events such as the death or disability of a family member, sexual assault, and major housing transitions tended to occur in early childhood and early adolescence. Moreover, initiation of sexual intercourse began around early adolescence among participants, with exposure to sexually transmitted infections, pregnancy and well woman care emerging soon after during middle adolescence. Other life events such as intimate partner violence appeared to occur as early as middle adolescence. The occurrence of fetal or infant death appeared to begin as early as late adolescence among participants, and continued into young adulthood.

**Limitations of life timelines**

Most importantly, the data represented in Figure 8 were taken from participants’ life timelines only. There may appear to be discrepancies in life events reported during interviews and those recorded on life timelines. For example, every participant indicated that they always made well woman visits, but only a few recorded the age at which they received their first well woman visit. This issue should be noted when interpreting the figure. Another issue is that one of the participants, whose information is included in Figure 8, experienced a total of seven miscarriages. Based on the number of fetal deaths that she experienced in comparison to other participants she represents an outlier among this sample. This participant’s miscarriages do contribute to the darker shaded boxes in the figure, and this issue should be noted when interpreting this figure as it may skew the data. It is most important to point out, however, that
the figure does serve to illustrate the ages at which participants began to experience fetal or infant death. Overall, this figure should not be used to suggest any causal associations; instead it serves to describe only some characteristics of participants’ life experiences.

**Implications of life timelines**

Figure 8 provides an interesting picture of participants’ life experiences. It illustrates the ages at which participants first experienced (or continued to experience) certain life events. The early occurrence of traumatic or disruptive events (e.g., sexual assault, housing transitions which include homelessness and relocating to different settings) among Black females may be important to investigate. For example, in the case of major housing transitions, it may be important to examine the characteristics of those environments (i.e., environmental exposures, stressors) and how those characteristics might be impacting later health outcomes. Hence, the use of life timelines may be useful in identifying areas of further investigation as it relates to health and birth outcomes. Life timelines may also be useful for identifying areas of intervention. For example, being able to identify when a group of young women may be at risk for being exposed to certain situations (e.g., early sexual initiation) may aid practitioners in developing appropriately timed prevention and intervention strategies.

One of the most striking findings from Figure 8 is that participants reported experiencing fetal or infant death as early as late adolescence (ages 18-21). Prior research suggests that the risk for poor perinatal outcomes among Black women is lowest between ages 15 and 24 years (Geronimus, 1992, 1996; Love et al., 2010; Ruah, Andrews, & Garfinkel, 2001; Rich-Edwards, Buka, Brennan, & Earls, 2003). This, however, does not appear to be the case for participants in the present study. Perhaps, there might be contextual factors to consider when examining Black women’s first experience of fetal or infant death. It might also be important to explore regional
or geographic differences in the timing of exposures to certain risk factors and timing of first fetal or infant death among Black women.

Overall, although no causal inferences can be drawn, Figure 8 does serve as a ‘first step’ in understanding life course patterns among Black women. Future research might focus on incorporating life timelines or measures that allow for reporting the timing of certain life events among Black women. Perhaps, future work involves generating a comprehensive database comprised of longitudinal information about exposures to select risk and protective factors. Such a database could provide insights into factors and processes that shape Black women’s health over time; and aid in the development of effective intervention strategies.
The primary objective of this research was to describe Black women’s lived experience prior to fetal or infant death, and to uncover the meaning of these experiences as it may relate to their birth outcomes. Two central research questions were posed: (1) what are the factors that have shaped the lives of Black mothers who later experience infant death? and (2) what are their shared life course patterns?

**Life Course Perspective**

The overall findings of the present study suggest that the life course perspective is an appropriate framework for exploring birth outcomes among Black women. The life course framework has served as a valuable tool for understanding the life experiences that precede infant death and how those experiences may be related to Black women’s birth outcomes. The eight broad themes that emerged from the qualitative interviews were characteristic of known risk and protective factors identified within the literature. For example, prior research indicates that Black women experience greater amounts of stress (Hatch & Dohrenwend, 2007; Lu & Chen, 2004; Turner & Avison, 2003; Christian et al., 2013) and that exposure to chronic stressors, relating to financial difficulties, trauma and partner conflict, are associated with adverse birth outcomes among Black women (Giurgescu et al., 2013; Lu & Chen, 2004). There is also empirical evidence that implicates the role of individual-level factors such as poor maternal health status or risky health behaviors (Rosenberg et al., 2005, Chen et al., 2009, Graham et al., 2007; Henriksen et al., 2004; Pollack et al., 2000; Bell et al., 2006); and systems-level factors including institutional barriers to health care (National Research Council, 2003;
Jarlenski et al, 2014). The findings of this study are also consistent with earlier work by Kiely and colleagues (2011) that demonstrated an association between pre-conceptional factors (e.g., diabetes, body mass index/maternal weight, and intimate partner violence) and adverse perinatal outcomes in black women.

In the present study, the presence of key factors was evident. A major contribution of this study is that participants’ information-rich descriptions provided a conceptual meaning for each risk or protective factor. Furthermore, participants described their experiences dealing with “a great deal of stress” related to finances, trauma, and family or partner conflict. More interestingly, participants’ provided information regarding the degree of their reactivity and coping, and the degree of permanence for certain stressors. Similarly, participants provided in-depth information about the key motivators and facilitators of their health behaviors, and about perceived and actual institutional barriers to health care. In sum, the qualitative account of participants’ experiences provided a contextual understanding of their exposures to risk and protective factors. In response to the first research question, participants discussed many of the factors that have been identified in the literature. There were some novel themes which included past sexual assault as a salient stressor and exposure/meaning of infant death within family and community.

The second research question was posed to understand how participants’ experiences extended across the life course and to identify commonalities in participants’ experiences. Findings demonstrate that Black women’s exposure to key risks and protective processes begin in early childhood and extend well into adulthood. In line with the life course framework (Braveman & Barclay, 2009; Fine & Kotelchuck, 2010; Lu et al., 2010), these findings provide further support for the notion that risk and protective factors (i.e., stress, family support)
represent dynamic processes, rather than static occurrences, which have effects on physiological and psychological well-being that are far reaching. It is important to note that participants cited exposure to major stressors and risky health behaviors (i.e., domestic violence, sexual assault, early sexual initiation, unsafe sex practices) well before their periconceptional period. Similarly, participants’ exposure to protective processes (e.g., family cohesion, support systems, adaptive coping) occurred early in participants’ lives, but the amount of ‘protective resources’ also appeared to lessen as women approached adulthood. Thus, attention to life experiences prior to pregnancy is crucial in understanding Black women’s cumulative exposure to key risk and protective processes that are associated with adverse birth outcomes.

Although no causal inferences could be drawn, the research was interested in taking steps towards understanding how the examination of certain life course patterns among women who have experienced fetal and infant death may eventually provide insight into the underlying causes of adverse birth outcomes among Black women. The findings from the analysis of participants’ life timelines did demonstrate that participants tended to share some similar life events (e.g., sexual initiation, first pregnancy, infant death) during the same developmental stages. Although these particular findings are descriptive and self-report, they do provoke the notion that taking the approach of ‘epidemiological backtracking’ may provide crucial information about normative age-graded trends and non-normative trends among Black women as compared with women of other racial/ethnic backgrounds. At present, the findings do indicate that participants have some temporal commonalities in their experiences. Overall, these findings also suggest the appropriateness of the life course framework in examining the multi-level factors that impact Black women’s health early in life in relation to their birth outcomes.
Discussion of Emergent Themes

Early Childhood Context

The findings revealed that participants’ perceptions about their early childhood experiences varied. Although, most women believed that they had a good childhood experiences, others felt that they did not. This distinction appeared to be based largely on familial relations. For example, those women who reported having a poorer quality childhood experiences tended not to have strong, positive familial relationships early in life and in later years. Furthermore, positive familial characteristics in early life may be linked to having stronger relationships and adequate social support as an adult among participants. Second, participants discussed characteristics of their early childhood neighborhoods. Interestingly, participants’ perceived quality of their neighborhood experiences was based primarily on their social interactions within those neighborhoods. For example, participants tended to discuss the activities in which they engaged and how important it was to have other youth whom which they could engage in these activities.

In participants’ discussions about their early neighborhoods, however, there were minimal mentions of structural characteristics such as the degree of poverty or affluence, socioeconomic and racial composition, and physical environmental conditions. Prior studies have implicated the role of racial segregation (Bell et al., 2007; Britton & Shin, 2013; Kramer et al., 2010), neighborhood socioeconomic status (Ahern et al., 2003; Messer et al., 2008), and healthy neighborhood environments (Dadvand et al., 2012) in women’s health and birth outcomes. Some life course-informed studies have demonstrated a link between structural factors such as neighborhood socioeconomic status and birth outcomes (Collins et al., 2011; Love et al., 2010;
In general, black women who were born in poorer neighborhoods and resided in poorer neighborhoods as adults tend to have a greater risk of adverse birth outcomes (Collins et al., 2011; Love et al., 2010). Unfortunately, participants’ socioeconomic trajectories were not discussed thoroughly in the present study. Moreover, other structural characteristics (e.g., racial composition) of participants’ early and current neighborhood environments remain unclear. Further, the existing research suggests that the aforementioned factors may play an important role in birth outcomes, and in-depth investigation into the ways in which these factors shape Black women’s lives is warranted. Prior quantitative studies have measured neighborhood income and employment levels (Ahern et al., 2003; Messer et al., 2008; Pickett et al., 2002), physical deterioration (Kruger et al., 2011) and residential segregation using census data (Sparks et al., 2013). It may be necessary to (a) measure these neighborhood factors across the life course and (b) integrate these quantitative approaches with qualitative methods to understand context.

Overall, the findings point to the importance of social connectedness within the family and neighborhood context. Early neighborhood environments of Black females should be a key point of focus with regard to family and interpersonal relationships and the built environment

**Personal Relationships**

Social relationships and networks among African Americans, which consists of family, close friendships, and fictive kin, is recognized as an important predictor of well-being (Fung, Carstensen & Lang, 2001; Taylor, Chatters, Hardison, & Riley, 2001). Social support is also believed to play an important role in coping with stress and healthy birth outcomes (Zachariah, 2009; Almedia et al., 2014; Feldman et al., 2000; Shah et al., 2014); considering that Black
women tend to experience greater exposure to chronic stress (Giurgescu et al., 2013; Lu & Chen, 2004) social support is crucial. The findings from the present study demonstrate the importance of social relationships among black women.

Participants indicated that they had strong social support either through family relationships, intimate partners or both. The role of familial social support was evident across participants’ lives. For example, participants who reported having strong familial relationships and support in early life also reported having strong support systems as an adult. These relationships were characterized by having a prominent matriarch (e.g., grandmother, aunt, mother) within the family who participants believed shaped their lives substantially. In addition, close relationships with family also meant that participants’ trusted family’s advice and attitudes about issues concerning health providers. For example, for many participants, the decision to seek out or remain with a physician appeared to be influenced by prior family contact with a provider and shared family advice or positive attitudes (e.g., “But, she was a good doctor…everybody says she’s good”). Thus, the influence of familial relationships for many women is, to an extent, pervasive and greatly influences their health-related decisions. Furthermore, those participants who reported strong familial relationships also tended to report having strong and supportive intimate relationships (i.e., spouse, intimate partner).

In contrast, there were a few participants who reported that they did not have strong familial relationships. These participants did express that they felt it was important for them to have strong relationships with their families rather than constant family conflict. It is worth mentioning that participants who had weaker familial relationships in early childhood, also reported having little to no support from or relationship with their family. Moreover, it was observed that the two women who experienced a greater number of fetal or infant deaths tended
to have minimal familial relationships or support early in life as well as in adulthood. Although, this observation is only based on two participants, it may be worthwhile to explore quality and characteristics of familial relationships as protective factors over the life course and how this impacts general and reproductive health. Fortunately, though, these participants did report having strong and supportive intimate relationships which was believed to make up for their lack of familial support and relationships.

Overall, social support is multi-faceted. These findings suggest that Black women’s personal relationships with their family or intimate partners are characterized by trust and strong social support. Further, it may be especially important for health providers to engage family members and intimate partners in maternal and infant health interventions.

**Exposure to Multiple Sources of Stress**

It is widely recognized that Black women tend to report experiencing a greater amount of stress (Hatch & Dohrenwend, 2007; Lu & Chen, 2004; Turner & Avision, 2003), which has been associated with adverse birth outcomes (Holland et al., 2009; Schetter, 2009). The findings from the present study suggest that exposure to stress is pervasive and co-occurring.

Although several studies have found perceived racial discrimination to be a key source of stress among Black women (Earnshaw et al., 2013; Mendez et al., 2013; Rosenthal & Lobel, 2011), participants in the present study did not discuss any major experiences with race-related stress. Accordingly, only one participant mentioned that she had been subject to the prejudicial attitudes of her husband’s family. It was surprising that perceived racial discrimination did not emerge as a theme, but this may be due to contextual factors, such as general beliefs and
conceptualizations of racism. For example, racism may be conceptualized as overt behavior rather than a system of discriminatory practices and policies.

In line with prior research (Lu & Chen, 2004), participants from the present study reported experiencing partner-related stress, trauma-related stress and financial stress. One caveat is that earlier work has measured exposure to the aforementioned stressors during the periconceptional period (Giurgescu et al., 2013; Lu & Chen, 2004), but the present study revealed that participants reported experiencing these stressors as early as adolescence. This point is key because it provides a basis for the importance of examining exposure to chronic stress over the life span and its subsequent impact on health outcomes. Moreover, in measuring trauma-related stressors, Lu and Chen (2004) examined homelessness, experiences with substance abuse or incarceration. Thus, participants’ reports of sexual assault, the death or disability of a family member and parental domestic violence were surprising. For example, in the literature, studies tend to explore the impact of sexual assault on pregnant women and their subsequent birth outcomes (Gulliver & Dixon, 2014). Moreover, more research into the impact that trauma-related stress has on black women’s health and health behaviors is needed. For instance, a few participants from the present study described how they felt that their health risk behaviors were indirectly related to their history of trauma. Future research on Black women many need to also be trauma-informed and acknowledge the possible mediating role of trauma in birth outcomes.

**Maintenance of Mental Wellness**

As mentioned earlier, Black women, in general, report experiencing greater exposure to chronic stress compared with white women. Thus, the capacity and resources for coping with such stress is critical. In the present study, participants discussed their practices and strategies for
maintaining their mental wellness. For example, a strong spiritual identity was very important for women in terms of coping and meaning-making. In addition, many participants described adaptive coping strategies which involved taking time to rest mentally. Other participants discussed their desire to maintain a stable and stress-free life. These findings are consistent with earlier work suggesting the role of religion in coping and psychological wellbeing among Black Americans (Levin, Chatters, & Taylor, 2005). This finding represents an important protective factor that can be strengthened through mental health interventions that begin in early adolescence and adulthood. Such interventions should be tailored specifically for Black women, may need to integrate spiritual and/or religious based content.

**Sexual and Reproductive Health Experiences**

The findings of the present study revealed that participants did have early sexual intercourse and did engage in risky sexual behaviors that ranged from having unprotected sex to having multiple sexual partners within a given time period. Many of the participants also indicated that they had contracted a sexually transmitted infection during adolescence. Participants, however, did mention that they wished they would have abstained from sex longer. Moreover, it appeared that parents played a significant role in participants’ attitudes about their sexual health education and experiences during adolescence. Many participants, for example, mentioned that their mothers engaged in open, honest dialogue about issues related to sex and sexual health. Among participants whose mothers did not discuss sex with them, it was mentioned that they wished someone would have talked with them about the topic.

The findings from the present study are consistent with previous research on sexual health and risk behaviors. First, these findings support previous research that demonstrates the
association between early sexual initiation and risky sexual behaviors (Epstein, Bailey, Manhart, Hill & Hawkins, 2014), as well as the protective role that parents may play in teenagers’ capacity for safe early sex by promoting specific skills and values (Parkes, Henderson, Wight & Nixon, 2011; Sutton, Lasswell, Lanier, & Miller, 2014). Thus, it may be important for tailored interventions addressing sexual health and education to continue to target girls in middle school. Further, these interventions will need to include a parental component that encourages parent-child discourse on sexual health and parental transmission of skills and values that youth can use to navigate their sexual experiences if they do choose not to abstain from sex. This will be important for Black girls and women considering that Black females tend to be at greater risk for sexually transmitted diseases (Centers for Disease Control and Prevention, 2012).

There were also two interesting secondary findings that warrant more attention as related to sexual health. First, most of the participants mentioned their past or present involvement with men who were significantly older than them. For example, one participant indicated that she dated a twenty year old man when she was thirteen years old. A number of studies, mostly conducted in African countries, have investigated ‘age-discordant’ relationships (Wood et al., 2011), and have found that adolescent females who have early sexual experiences with male partners who are two to ten years their junior have higher rates of sexual risk behavior during adolescence and adulthood (Senn et al., 2011), and increased risk for acquiring sexually transmitted infections, experiencing sexual coercion, and unintended pregnancy compared with girls who are with same-age male partners (Wood, Hutchinson, Kahwa, Hewitt, & Waldron, 2011; Baumgartner, Geary, Tucker, & Wedderburn, 2009; DiClemente et al., 2002; Ford & Lepkowski, 2004; Gowen, Feldman, Diaz, & Yireal, 2004; Boyer et al., 2000; Vanoss Marin, Coyle, Gomez, Carvajal, & Kirby, 2000). In line with earlier studies, participants who were
sexually involved with older men were also exposed to sexually transmitted infections and engaged in risky sexual behaviors. These findings may have important implications regarding Black girls’ sexual health and the characteristics of their early sexual relationships.

Furthermore, other studies have suggested an association between childhood sexual abuse and later sexual risk behaviors (Jones et al., 2013; Senn, Carey, & Vanable, 2008; Senn, Carey, Vanable, Coury-Doniger, & Urban, 2006; Bensley, Van Eenwyk, & Simmons, 2000). Although only two participants discussed the impact of early sexual abuse on their sexual behaviors, it may be worthwhile to continue exploring the association between early sexual abuse and risky health behaviors and how this association may be linked to adverse birth outcomes among Black women.

With regard to reproductive health experiences, participants also mentioned the importance of having their mother discuss reproductive health issues with them (i.e., self-care during menstruation). It was notable that although participants engaged in early sexual risk behaviors, they also initiated well-woman care early. In contrast to physical health practices, participants discussed the meaning underlying their adamance about receiving consistent well-woman care. Thus, it appears that participants had general positive attitudes towards reproductive health maintenance, although they were embedded within a context of high sexual risk. The majority of participants also expressed concern and/or negative attitudes about hormonal contraceptives. For example, there were concerns about the influence of contraceptives on excessive weight gain, long term effects on their reproductive potential and side effects. This information is especially important for health providers with regard to discussing contraceptive options among Black girls and women. These attitudes about contraceptive use may be a significant barrier for some women, and further education and availability of ‘safer’ family
planning options may be warranted. A secondary finding was related to one participant’s experience with abortion. Consistent with previous studies (Finer, Frohwirth, Dauphinee, Singh & Moore, 2007), the participant cited her main reason for opting for her two abortions was because having a child would interfere with her future goals, affordability of child care and the reality of having relationship problems with the father of the unborn child. Although, use of abortion services was not a prominent theme it may be important for health providers to promote preventative family planning options and clearly communicate any impacts that induced abortions may have on reproductive health outcomes.

**Pregnancy Experiences**

Pregnancy intentionality varied depending on participants’ marital status. Participants who were married discussed their experiences with actively planning for a child; whereas mentions of unintended pregnancies tended to be among participants who were either never married or not married at the time of conception (note: several women who became pregnant during late adolescence or young adulthood married later in life). Among those women who experienced unintended pregnancies, there were mentions of a process of initial shock and later acceptance of the pregnancy. As mentioned earlier, the role of early sexual health and family planning interventions may be especially important for Black girls and women who might be at risk for unintended pregnancy. In addition, the availability of support and resources during pregnancy—among women with unplanned and planned pregnancies—was viewed as valuable. Participants expressed an openness to being educated during their pregnancies as well as having family members present to ask health providers questions. Although research on prenatal support services and birth outcomes has yielded mixed findings (Kothari et al., 2014; Baldwin et al., 1998; Klerman et al., 2001), the literature does suggest that prenatal support services may be a
critical aspect of women’s pregnancy experiences by increasing knowledge, perceived social support and satisfaction (Klerman et al., 2001). Moreover, although only one participant reported the usefulness of mobile devices during her pregnancy, there is growing literature focused on e-mediated health promotion (e.g., prenatal monitoring) technology (Rodger et al., 2013), which may also be a useful resource among Black women. It may also be important for providers to encourage Black women to have a family member or intimate partner present during visits to ease any distress or concerns and provider practices.

Participants’ discussion of maternal health status was nuanced. There were no in-depth discussions about women’s overall physical health status or maintenance prior to pregnancy. In contrast to reproductive health, it plausible that physical health characteristics and behaviors were not very salient factors for participants, which may explain why they provided somewhat superficial descriptions for their health status (e.g., “it [my health] was good”, “I may be considered obese”, “I’m not really health conscious”, “I was skinny”). Moreover, although maternal health status was not explicitly discussed, participants described their experiences with significant health complications during their pregnancy. Consistent with the literature on maternal health risks among Black women (Stothard et al., 2009; Bodnar et al., 2010; Wise et al., 2010), participants reported experiencing health complications that were associated with preeclampsia, diabetes, and infection. One study, for example, examined how pregnant Black women viewed pregnancy weight gain and reported that there was little focus on limiting gestational weight gain which was viewed as an indicator for a healthy infant (Groth et al., 2012). These findings underline the importance of cultural context (e.g., acceptance of larger body figures) and health beliefs. Further, a more in-depth exploration of Black women’s conceptualizations of health and health behaviors over the life course and during the
periconceptional period may be important for targeted interventions focused on improving health status and behaviors among Black women.

**Health Systems Experiences**

A number of studies have investigated provider-patient interactions within health care settings. Several studies examining provider-patient interactions have reported the importance of patient-centered care on patient satisfaction (Krupat et al., 2000) and effective physician-patient communication and prenatal care use among Black women (Bennett et al., 2006). Black women have also reported that although their provider’s race is not a primary concern, provider proximity, perceived interest and ability to convey information clearly are strong preferences (Dale et al., 2010). In the present study, participants reported both positive and negative experiences with providers, and many of their experiences were consistent with the existing literature. Participants expressed satisfaction with providers with whom they felt a connection, and providers who appeared to be compassionate, knowledgeable, competent and able to communicate effectively. Moreover, several women expressed their frustration regarding incomplete or inconsistent explanations for their own health as well as the health (or death) of their infants. These findings have important implications regarding Black women’s trust in health providers and how unsatisfactory provider interactions may influence subsequent health seeking behaviors (e.g., Bennett et al., 2006).

Black Americans are more likely to be uninsured and less likely to work in jobs that provide health insurance coverage (National Research Council, 2003), consistent with this data, most participants did not have health insurance through their employer. Instead, four of the five participants did not have health insurance coverage beyond Medicaid coverage (during
pregnancy). Furthermore, national data indicates that the percentage of reproductive-age women without insurance has increased (Kozhimannil, Abraham, & Virnig, 2012) Further, at the institutional level, there are policies in place that create barriers for women, especially black women. For example, health policies that facilitate inconsistent insurance coverage across women’s life span (Dennis et al., 2013) and inconsistencies in Medicaid expansions across states (Jarlenski et al., 2014). Furthermore, each of the participants described at least one issue regarding the continuity, coordination and access to prenatal care. During their pregnancies, participants reported experiencing a lack of provider and care setting continuity, lapses in insurance and delayed Medicaid coverage. These systems-level issues created significant barriers to women’s prenatal care, and may provide some understanding of why some women do not receive early or adequate prenatal care. Thus, it may be important for studies focused on prenatal care initiation and adequacy to also explore systems-level—in addition to individual-level—determinants of inadequate prenatal care. These issues also point to the need for affordable, high-quality ‘cradle-to-the grave’ health insurance coverage for girls and women (Jarlenski et al., 2014). This is especially salient as many participants reported experiencing gaps in their insurance coverage over their life time, and sometimes these gaps prevented them from receiving well-woman care and other reproductive care services.

**Exposure to Fetal or Infant Death**

Most participants reported some degree of exposure or prior knowledge of fetal or infant death. Several participants indicated that they had family members, specifically first cousins, who had also experienced fetal or infant death. Although, participants were aware of these cases, there appeared to be a general belief that it would not happen to their infant. Other women indicated that they had a personal history of recurrent fetal or infant death. The amount of fetal
and infant deaths that have occurred within families is striking, and presents the idea that family case studies may be important in identifying key genetic or environmental factors within families that have a high prevalence of fetal or infant death. Interestingly, an early study estimated the recurrence risk for stillbirth and infant death among first-cousin parents and unrelated parents (Stoltenberg, Magnus, Skrondal & Lie, 1999). This study found that the risk of recurrent stillbirth or infant death is higher for infants of first-cousin parents compared with infants of unrelated parents (Stoltenberg et al., 1999). Another study reported similar findings, and suggested that interactions between common environmental and genetic factors among families may provide further explanation for the occurrence of infant death in families (Hunt, 1999). Overall, the present findings and early research on recurrent infant death suggests that more research on infant death within Black families is needed.

**Strengths of the Study**

There are several notable strengths of the present study. First, within the maternal and child health literature, there continues to be a substantial focus on Black women’s exposure to risk and protective factors during the periconceptional period. In contrast, the life course perspective emphasizes the impact of a variety of factors on health, which begin before conception and continue throughout the life span (Halfon et al., 2014). The present study contributes to the current gaps in knowledge concerning how Black women’s differential exposure to risk and protective processes may impact their health across the lifespan.

Second, the five in-depth interviews generated a significant amount of information-rich data. Thus, using a phenomenological approach in this study aided in generating a contextual
understanding of Black women’s exposure to key risk and protective factors, and uncovering the meaning of those exposures.

A third strength is in relation to the precautions that were established to ensure the best possible interview experience for the participants. For example, each interview was accompanied by a licensed bereavement specialist and at the end of the interview participants were connected to support services and ongoing activities related to infant death. Most importantly, participants were open and enthusiastic about the opportunity to share their lives with the researchers. Regarding participants’ personal grieving process, many mentioned how appreciative they were of the opportunity and how they “needed this” time to talk about themselves.

A fourth strength is that the overall project was a community based participatory partnership with a local organization that is focused on providing bereavement services and preventing infant deaths. This is beneficial because the findings of the present study will be translated into information that can be used to inform new and existing initiatives within the community.

Finally, the researcher employed several methods to ensure the trustworthiness and quality of the study using techniques such as bracketing, inter-coder agreement and member checking. These techniques ensured that the researcher stayed true to the phenomenological approach.

Limitations of the Study

Despite these strengths, there are also some limitations. First, this study relied on participants’ retrospective accounts of key life events. It is very possible that participants either failed to remember certain details of their experience or intertwined memories of separate
experiences. Moreover, the effect of grief on memory functioning should also be acknowledged. Prior research suggests that during the grieving process there may also be instances of selective forgetting and memory impairment among the bereaved individuals (Maccallum & Bryant, 2010). With this in mind, it is very likely that participants may have forgotten certain details of their experience. A similar limitation concerns participants’ potential selectivity in their sharing of details about their experiences. Although participants articulated their enthusiasm about being open and honest, it is reasonable to believe that certain details, especially about individual behaviors, may have been omitted. It is important to understand that infant death is a very traumatic experience, and a key part of the grieving process is meaning-making. Thus, the researcher had to be very careful about questions regarding health behaviors during pregnancy so as not to offend or give the impression that the participants were to blame in any way for their infant’s deaths. A third limitation is that participants’ experiences are context-specific. That is, the lived experiences of Black women in Kansas may be qualitatively different than Black women in New York. Although, it is not the intent of phenomenology to generalize findings to a larger population, it should be noted that Black women in Kansas represent a specific context, and experiences may or may not look different in other locations.

Future Research

The purpose of the present study was to describe the lived experiences preceding infant death among Black women. The findings of the present study have contributed to the existing literature by using a qualitative approach to apply the life course perspective to describe and understand Black women’s social contexts. There are significant gaps in knowledge pertaining to birth outcomes among Black women, but the life course perspective provides a more contextual account of their experiences. The findings from this study have demonstrated that Black
women’s exposure to key risk and protective is nuanced, in that they may experience acute, chronic and cumulative exposure to a specific set of factors throughout life. Future research could continue to explore the life experiences of Black women in multiple regions (e.g., South) of the United States to understand any commonalities or dissimilarities in Black women’s lived experiences. Moreover, the summary of life timelines serves only as a small stepping stone for a much larger idea about how to ‘map’ Black women’s exposures over the life course. Future research could focus on further development of a comprehensive life timeline that could potentially be useful for (a) understanding the degree of exposures to risk and protective factors, and (b) identifying normative and non-normative age-related trends and timing of exposures. For example, consider a state or national database containing information about the ages in which women were exposed to select risk and protective factors, and the creation of a comprehensive ‘life timeline’ that illustrates women’s exposures across each developmental stage.

The present study has also contributed to a contextual understanding of the life experiences of Black women in Kansas who experienced fetal or infant death. It is significant that most of the findings from this study were consistent with existing earlier studies regarding the importance of social relationships (Fung et al., 2001; Taylor et al., 2001; Feldman et al., 2000), the amount and types of stressors that impact Black women (Lu & Chen, 2004; Turner & Avision, 2003), the role of spirituality in maintaining mental wellness (Levin et al., 2005), the implications of early sexual initiation, parental involvement and older sexual male partners on risky sexual behaviors (Epstein et al., 2014; Parkes et al., 2011; Sutton et al., 2014; Wood et al., 2011), the role of support and resources and health beliefs during pregnancy (Klerman et al., 2001; Rodger et al., 2013; Groth et al., 2012), the impact of health care system experiences on satisfaction (Krupat et al., 2000; Bennett et al., 2006; Dale et al., 2010; National Research
Council, 2003) and the increased risk of recurrent infant death within families (Stoltenberg et al., 1999; Hunt, 1999).

There were also some findings (e.g., early sexual assault, exposure to infant death in family) that have not been as widely studied. Thus, rather than overreliance on quantifying the experience of Black women, there is value in exploring the social contexts of Black women and uncovering how these social contexts may shape their health and health behaviors. It will be important for future research to consist of both quantitative and qualitative approaches to understanding birth outcomes among Black women for two reasons. First, there is a dearth in the literature with regard to in-depth, context-specific investigating into the life experiences of Black girls and women. Second, continued research will be able to inform the development of effective, context-appropriate interventions targeting Black girls and women at varying developmental stages.

Participants in the present study did not discuss in detail their perceived/actual health status and behaviors. Future research could also explore the conceptualization of health among Black woman across the life span, especially during the periconceptional period. Future research might also explore Black women’s exposure to neighborhood/community-level factors (i.e., air pollution, built environment, access to fresh produce) across the life course and how those exposures (or lack thereof) may be linked to birth outcomes.

**Implications for Practice and Policy**

Overall, the findings of the present study might be useful for generating discussion about how interventions may be able to address individual health characteristics and behaviors and health system factors across Black women’s lifespan. Participants reported experiencing a
significant amount of stressors and other modifiable risk factors which typically began to emerge in early childhood. This finding has important implications for considering the appropriateness of early family strengthening interventions that address family conflict, parent-child communication about sexual and reproductive health, and support services for girls who have experienced sexual assault. It is possible that early intervention with girls from low- to high-risk backgrounds may aid in modifying adverse health and health behaviors outcomes which may later impact their reproductive health. Although many participants reported prior exposure to infant death, it is a phenomenon that is not well understood among women. Community-wide efforts to raise awareness about fetal and infant mortality will be important for (a) creating an ongoing dialogue among community members about the infant mortality as a public health issue, (b) informing families about the risk and protective factors associated with infant death, and (c) increasing mobilization of grassroots infant mortality prevention initiatives (e.g., changes to the built environment, demanding health policy change). Furthermore, the availability of support services for pregnant Black women, particularly those women who are low-income or have very little social support. It will also be necessary for communities to ensure the availability of support services for Black women who have experienced infant death, especially recurrent infant death.

The findings of this study also underline the need for system-level changes that positively impact Black women’s health. At the provider and health system-level, improvement in provider interactions with low-income patients and patients of color are critical. It is important for providers to understand how their interactions with patients may impact trust and subsequent health seeking behaviors. Further, there is room for improvements in the coordination of medical and prenatal care. Currently, Black women, and other women of color, are experiencing
institutional barriers to care as a result of clinical bureaucracies rooted in institutional racism and
classism (National Research Council, 2003). These institutional barriers may very well be
contributing to some variance in racial/ethnic disparities in health and birth outcomes.

Participants in the present study also reported experiencing inconsistent health coverage
over the course of their lives, which subsequently interfered with their ability to received
adequate medical or prenatal care. The advantage of the current health system is the
implementation of the Patient Protection and Affordable Care Act (ACA) of 2010, which
includes provisions that ensure women’s access to preventative health care needs through their
insurance plans with no co-payments (U.S. Department of Health and Human Services, n.d.).
Insured women have coverage for eight preventative health services: (1) well woman care, (2)
screening for gestational diabetes, (3) Human Papilloma Virus (HPV) DNA testing, (4) sexually
transmitted infection counseling, (5) FDA approved contraceptives and counseling, (6)
breastfeeding support, supplies and counseling, (7) HIV screening and counseling and (8)
domestic violence screening and counseling (U.S. Department of Health and Human Services,
n.d.). The ACA also allows young adults to remain on their parents’ health insurance plan until
the age of twenty-six (U.S. Department of Health and Human Services, n.d.). The U.S.
Department of Health and Human Services (n.d.) has indicated that it “understands the need to
take into account the unique health needs of women throughout their lifespan.” Thus, although
Black female adolescents may have insurance through their parents’ plan or Medicaid, their
coverage ends at the age of twenty-six (or much earlier for youth in live in states that do not
provide Medicaid expansions). This is problematic for several reasons. First, young women in
their mid-twenties are typically less established and are not usually employed in full-time
positions with full benefits, which brings into question affordability of health coverage. Second,
women’s mid-twenties are often considering prime childbearing years, and consistent preventative reproductive care is also crucial during this time frame (Jarlenski et al., 2014). Future policy developments will need to modify implementation of the ACA to address the preventative health care needs of adolescent girls through adulthood.

**Conclusion**

The disproportionately higher rate of infant mortality among Black women has been a serious public health matter for the last fifty years. Although, prior research and interventions have contributed to a better understanding of key risk and protective factors associated with infant mortality, the disparities in birth outcomes continue to persist. In the last fifteen years, however, there has been greater application of the life course perspective in maternal and child health research. The present study sought to contribute to the gaps in knowledge regarding possible life course determinants of adverse birth outcomes among Black women. The overall findings of the present study demonstrated the importance of exploring women’s early childhood and adolescent years to gain insight into how these early life experiences may shape their health and behaviors in later life. The results have also uncovered key protective factors, such as the practice of faith/spirituality, mental wellness strategies, and strong family support. Further, it is especially important to identify protective factors that may serve as ample buffers against the adversities that Black women face daily. Based on other key findings around chronic stress and health care system experiences, this research can begin to inform a number of intervention programs that target Black girls and women across the life span, as well as inform policy changes that consist of significant modifications to practices that have historically created barriers for women of color. Overall, it is clear from the present study that the next steps for
research, practice and policy matters is to integrate the life course perspective into efforts geared towards optimizing maternal and infant health within the Black community.
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MEMORANDUM OF UNDERSTANDING

Christy Schunn, of the Kansas Infant Death and SIDS Network, Inc, and Kyrah Brown and Dr. Rhonda Lewis (research advisor), of Wichita State University, have come together to collaborate on the “Mothers’ Voices Project”.

The Mothers’ Voices Project is a community-university collaboration. The project will capture the stories of African American mothers regarding their preconception health, prenatal care experiences and shared experiences in losing their infant and bereavement. This project involves conducting in-depth interviews (and the collection of some data) and providing educational materials/resources to participants.

The Mothers’ Voices Project is expected to begin June 2013 and conclude in June 2014.

KIDS Network, Inc.

Roles and Responsibilities

1) The KIDS Network will aid in recruiting current and/or past clients of the organization who may be interested in participating in this project.

2) The KIDS Network will aid in the development of interview questions for this project.

3) The KIDS Network will be involved in the actual interviews with women who agree to participate in this project.
   a. Libby Baumgartner, KIDS Network bereavement specialist, will be present to co-facilitate or offer bereavement support at interview sessions
b. KIDS Network will provide educational materials which will be given to women after interview during debriefing.

c. KIDS Network will provide office space for interviews

d. Christy Schunn and Libby Baumgartner will be active in the interview coding process.

4) The KIDS Network, Inc. will provide a locked office room for storage of project-related data.

**Dissemination Plans**

5) The KIDS Network will use the de-identified, aggregated project data to inform any existing or future intervention programs for the organization.

**Data Ownership**

6) The KIDS Network will have joint-ownership of the project data.
   a. Kyrah Brown will provide the KIDS Network with the project database

7) The KIDS Network staff will be included as authors on any publications or presentations which take place after the completion of the project (and will be notified of such activities).

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**Kyrnah Brown/Wichita State University Student**

**Roles/Responsibilities**

1) Kyrah Brown will be responsible for coordinating the project activities.

2) Kyrah Brown will submit proposal for the project through the Wichita State University Institutional Review Board for approval.
   a. Will provide informed consent forms for participants
b. Will provide a copy of the approved application to the KIDS Network before project begins

3) Kyrah Brown will engage in the following project-related activities at the KIDS Network, Inc. offices.
   a. Make phone calls to participants for recruitment or participation
   b. Facilitate interviews with participants
   c. Store project-related data (consent forms, contact information, etc.)

4) Kyrah will prepare 1-3 data briefs for the KiDS Network which will be used to inform existing programs.

Dissemination Plans

5) Kyrah Brown plans to use de-identified, aggregated project data in publications and presentations.
   a. KIDS Network, Inc. staff will be listed as authors on all publications or presentations (and will be notified of such activities)

Data Ownership

6) Kyrah Brown has joint-ownership of the de-identified, aggregate project data and will retain project database for future dissemination activities (e.g., publication, presentations)

COMMITMENT TO PARTNERSHIP

1) The partners agree to collaborate on the aforementioned project and assume the aforementioned roles and stipulations.

2) We, the undersigned have read and agree with this M.O.U. Further, we have reviewed the proposed project and approve it.

Christy Schunn, LSCSW
Executive Director
KIDS Network, Inc.

Kyrah K. Brown
Doctoral Student
Wichita State University

Rhonda K. Lewis, Ph.D., M.P.H.
Professor of Psychology
Wichita State University

Signature: ____________________________ Date: 4/24/15

Signature: ____________________________ Date: 4/24/13

Signature: ____________________________ Date: 8-7-2013
LETTER OF COOPERATION

June 18, 2013
Office of Research Administration
Institutional Review Board
Wichita State University
1845 Fairmount, Box 0007
Wichita, KS 67260

To Whom It May Concern:

My name is Christy Schunn and I am the executive director of the Kansas Infant Death and SIDS (KIDS) Network, Inc. I am submitting this letter of cooperation for the project “Mothers' Voices: African American Mothers’ Experiences with Infant Mortality.” Kyrah Brown, a community psychology graduate student, has requested permission to collect research data from current and past clients of the KIDS Network. I have agreed to collaborate with her on this research project which is expected to end early June 2014.

As a partner in this research endeavor, I understand that the purpose of the proposed research is to understand African American women’s life experiences around maternal and child health issues, particularly infant death. I agree to allow Ms. Brown to work as a volunteer for our organization in which she will have access to our office space and resources. Together, Ms. Brown and I have outlined the stipulations of this project.

- To ensure participants' confidentiality and protection, all correspondence that Ms. Brown has with participants will be conducted on-site at the KIDS Network office (e.g., phone calls, mailings, scheduling etc.). In addition, all documents will remain in a locked room at the KIDS Network office.

- Ms. Brown will facilitate the in-depth interviews. A KIDS Network staff member who is a bereavement specialist will also be present during interviews to either co-facilitate and/or provide bereavement support to participants, as appropriate.

- The interviews will be held at the KIDS Network office or an agreed upon location as decided by the client and staff.
As a partner, I have agreed to recruit women who may be interested in project participation, to assist in development of research questions to improve KIDS Network services and to be involved in the entire research process.

The following benefits and deliverables for the KIDS Network have been agreed on. Following the completion of the research project, Ms. Brown will provide data briefs for our organization which will be used to inform existing interventions as well as a tool to demonstrate the relevance of bereavement services provided by our organization. I and my staff will also be listed as authors on any publications that are the result of this research project.

Lastly, Ms. Brown has agreed to provide our organization with a copy of the Wichita State University IRB-approved, stamped consent document before we begin recruiting participants.

If there are any questions, please feel free to contact me.

Sincerely,

Christy Schunn, LSCSW
Executive Director
KIDS Network, Inc.
1148 S. Hillside, Suite 10
Wichita, KS 67211
Email: edirector@kidsks.org
Telephone: 316-682-1301
APPENDIX C

IRB APPROVED INFORMED CONSENT FORM

1. DESCRIPTION AND PURPOSE OF THE STUDY

You are invited to participate in a study focused on understanding the life experiences of African American mothers in Kansas who have experienced perinatal or infant death. This study is led by Wichita State University and the Kansas Infant Death and SIDS Network, Inc. (KIDS Network, Inc.). The intentions behind this study are to (a) hear the voices and stories of African American women and (b) use this information to help improve infant health efforts in the Wichita community. A total of 10 women are expected to participate in this study.

You were selected as a possible participant in this study because (a) a KIDS Network Inc. staff member listed you as someone who might be interested in participating in the study, or (b) you expressed interest in participating in the present study after speaking with a KIDS Network, Inc. staff member and provided your contact information you received information from a KIDS Network Inc. staff member. You were also selected because you met the criteria for participation in this study: (a) African American women, (b) between 18-40 years old, (c) lives in Kansas, (d) experience perinatal or infant death in the last 8 years.

2. NATURE OF YOUR PARTICIPATION

Participants in this study will be asked to take part in one-to-one interviews. In these interviews, participants will be asked questions about their early life experiences, preconception health, past prenatal health, and the overall experience of infant loss. In addition, participants will be asked about positive and challenging life experiences. The expected length of interviews will be a maximum of 90 minutes in length. All interviews will be audio recorded for research purposes and will be kept in a locked file cabinet. No identifying information will be mentioned on the audio-recorded interviews. Interviews will be held at the KIDS Network offices or at the home of the participant (if you ask).

Two to three weeks after your interview, the interviewer (Kyrarah Brown) will contact you by telephone to do what is called “member checking”. Because we value your experiences, we want to make sure that we are presenting your experiences accurately. She will provide you with a copy of your statements in the form of categories (or themes) and ask you to verify the truthfulness of how the information is portrayed and provide any feedback. This member-checking process will take between 15-30 minutes depending on how much feedback you share.
3. POSSIBLE RISKS OR DISCOMFORT
A. Infant loss is a challenging topic to talk about and there is a chance that you may experience discomfort during the interview. During the interview, you may be asked questions that you may find uncomfortable to discuss. For example, some questions may cause you to think about difficult emotional states or moments in your life. If any discomfort does arise, you are free to take a break from the interview or discontinue your participation in the study. A bereavement specialist will be available at the interview to provide any support that you may need should you experience emotional discomfort.

B. You will be asked to provide confidential information about yourself (e.g., details about your life experiences). Please see the CONFIDENTIALITY section for details on the steps that will be taken to protect your identity and your information.

4. BENEFITS OF THIS RESEARCH STUDY
A. When your participation is complete, you will be given an opportunity to learn more about community services and resources related to infant health, maternal health and life after loss (e.g., bereavement services).
B. At the end of your interview, you will have the opportunity to share words of encouragement or inspiration that will be shared with other women who have experienced infant loss.
C. Your participation in this study will contribute to scientific knowledge about the life experiences of African American women who have experienced infant death. Such information is important for developing community efforts to address infant mortality in Kansas.

5. CONFIDENTIALITY
To make sure that your information is kept private, you will be assigned a code number which will be used on documents. All identifying information will be removed from questionnaires and other documents when your participation is complete. Although you are participating in individual interviews, no individual person’s responses will be reported. Instead, only ‘group data’ will be reported (for example, “80% of participants said that they had used bereavement services in the past”). All files will be kept in secure folders in a locked file cabinet at the offices of KIDS Network. Information will be kept on file for up to 5 years after the completion of the project.
6. DATA SECURITY
All hardcopy documents and digital tape recordings will be kept in a locked filing cabinet at the KIDS Network offices. The only persons with access to this filing cabinet are the key personnel of this project. These people include Christy Schunn, Libby Baumgartner and Kyrah Brown. After the completion of this study, all information will be shredded for security purposes.

7. COMPENSATION FOR PARTICIPATION
Participants will be compensated for their participation at the end of the interview in the amount of a $20.00 cash stipend. Please note that in order to receive this cash stipend you must complete a form that requires you to list your social security number. This information is used only for administrative purposes for Wichita State University. Your information will be kept strictly confidential.

Wichita State University does not provide medical treatment or other forms of reimbursement to persons injured as a result of or in connection with participation in research activities conducted by Wichita State University or its faculty, staff, or students. If you believe that you have been injured as a result of participating in the research covered by this consent form, you can contact the Office of Research and Technology Transfer, Wichita State University, Wichita, KS 67260-0007, telephone (316) 978-3285.

8. OPPORTUNITY TO WITHDRAW FROM STUDY
Participation in this study is entirely voluntary. Your decision whether or not to participate will NOT affect your future relations with Wichita State University and/or the KIDS Network, Inc. If you agree to participate in this study, you are free to withdraw from the study at any time without penalty.

9. OPPORTUNITY TO BE INFORMED OF RESULTS
We expect the results will be fully available around mid-May 2014. If you wish to be told the results of the study, please contact Kyrah Brown, at 316-682-1301.
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the results of the study, please contact: Kyrah Brown, at 316-682-1301.
PROJECT INFORMATION

If you have any questions pertaining to your rights as a research participant, or about research-related injury, you can contact the Office of Research and Technology Transfer at Wichita State University, Wichita, KS 672060-0007, telephone (316) 978-3283.

Project Title: Mothers’ Voices: A Phenomenological study exploring the lived experiences of African American women who have experienced perinatal or infant death

IRB Number: Approval # 29-80

Organizations:
- Wichita State University: Kansas Infant Death and SIDS Network, Inc.

Principal Investigator: Rhonda K. Lewis, Ph.D., M. P.H.
Phone: 316-978-3695

Community Investigator: Christy Schumm, LCSW
Phone: 316-682-1301

Project Coordinator: Kyrah Brawn, M.A.
Phone: 501-978-3695/316-682-1301

10. AUTHORIZATION. Please write your initials in the boxes provided to indicate that you agree with the statement.

A. □ I am at least 18 years of age.

B. □ I have read and understand this consent form, and I volunteer to participate in this research study.

You are under no obligation to participate in this study. Your signature indicates that you have read the information provided above and have voluntarily decided to participate.

You will be given a copy of this consent form to keep.

Participant Full Name (print): ____________________________ Date: __________

Participant Signature: ____________________________

Principal Investigator Signature: ____________________________ Date: 10-2-2013

Signature of Person Obtaining Consent: ____________________________ Date: __________
Volunteers Needed for a Research Study: The Mothers’ Voices Project

WHO IS LEADING THIS STUDY?
The Kansas Infant Death and SIDS Network, Inc and Wichita State University are collaborating on this research project to understand the experiences of African American women who have experienced perinatal or infant death.

WHAT IS THE PURPOSE?
- To understand the experiences of African American women who have experienced perinatal or infant death as a way to shape future maternal and child health intervention efforts.

WHO IS ELIGIBLE TO PARTICIPATE?
- African American/Black woman
- Have experienced perinatal or infant death (i.e., due to complications from prematurity/LBW, birth defect, stillbirth) in the last 8 years
- Are 18-40 years of age
- Are currently living in Sedgwick County

WHAT WILL YOU BE ASKED TO DO?
- After completing an informed consent form, you will be asked to participate in a 90 minute interview to discuss your early life experiences, preconception health, and your overall experience of perinatal or infant death.

DO I GET COMPENSATED FOR MY PARTICIPATION?
- Yes, participants who meet selection criteria will be compensated for their time.

TO LEARN MORE INFORMATION:
- If you are interested in learning more about this study, please contact Kyrah Brown, project coordinator, at (316) 682-1301, or Libby Baumgartner at (316) 682-1301 or support@kidsks.org.

If you have questions pertaining to your rights as a research participant or about research-related injury, you can contact the Office of Research and Technology Transfer at Wichita State University, Wichita, KS 67250-0007, telephone (316) 978-3255.
APPENDIX E

DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

ID Number: ________________ (staff use only)

The purpose of this project is to understand the life experiences of African American mothers who have experienced pregnancy loss and infant death. We believe that it is important to hear your voices/stories because they can help to build on efforts to support other women like you. Your information will be kept strictly confidential and will only be used for the purposes of this project.

Please take a moment to complete the following questions.

Demographic Questions:

1. What year were you born? ________________ (e.g., 1977)
2. What is your current zip code? ________________
3. What do you currently do for a living? ________________
4. What level of education have you completed?
   A. Less than high school
   B. High School Diploma/GED
   C. Some College
   D. 2-Year College Degree
   E. 4-Year College Degree
   F. Master’s Degree
   G. Professional Degree (M.D., J.D., Ph.D.)
   H. Trade/Vocational Degree (e.g., Cosmetology License)

5. What is your relationship status?
   a) Single, Never Married
   b) Committed relationship, not married
   c) Married
   d) Separated
   e) Widowed

Birth History Questions:

6. What year was the death of your infant? __________
7. What was the cause of death for your infant?
   □ SIDS/Sleep-related
   □ Birth defect/abnormality
   □ Disorder related to prematurity/low birth weight
   □ Stillbirth
   □ Miscarriage
   □ Accident (unintentional injury)
   □ Other: ________________

8. Have you ever used any bereavement or support services provided by the KIDS Network, Inc.?
   □ Yes    □ No
APPENDIX F

INTERVIEW AND SCRIPT

Interviewer:

Hello ____, thank you so much for agreeing to participate in the Mothers’ Voices Project. As I mentioned when we talked over the phone, my name is Kyrah Brown and I am a graduate student at Wichita State University working with Libby and Christy of the SIDS/KIDS Network on this project. **My name is Libby Baumgartner. and I am the bereavement specialist and art therapist at the KIDS Network, Inc..**

The purpose of this project is to understand the life experiences of African American mothers who have experienced perinatal and infant loss. We believe that it is important to hear your voices/stories because they can help to build on efforts to help other women like you. Please think of this as more of an informal conversation rather than an interview. We want you to be as comfortable as possible. Our session should last 60-90 minutes. Before we get started, I will have you complete an informed consent form and then a short demographic questionnaire.

**Informed Consent Process**

We will begin by having you read and sign an informed consent form. This details everything that you need to know about this study. Before you sign it, I will go through and re-emphasize some important areas to make sure that you have a clear understanding of everything. I will then provide you with a copy of this document. Please feel free to ask me any questions.

**Administer Socio-demographic questionnaire**

Next, I need you to complete a short questionnaire which asks you several questions about your background. As you can see, we will only use a personal ID number (instead of your name) to protect your identity and privacy. This information will be stored in a locked file cabinet in a locked room at the KIDS Network, Inc. office.

**Begin Interview Session**

Now, we will begin our conversation. We will take a 5-10 minute break, but if you need a break sooner please feel free to let me know and we will take a break.

I am also going to provide you with this large sheet of paper which will represent your life timeline. A life timeline is a creative way to record important events and trends in your life. This timeline (point to line on paper) represents your life from birth to now and has four marks to indicate where you are on the timeline: childhood, adolescence, young adulthood, middle adulthood. You are free to make new marks. I will be asking you several questions and as we talk through your responses, you will mark on your timeline where major life events occurred. For example, we will talk about early adulthood and you may speak about the time that you first moved out on your own or the time you may have lost a job. You will note that life event on your time line. Does that make sense? Do you have any questions or concerns before we get started?
APPENDIX F (continued)

1. **What can you share with me about yourself?**
   Prompts: Where are you from? What do you do? What’s your family like? What do you do for fun? What things are important to you?

2. **What can you share with me about your ‘girlhood’ or ‘early adulthood’?**
   *Possible follow-up questions:*
   a. What major positive events impacted you and your family? Stressful/difficult events?
   b. What was family life like? Neighborhood characteristics?
   c. What was your health like back then?
      i. What healthy behaviors did you have? Risky behaviors?

*The next series of questions will be related to your preconception health and pregnancy experience.*

3. **Prior to becoming pregnant, what was your understanding/thoughts about preconception health, or family planning?**

4. **Thinking back to when you were pregnant with (say infant’s name),**
   a. What were your feelings when you found out you were pregnant? What did you do?
   b. What were some healthy behaviors that you engaged in? risky/not-so health behaviors?
   c. What was your environment like? (e.g., social, physical environment)
   d. What was your pregnancy like? (e.g., easy, difficult, in what ways)
   e. What was your experience in the health care system?
   f. What things helped you through your pregnancy? What things made it more difficult?

[TAKE 5-10 MINUTE BREAK]

5. **Could you please tell me about what is like for you having experienced the death of an infant?**
   *Possible follow-up questions:*
   a. What can you tell me about how you make sense of this experience? or not?
   b. What is the most difficult/less difficult thing(s) to deal with during this time?
   c. What can you tell me about what has happened within your family? What impact, if any, as has this experience had on you and your family?
   d. What can you tell me about your coping and grieving process? What has helped?(not helped?)
   e. What do you know about infant mortality?
   f. What are your thoughts about bereavement support? What would an ideal support service have?
Interviewer: Thank you so much for your willingness to share all of this information. Before we end today, let’s take a step back and look at what you’ve written. Could you tell me a bit about what you were thinking as you were writing? What are you thinking as you look at your timeline?

Participant: { participant speaking}

Interviewer: Thank you so much for all of your sharing. Let’s switch gears for a moment. As I mentioned, we hope that this project will help other women who have experienced perinatal or infant death. I would like to ask you what words of inspiration or encouragement would you share with other women who have experienced perinatal or infant death?

Participant: {participant speaking}

[KIDS Network, Inc. information will be provided to interview participant]

Interviewer: Thank you again for sharing. We would like to make sure that you are able to stay connected with the KIDS Network, Inc. and the support that they provide. We’ve prepared a packet of information about these supports and we/Libby is here to answer any questions that you may have about this information. Please let us know if you have any questions or would like additional information about something that we haven’t talked about.

Again, thank you so much for taking out the time to participate. We deeply appreciate you for sharing your story. As a token of appreciation, we would like to offer you $20 for your participation. We will also be sending you a token of appreciation, which will include words of inspiration from bereaved mothers. Once the interview data is analyzed, we would like for you to look over and verify that our interpretation of what you’ve shared is correct. So in the next 2-3 weeks, I will send you your statements in the form of categories and I will call you to discuss them.
APPENDIX G (continued)

Sarah Life Timeline

Mother went blind
Received award for track & field
Bought first car
1st sexual intercourse
1st well woman
Aged out of insurance
Exited abuse relationship
Abused by former boyfriend
2nd pregnancy
Going back to school

Moved in with Grandmother
Cousin passed away
Death of Grandmother
Joined Army Reserves
Dropped out of HS
Left Army
1st attempt at GED
1st pregnancy
Infant Death

Ruth Life Timeline

1st began cheerleading
Ran the house
Joined praise team for 6 years
Found dream profession
1st boyfriend/law
Made cheer captain on college
Infant death/Stillbirth
Precedence

Sexually molested by family member
Mental cycle
1st sexual intercourse
Raped by acquaintance
1st pregnancy
Engaged
First year of college
Daughter's memorial

Love me some me take an active part in my own happiness and success