EXPLORING BLACK WOMEN'S EXPERIENCES WITH PERINATAL LOSS, GRIEF, AND COPING

by

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ABSTRACT

This study's purpose is to better understand the lived experiences of Black women who have experienced perinatal loss using Stroebe and Schut's (1999) Dual Process Model of Coping with Bereavement as a guiding framework. A descriptive phenomenological design was used to conduct semi-structured one-on-one interviews with a purposive recruited sample. The sample consisted of five Black mothers who had experienced a perinatal loss between 20 and 36 weeks gestation within the past five years. Colaizzi's (1978) framework was used to conduct data analysis. Each woman's unique story is detailed, following a description of the three emergent themes and seven theme clusters. The three emergent themes found were medical negligence, social relationships, and transformation. These findings build upon existing literature and offer implications for healthcare and research professionals. Future research directions are also explored.

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TABLE OF CONTENTS

TITLE PAGE……i

COPYRIGHT……..ii

ACKNOWLEDGEMENTS……iii

LIST OF TABLES……vii

CHAPTER 1: INTRODUCTION.....1

CHAPTER 2: LITERATURE REVIEW 3

Defining Perinatal Loss, Grief, Bereavement, and Mourning 3

Theoretical Framework.....4

Racialization 7

Interpersonal Racism 8

Structural Racism.....9

Historical Context and Medical Racism 10

Stressors.....12

Social Stressors.....13

Financial Stressors 14

Post-Death Rituals and Decision-Making.....15

Concurrent Losses and Concerns about Subsequent Pregnancies.....17

Coping 17

Social Support 18

Religious and Spiritual Coping 19
Professional Mental Health Care 21
Remembering the Baby 22
Conclusion 23
CHAPTER 3: METHODOLOGY 25
Methodological Approach 25
Sampling and Recruitment 26
Participants 28
Procedure 29
Analysis 30
Data Trustworthiness 31
Positionality Statement 31
CHAPTER 4: RESULTS 33
Participant Descriptions 33
Denise 33
Courtney 33
Nicole 34
Gabrielle 35
Erika 35
Themes 36

Emergent Theme 1: Medical Negligence....37
Emergent Theme 2: Social Stressors....42
Emergent Theme 3: Transformation....49
Exhaustive Description....58
CHAPTER 5: DISCUSSION....60
Medical Negligence....60
Social Stressors....64
Transformation....67
Implications....73
Future Directions....72
Conclusion....75
REFERENCES....76
APPENDIX A: IRB APPROVAL....92
APPENDIX B: RECRUITMENT FLYER....94
APPENDIX C: INFORMED CONSENT....95
APPENDIX D: INTERVIEW GUIDE....99
APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE....100

LIST OF TABLES

1. Participant Demographics 28

2. Emergent Themes and Thematic Clusters 37

CHAPTER 1: INTRODUCTION

> I think that if I had been a middle-aged White woman, this would've been a completely different conversation we'd be having. I'm trying to make the change where it's less about what you look like on the outside. Where you are just a woman having a baby.

These words from one of the study participants, Nicole, capture the essence of the project and the meaning behind this work. In general, the loss of a child is considered one of the most devastating losses a person can experience, with parents feeling the pain of the death for decades afterwards (Rogers et al., 2008). Perinatal loss, encompassing deaths occurring between 20 weeks gestation and 28 days past birth (Barfield, 2016), is distinct from the loss of older children due to its ambiguity and tendency to be disenfranchised (Lang et al., 2011). Disenfranchised grief occurs when there is a lack of social acknowledgement of the grief (Doka, 1989), which often occurs in perinatal loss due to the absence of social norms surrounding the death of a baby.

For Black women in particular, the historical denial of Black maternal grief (William & Bonner, 2023) and social pressure on Black women to be "strong" can amplify feelings of disenfranchisement. Black women have the highest rates of perinatal mortality in the United States, with infants born to Black mothers 2.4 times more likely to die than infants born to White mothers (Ely & Driscoll, 2023). This startling discrepancy calls for a thorough examination of Black women's lived experiences of perinatal loss to better understand their experiences.

The grieving process can produce a variety of stressors for individuals. Lazarus and Folkman (1984) described stress as a situation in which a person's resources cannot meet the demands of the given circumstance and coping as the behaviors individuals will engage in to decrease feelings of distress. Stroebe and Schut's (1999) Dual Process Model of Coping with Bereavement (DPM) conceptualized coping with death as a fluid, ebb-and-flow process between

activities that focus on the loss and activities to adapt to life without the person. To date, no identified qualitative studies focusing solely on perinatal loss in Black women has utilized the DPM despite its identified usefulness for research on infant loss (Shannon & Wilkinson, 2020). Thus, the purpose of this study is to examine Black women's stressors and coping strategies related to perinatal loss using the DPM.

CHAPTER 2: LITERATURE REVIEW

Defining Perinatal Loss, Grief, Bereavement, and Mourning

The following definitions are used for this research study:

Perinatal death is a term that encompasses both late fetal deaths and live births with short survival periods, which are grouped together for statistical purposes (Barfield, 2016). The parameters for inclusion for perinatal death can vary, with factors such as cultural perspectives and availability of information influencing what counts as perinatal. Three common definitions of perinatal deaths include infant deaths at less than seven days of age and fetal deaths at 28 weeks or more, infant deaths at less than 28 days of age and fetal deaths at 20 weeks or more, and infant deaths at less than seven days of age and fetal deaths at 20 weeks or more. For the purposes of this study, the second definition (infant deaths at less than 28 days of life and fetal deaths at 20 weeks or more; Barfield, 2016) was chosen to include the broadest range of participants possible while still within the bounds of a common, recognized definition of perinatal loss. Perinatal loss was chosen for its unique scope of covering both pre- and post- birth deaths while excluding early miscarriages and older child deaths, allowing an in-depth look at one specific time frame of loss.

Eyetemitan's (2020) definitions of grief, mourning, and bereavement were used for this study. Grief is defined as one's personal reaction to the death of a person, encompassing cognitive, physical, social, emotional, and spiritual responses. Mourning is a culture's response to a loss; the public display of grieving that often includes death rituals such as funerals and wakes. Bereavement describes a state of being or the time after the loss during which grieving and mourning occur. As this study was focused on individual experiences, grief and bereavement will be the primary focus.

Theoretical Framework

The Dual Process Model of Coping with Bereavement (DPM) proposed by Stroebe and Schut (1999) conceptualizes grief as an ongoing process involving oscillation between loss-oriented and restoration-oriented actions to cope with the loss of a close loved one. Rather than viewing grief as a list of tasks or steps to be completed as grief models prior to the DPM describe, this framework suggests that grief is more complex and grief progression is often non-linear. This theory was chosen for its emphasis on the concepts of stressors and coping, as well as its continuous, dynamic view of grief as an ongoing process rather than a predetermined set of sequential stages.

The DPM employs several key concepts outlined by Lazarus and Folkman's (1984) Cognitive Stress Theory to define stressors and coping. Lazarus and Folkman (1984) defined stress as a situation that arises and places demands on an individual that exceeds that person's resources, endangering their well-being. Coping is then defined as the "cognitive and behavioral efforts" (Lazarus & Folkman, 1984, p. 178) the individual utilizes to manage these demands, undergoing a cognitive process called "appraisal" (p. 31) to determine if the situation is indeed stressful. Stroebe and Schut (2010) highlighted the importance of differentiating between stressors, coping, and outcome when using the DPM, referencing Lazarus and Folkman (1984) again to explain that stressors are the nature of the stress or the reason why coping must occur, coping processes are a way to deal with the stressor, and the outcome is the end result of the coping action taking place.

Stroebe and Schut (1999) further divided stressors into two distinct categories: loss-oriented stressors and restoration-oriented stressors. Loss-oriented stressors are those that center on the loss itself, including activities such as ruminating over the deceased loved one, looking at

sentimental items or photographs, crying over the death, and reminiscing about life before the death. Restoration-oriented stressors are those that center on adaptation to life after the loss, including distraction, denial or avoidance, dealing with life changes, or the formation of new identities or roles. These stressors are not framed as beneficial and detrimental, but are instead described as equally necessary to grieve healthily (Stroebe & Schut, 1999).

A key component of the DPM is the concept of oscillation, or the ebbing and flowing between loss- and restoration-oriented stressors over the course of bereavement (Stroebe & Schut, 1999). In contrast to other models of grief that suggest a series of phases one must move through in sequence in order to adjust, Stroebe and Schut's (1999) model posits that the grief and bereavement process is an ongoing fluctuation between focusing on and off of the loss, recognizing that at times the bereaved may engage in voluntary or involuntary "time off" (p. 212) from their grieving. This denial is not characterized as unhealthy or detrimental to the grieving process, but rather as necessary for eventual adjustment to the death.

While Stroebe and Schut (2010) emphasized that the DPM is not a phasic framework, they do acknowledge that over time the patterns of oscillation do change, with loss-oriented stressors eventually becoming less salient as restoration oriented stressors take their place. Additionally, time spent on both loss and restoration oriented stressors will decrease as time goes on. Finally, after sufficient and possibly repeated confrontation of the loss, habituation may occur and the need to ruminate over aspects of the loss may dissipate (Stroebe & Schut, 1999).

The DPM provides context for the experience of perinatal loss specifically by offering a comprehensive explanation of disenfranchised grief. Doka (1989) defined disenfranchised grief as grief that occurs in relation to a loss that "is not or cannot be openly acknowledged, publicly mourned, or socially supported" (p. 4). Under the DPM, disenfranchised grief arises from an

imbalanced social emphasis on restoration-oriented stressors due to the loss being unrecognized, resulting in loss-oriented stressors being disregarded (Stroebe & Schut, 2010). Disenfranchised grief in perinatal loss can occur due to the ambiguous nature of the baby to others outside of the mother, as their lack of tangible presence can lead others to view the death as minor compared to the loss of others (Shannon & Wilkinson, 2020).

In addition to the context the DPM provides for disenfranchised grief, the characterization of grief as a back-and-forth process provides context for complicated grief when there is an imbalance of loss- and restoration-oriented stressors or if there is a disruption in the oscillation process (Stroebe & Schut, 1999). Complicated grief is a condition that is marked by intense, prolonged grief causing impairment to daily functioning (Shear, 2015). Perinatal or pregnancy loss can result in complicated grief. Previous research suggests that parental grieving after pregnancy loss most steeply declines after one year (Lin & Lasker, 1996), while general research on grief suggests that negative grief indicators like disbelief, depression, and anger peak and then decline around six months after the loss (Maciejewski et al., 2007). Under the DPM, extreme reactions to grief by avoiding the oscillation process and exhaustively focusing on one orientation could result in one of the various forms of complicated grief, including absent and chronic complicated grief (Stroebe & Schut, 2008). Avoidance of confronting the reality of the loss through denial or distraction (i.e., restoration-orientation) aligns with absent complicated grief, while avoidance through focusing on the loss and excessive attachment to the deceased (i.e., loss-orientation) aligns with chronic complicated grief. Therefore, individuals must engage in both loss- and restoration-oriented stressors to adapt to life without the person they have lost.

Stroebe and Schut (1999) discussed gendered differences in coping, noting that women are more likely to be loss-oriented while men tend to be restoration-oriented. They note that this

pattern is not necessarily detrimental to healthy grieving, but that adherence to extremes on either side by any gender with the absence of oscillation is where dysfunction in coping appears (Stroebe & Schut, 2010). Gender correspondence in coping could lead to miscommunication within heterosexual couples, with fathers' tendencies towards restoration-orientation leaving mothers feeling as if they are not grieving enough when they are just grieving differently (Stroebe & Schut, 2010). It should be noted that Stroebe and Schut's (1999) original description of gender and coping did not include evaluations of LGBTQ+ couples, with later writings (Stroebe & Schut, 2015) acknowledging the need to further research DPM across different family dynamics. Similarly, research on parental bereavement using the DPM tends to focus primarily on couples (Currie et al., 2019; Meij et al., 2008), leaving one to wonder how partnership status may impact the oscillation process. Finally, while little research has been done on the applicability of the DPM on Black grieving specifically, the model has been used in a variety of cultural contexts successfully (Fiore, 2021).

Overall, the DPM of Coping with Bereavement provides rich context for the process of grieving a perinatal loss. The model's unique conceptualization of stressors and coping as well as the dichotomy of loss-orientation and restoration-orientation allow for a deeper understanding of why individuals elect to engage in the coping behaviors they do. Finally, the model's view of grief as a dynamic, fluid process allows for a flexible, more comprehensive analysis of stressors and coping behaviors within the context of perinatal loss.

Racialization

There are clear discrepancies in infant mortality rates between Black and non-Black women, with the infant mortality rate for Black women being approximately double that of White women for over 35 years (Ely & Driscoll, 2023; Hogue et al., 1989). In 2021, 21,105 fetal

deaths (Gregory et al., 2023) and 12,797 neonatal deaths (Ely & Driscoll, 2023) were reported for a total of 33,902 perinatal deaths in the United States. Of these, 8,464 were fetuses or infants of Black mothers (Ely & Driscoll, 2023; Gregory et al., 2023). Overall, Black infant mortality was 2.4 times higher than White infant mortality (Ely & Driscoll, 2022). While individual risk factors are often blamed for racial infant mortality rate discrepancies, current research points to larger, structural barriers to positive birth outcomes (Smith et al., 2018).

Racialized stressors are heavily tied to Black women's perinatal loss experiences; an underlying current compounding with the stressors described to create a perinatal loss experience distinctly different from that of White women. Racialized stressors include structural racism and interpersonal racism. Structural racism refers to the "totality of ways in which societies foster discrimination via mutually reinforcing systems of discrimination" (Krieger, 2014, p. 650), while interpersonal racism encompasses individual interactions perceived as discriminatory.

Interpersonal Racism

Interpersonal racism has been identified as an underlying factor contributing to the disproportionate number of Black infant deaths (Alio et al., 2010) and adverse infant health outcomes such as low birth weight and preterm delivery, with self-reported experiences of racism associated with a three-fold increase in adverse infant health outcomes (Mustillo et al., 2004). These self-reported experiences happened over a range of settings including at school or work, while accessing jobs, housing, and medical care, on the street or in public, and while dealing with the police or court system. This array of settings supports the idea that interpersonal racism can occur between persons within institutional roles (e.g., employer and employee) and non-institutional roles (e.g., store owner and store patron; Krieger, 2014).

Distress resulting from racial discrimination in the 12 months prior to delivery has been linked to preterm birth in Black women (Bower et al., 2018). Complications related to preterm birth and low birth weight were the leading causes of death for Black infants in 2020, with Black infants four times more likely to succumb to low birth weight than White infants (Ely & Driscoll, 2022). Adverse birth outcomes such as low birth weight are intrinsically related to infant mortality, and data on one can often give insight into the other (Smith et al., 2018).

Structural Racism

Structural racism encompasses various systems of discrimination including employment, housing, education, and health care (Krieger, 2014). As these systems are mutually reinforcing, they must be considered in conjunction with each other rather than as separate, individual issues. These interconnected systems can have serious impacts on maternal and infant health.

Socioeconomic factors related to structural racism are heavily tied to adverse infant health outcomes. Increased state-wide racial inequity in unemployment is linked to increased Black infant mortality (Wallace et al., 2017). These connections between economic disadvantage and infant health outcomes are especially troubling when taken in conjunction with the fact that Black families have the lowest mean and median wealth of all racial groups in the United States and are the least likely to own their homes (Aladangady et al., 2023). However, socioeconomic status alone does not explain racial birth outcome disparities. As low birth weight is one of the leading causes of death for Black infants (Ely & Driscoll, 2022), data on these conditions can shed light on infant mortality. Low-income Black mothers are more likely than low-income White mothers to give birth to a low birth weight infant, and improvements in socioeconomic status result in a greater reduction in low birth weight rates for White infants than Black infants (Kothari et al., 2021).

Structural racism can also affect housing and neighborhoods. Racial segregation has been recognized as a key risk factor in health outcomes across the lifespan (Williams & Collins, 2001). Racial residential segregation refers to the physical separation of racial groups in neighborhoods and housing. Redlining (the practice of denying loans for creditworthy individuals based on race) is one institutional practice that has caused persisting racial residential segregation. While redlining has been illegal since the 1960s, the practice has left a lasting impact on Black neighborhoods by limiting available resources (Dagher & Linares, 2022). Black women have the highest likelihood of living in a redlined neighborhood (Mendez et al., 2011). While evidence for a direct link between redlining and Black infant mortality is mixed, there is evidence to support a relationship between racial residential segregation, a result of redlining, and birth outcomes (Mehra et al., 2017).

Education is another structural factor contributing to racial disparities in infant mortality rates. Hispanic, American Indian/Alaskan Native, and Black individuals are the least likely to have completed high school (National Center for Education Statistics, 2019), and infants born to mothers with less than a high school education were 2.4 times more likely to die than those born to mothers with more education (Singh & Yu, 2019). However, as with socioeconomic status and neighborhood environment, education alone does not explain racial infant mortality disparities as college-educated Black mothers still had higher rates of infant mortality (7.8 deaths per 1,000 births) than high-school educated White mothers (6.7 deaths per 1,000 births; Petersen et al., 2019).

Historical Context and Medical Racism

Within structural racism is institutional racism, defined as the discriminatory policies and practices that social institutions engage in (Krieger, 2014). The aforementioned practice of

redlining is one example of institutional racism. Another example that is of particular importance in understanding perinatal loss is medical racism. The long and sordid history of racism and colonialism in the United States within maternal healthcare has been well-documented (Owens & Fett, 2019; Washington, 2006). Black midwives were the most common pregnancy and birthing care workers for Black women from the 17th through the mid-20th centuries, when White healthcare and public health professionals attempted to eradicate Black midwifery through smear campaigns and restrictive legislation (Bonaparte, 2014). Black midwifery was characterized as unclean, unprofessional, and dangerous, despite midwives producing better infant and maternal health outcomes than physicians (Devitt, 1979a; Devitt, 1979b). White physicians often blamed enslaved Black women for infant deaths despite the inhumane working conditions and malnutrition forced upon them. Nonconsensual and unanesthetized medical experimentation on Black women led to the creation of several modern gynecological and obstetrical practices such as the cesarean section and the vaginal speculum (Owens & Fett, 2019; Washington, 2006).

This repeated practice of Black medical exploitation for White physician gain has led many Black patients to prefer prenatal and birthing care providers who are of the same race, a concept referred to as racial concordance (Altman et al., 2020). Racial concordance is associated with lower levels of Black infant mortality (Greenwood et al., 2020). However, the field of obstetrics within the United States is permeated with systemic racism and violence (Scott & Davis, 2021; Vedam et al., 2019), meaning that racial concordance alone is not enough to solve racial disparities within infant and maternal health (Jeffers et al., 2023). While patient-provider racial consistency may alleviate the harm caused by interpersonal racism, it cannot overcome the racism woven into the fabric of the field as a whole. Kemet and colleagues (2022) found that Black women had complex feelings on racial concordance within prenatal mental healthcare,

feeling that Black practitioners were indoctrinated by anti-Black societal structures and forced to adopt racist practices and viewpoints in order to succeed in the White-dominated medical field. Overall, some of the women wanted concordant care, others wanted concordant care only if it was accompanied by anti-racist practices, and others preferred anti-racist care regardless of racial concordance. Anti-racist care included provider knowledge of the effect racism has on the pregnancy experience, willingness to discuss racism, and the offering of resources that addressed Black women's unique experiences (Kemet et al., 2022).

Additionally, many physicians subscribe to the "mother blame" idea, a narrative of poor infant health outcomes that places the onus of responsibility for the death on the actions of the mother. While individual behaviors are important for a healthy pregnancy, this myopic view of maternal and infant health fails to consider the social, political, economic, and environmental circumstances that could impact the mother's health and decision-making. Scott et al. (2019) summarized the issue of this narrative as, "blaming Black women for poor reproductive health outcomes ignores the circumstances, environments, and situations in which each woman seeks to maintain health, to become pregnant, and to safely give birth to children" (p.110).

Stressors

Broadly, the loss of a baby is recognized as highly traumatic (Ljungman et al., 2015) and is often connected to adverse mental health outcomes like major depressive disorder, generalized anxiety disorder, and posttraumatic stress disorder (Davoudian et al., 2021; Gold et al., 2016; Youngblut et al., 2013). Common stressors experienced by parents related to their perinatal loss include social stressors related to relationships with family and friends (Currie et al., 2019; Fernández-Sola et al., 2020; Nuzum et al., 2018), professional relationships at work (Currie et al., 2019; Fernández-Sola et al., 2020; Hazen, 2003), post-death decision making (Brooten et al.,

2016), spiritual suffering (Currie et al., 2019; Rosenbaum et al., 2011) and managing multiple losses (Currie et al., 2019). There is limited literature focused solely on Black individuals' experiences with perinatal loss or stillbirth (Brown, 2014; Brown et al., 2017; Evans, et al., 2023; Fenstermacher, 2014; Fenstermacher & Hupcey, 2019; Jones et al., 2021; Kavanaugh et al., 2004; Kavanaugh & Hershberger, 2005; Van, 2001; Van & Meleis, 2003), but within the existing literature are similar themes of social stress, financial stress, post-death decision making, and concurrent losses and concerns about future pregnancies.

Social Stressors

Interpersonal relationships can impose unique stressors on grieving parents. Unsolicited advice (Kavanaugh et al., 2004), insensitive comments from others (Currie et al., 2019; Van & Meleis, 2003), and ineffective conversations with family and friends (Evans et al., 2023) are all examples of stressors stemming from social interaction after perinatal loss. Additionally, the lack of customary social responses to infant death in comparison to other deaths can lead to a lack of societal acknowledgement of the loss by otherwise well-meaning friends and family, amplifying feelings of disenfranchised grief (Shannon & Wilkinson, 2020). Some mothers expressed feelings of jealousy arising around other pregnant women, wondering why they were able to continue with a healthy pregnancy when they were unable to (Fenstermacher & Hupcey, 2019). Finally, holidays and family gatherings can be sources of stress for mothers who have lost an infant, with the absence of their baby serving as a painful reminder (Evans et al., 2023; Kavanaugh & Hershberger, 2005).

Insensitive comments about the loss can be dismissive to a bereaved parent's grief, such as, "You don't want no kids, they're a headache" (Evans et al., 2022, p. 12), or inappropriately timed but well-meaning advice from others (Kavanaugh et al., 2004). Black women describe

letting the insensitive comments roll off their back, with one woman noting that she understood that some people just don't know what to say in that situation and chose to excuse the person and pray for them instead of dwell on the conversation (Van & Meleis, 2003). This sentiment is echoed in research with primarily White participants, with some parents saying that while the comments were hurtful, they understood that others around them were doing their best to support them and some people don't know how to approach sensitive situations (Currie et al., 2019).

Partner-related stress after fetal or infant loss can include distress regarding the partner's lack of emotional reaction (Fenstermacher et al., 2019), intimate partner violence (Brown et al., 2017; Evans et al., 2023), and infidelity (Brown, 2014). Mothers report a desire for their partners to express their emotions regarding the death instead of keeping emotions inside (Kavanaugh & Hershberger, 2005), a sentiment closely related to Stroebe and Schut's (1999) aforementioned identified gendered difference in coping orientation. Intimate partner violence was mentioned briefly as both an existing stressor prior to the loss (Brown et al., 2017) and as a stressor after the loss (Evans et al., 2023), as was infidelity in one woman's case (Brown, 2014).

Financial Stressors

A shining example of the role of contextual factors in Black women's experiences with perinatal loss is the impact of financial stress. Financial hardship like the inability to pay for basic necessities (Brown et al., 2017; Wallace et al., 2017), difficulties finding employment or facing adverse working conditions (Kavanaugh & Hershberger, 2005), and concerns with affording healthcare services (Brown et al., 2017) and post-mortem expenses like funerals and burials (Fenstermacher & Hupcey, 2019) were all described by post-perinatal loss Black women as significant stressors in their lives. These financial concerns are compounded by the effects of structural racism resulting in Black women having higher rates of unemployment (U.S. Bureau

of Labor Statistics, 2023) and significantly lower wages (Hegewisch & Mefferd, 2021) than White women.

Direct medical costs associated with stillbirth can vary, but a systematic review of research on stillbirth prices in high-income countries revealed a range of $6,934 to $9,220 (Veettil et al., 2023). Research on the United States in particular reveals that stillbirths cost an average of $750 more than live births in the same geographical area, despite stillbirth patients having similar lengths of stay (Gold et al., 2013). Additionally, stillbirth can lead to indirect costs stemming from lost wages and decreased productivity in parents following the death (Veettil et al., 2023). This is especially troubling when factoring in racial disparities in access to health insurance, with Black women significantly less likely to have perinatal health insurance coverage compared to their White counterparts (Daw et al., 2020).

Post-Death Rituals and Decision-Making

The cost of perinatal loss extends past hospital charges and missing wages. Decision-making after the death can be a source of stress heavily tied to finances for parents after losing their baby (Brooten et al., 2016; Fenstermacher & Hupcey, 2019). Cultural customs play a large role in post-death proceedings, with Black mourners often expressing the desire to give "a big send-off" (Lobar et al., 2006, p. 48), a belief that can lead to increased spending to ensure that the funeral is sufficient for the lost loved one. Other cultural customs influencing funeral services include waiting to bury until all family is present, taking special care in preparation of the body, and expressing strong emotion through loud crying, wailing, or prayer to show love and respect for the deceased.

Choosing whether to bury or cremate the body can be influenced by familial input, religious or spiritual beliefs, and cultural customs (Brooten et al., 2016; Fenstermacher &

Hupcey, 2019; Lobar et al., 2006). Black Americans are less likely to accept cremation than White Americans, with many citing religious beliefs and the importance of funeral proceedings as reasons for preferring burial (Buchanan & Gabriel, 2015). Some Black Americans state that cremation prevents the deceased's soul from going to heaven (Lobar et al., 2006), demonstrating the salience of religion and spirituality in the post-death decision-making process. Cremation is generally less expensive than burial (National Funeral Directors Association, 2021). For fetal remains specifically, average cremation costs are approximately $250 less than burial (Henkel et al., 2023). However, some funeral homes do not accept fetal remains at all (Henkel et al., 2023), making service availability another factor in post-death decision-making. Additionally, this unavailability of services could serve as further confirmation of feelings of disenfranchised grief, with the denial of services suggesting that services for fetal remains are less valid than services for older children or adults.

The cultural significance of funeral services and post-death proceedings, in combination with the societal tendency to minimize the validity of perinatal loss, could amplify feelings of disenfranchised grief within Black families. Among non-Black parents experiencing perinatal loss, dismissal of comments expressing the desire for funeral services for fetal deaths has been perceived as dehumanizing to their baby (Lang et al., 2011). A similar experience was described in one study of Black women who had experienced perinatal loss, with one mother expressing anger after a funeral director buried her son without her presence, stating that he did not realize she would want to be there for the burial (Kavanaugh & Hershberger, 2005). The assumption that a burial for an infant would not be emotionally significant falls in line with the false idea that perinatal loss is not as important or as worthy of grieving as other losses. This lack of

acknowledgement is one of the key features of disenfranchised grief (Shannon & Wilkinson, 2020).

Concurrent Losses and Concerns about Subsequent Pregnancies

Experiencing concurrent adverse life events like the death or serious illness of another family member in addition to the loss of the baby was described as especially stressful (Fenstermacher & Hupcey, 2019; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003), with one woman describing the experience of losing her father and daughter within months as "a deep hole I couldn't escape" (Fenstermacher & Hupcey, 2019, p. 15). Among a sample of low-income Black parents who had experienced perinatal loss nearly half had lost a parent or parental figure, with several of these losses occurring during the course of the pregnancy (Kavanaugh & Hershberger, 2005). Some concurrent losses described were sudden and unexpected, like suicides and homicides of close friends, and were described by parents as devastating.

In both the general population and Black mothers specifically, fears and concerns about losing subsequent pregnancies or infants are present among women who have experienced perinatal loss, with mothers experiencing higher levels of prepartum anxiety and depression, problems with the process of attachment to the unborn fetus, and some level of denial of the pregnancy (Hawthorne et al., 2020; Hunter et al., 2017; Van & Meleis, 2003). Many mothers indicate they want another child after perinatal loss, but some display hesitancy (Dyer et al., 2019). Regardless of intention to have another child, mothers often find it inappropriate for others to offer unsolicited advice on subsequent pregnancies (Currie et al., 2019; Kavanaugh et al., 2004).

Coping

Coping can be defined as the "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing on or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 174), going hand-in-hand with the above-described definition of stress. Parents engage in various forms of coping following perinatal loss, such as seeking professional mental health services (Clark et al., 2021; Hawthorne et al., 2020; Van & Meleis, 2003), religion and spirituality (Clark et al., 2021, Jones et al., 2021; Kavanaugh & Hershberger, 2005; Van, 2001; Van & Meleis, 2003), remembering the baby (Brooten et al., 2019; Fenstermacher & Hupcey, 2019; Kavanaugh & Hershberger, 2005 Van & Meleis, 2003), and social support (Clark et al., 2021; Hawthorne et al., 2021; Kavanaugh et al., 2004, Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Some parents describe avoiding coping altogether, with some participants in one study stating that the interview was the first time they had ever discussed the loss with someone else (Van & Meleis, 2003).

Social Support

Social support can be a critical element in coping with infant loss. Social support can manifest as having someone to talk to and being heard (Clark et al., 2021; Hawthorne et al., 2021; Kavanaugh et al., 2004), financial support (Currie et al., 2019; Kavanaugh et al., 2004), or providing fun social interaction as a distraction (Kavanaugh et al., 2004). Practical assistance such as assistance with cooking meals and funeral planning is also an important aspect of social support for parents (Kavanaugh et al., 2004).

Among literature focused on Black women's experiences specifically, social support from partners, close friends, and family is a commonly discussed method of coping (Kavanaugh & Hershberger, 2005; Van & Meleis, 2003), with some mothers stating that the authentic presence of family and friends was their main source of support following the death (Jones et al.,

2021). Spending time with living children was also described as helpful (Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Black women also report receiving support from close relatives who had also experienced the death of a baby, an experience not reflected in the interviews of White participants in the same study (Kavanaugh et al., 2004). Bonding over this shared experience through comfort, advice, and reassurance helped mothers to feel like they weren't alone in the experience and helped them to deal with the loss.

Black women also describe high levels of social support through church and religious communities. Churches have provided a place of social connectedness for the Black community for centuries, offering a center of healing and spiritual support for the oppressed and marginalized (Brewer & Williams, 2019). One woman's partner described her contact with a friend from church being the most helpful thing in her healing (Kavanaugh et al., 2004), and another discussed a pastor who was particularly impactful in helping her forgive herself for the loss (Jones et al., 2021).

Religious and Spiritual Coping

Across cultures, religion and spirituality are an important part of the coping process for many parents experiencing perinatal or infant loss (Wright, 2020), with spiritual beliefs assisting some parents in making sense of or finding meaning in the loss. Religious coping can include prayer, returning to church, reading the Bible, and spiritual counseling (Jones et al., 2021; Kavanaugh & Hershberger, 2005). Black parents found comfort in believing in an afterlife, with some believing that ancestors were caring for their babies (Van, 2001), or that their baby was in heaven surrounded by angels (Kavanaugh & Hershberger, 2005). These parents often found religious books to be helpful.

Meaning-making through prayer was featured in several studies with primarily Black participants (Jones et al., 2021; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003), largely regarded as a helpful way to work through the loss and obtain a better understanding. Prayer was also described by one woman as a strategy to talk to someone about the loss when she felt there was no one else to talk to (Jones et al., 2021). Content of prayer included asking forgiveness for sins, asking for peace, understanding, or a subsequent healthy pregnancy, expressing faith in God, or asking for God's assistance to strengthen their faith (Van & Meleis, 2003).

Several women described spiritual coping that did not fit within the context of a specific religion. The distinction of spiritual coping from religious coping can be difficult to define but can be described as the way that individuals express connectedness (Wright, 2020). While this connectedness is often expressed through religion, spirituality can appear in many forms. In the context of perinatal loss, some women described a method of spiritual coping referred to as "going inside myself" (Van & Meleis, 2003, p. 33). This coping method was akin to meditation or prayer and consisted of the women taking quiet time to themselves to internally sort out thoughts and feelings related to the loss. Other non-religious spiritual coping included a woman with no religious affiliation who described comforting messages from her baby in her dreams, saying that she felt he was letting her know that he was in a good place (Van, 2001).

Despite religion being generally regarded as a helpful method of coping, some parents experience spiritual suffering or questioning as part of the grieving process, wondering why God had allowed the death to happen or what they had done wrong to deserve it (Fenstermacher, 2014; Jones et al., 2021; Van & Meleis, 2003). These feelings of guilt or responsibility may be exacerbated by the aforementioned "mother blame" narrative present in many healthcare settings (Scott et al., 2019). Interestingly, multiple women mentioned how unfair it was to them that

other mothers who used substances, had criminal records, or took inadequate care of their children got to carry a baby to term while they did not (Fenstermacher, 2014; Jones et al., 2021), suggesting that the internalization of this false narrative by Black mothers could contribute to feelings of confusion and jealousy surrounding the loss.

Professional Mental Health Care

Many parents do not engage in formal mental health care such as counseling or support groups following perinatal loss, both in the general literature (Currie et al., 2019; Hawthorne et al., 2020) and study focused solely on Black parents (Fenstermacher & Hupcey, 2019; Jones et al., 2021; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Barriers to mental healthcare discussed by these parents strongly reflect barriers for pre- and perinatal Black women discussed by Kemet and colleagues (2022), including lack of access, provider mistrust, and lack of advocacy. Some Black women report feeling that they must escalate their symptoms in order to be taken seriously enough to obtain a mental health care referral from a provider, feeling that providers only recognize them as mentally distressed enough to require care if they are a danger to themselves or others. Kemet and colleagues (2022) argued that this arbitrary external measure of distress is detrimental in several ways; one, it requires patients to reach a point of "breaking down" (p. 782), and two, it requires Black women to express their feelings in ways that reinforce the stereotype of the "angry Black woman" to receive care. Racialized stereotypes impact Black women's mental health treatment experiences inside the therapy room as well. The idea of the angry Black woman may be internalized by Black women and misinterpreted by their clinician, resulting in the dismissal of Black women's experiences or the application of inappropriate treatment methods (Ashley, 2014). Similarly, the strong Black woman or "superwoman" stereotypes can discourage Black women from accessing mental health services by generating

feelings of guilt when engaging in personal commitments or self-care tasks such as therapy (Carter & Rossi, 2019).

While stigma against accessing mental health care services is associated with lower levels of utilization of postpartum depression treatment, stigma does not explain racial disparities in access to mental health services in mothers, with Black women reporting lower levels of perceived stigma as well as lower acceptance of postpartum therapies and psychiatric medications (Bodnar-Deren et al., 2017). Additionally, recent research suggests that Black women are open to counseling as treatment for postpartum depression (House et al., 2020), and that online mental health support groups appear promising for women of color after perinatal loss (Gold et al., 2022). While these online support groups did not show statistically significant improvements in mental health measures, they did prove the feasibility of recruitment and retention of participants for virtual support groups.

As for perception of support groups in general within perinatal loss literature, some Black mothers found support groups to be helpful as they provided a place to discuss their loss with others who had experienced it (Wallace et al., 2017; Van & Meleis, 2003), others stated they did not find attending to be helpful (Fenstermacher & Hupcey, 2019). Some felt that the groups lacked diversity of age or marital status (Fenstermacher & Hupcey, 2019), and others felt that majority-White groups placed restraints on what they could share (Van & Meleis, 2003).

Remembering the Baby

Descriptions of loss-oriented activities meant to help parents remember their baby are present in both broad literature (Brooten et al., 2019; Currie et al., 2019) as well as studies with solely Black participants (Fenstermacher & Hupcey, 2019; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Many parents find comfort in participating in activities that allow them to

remember the baby, such as looking at mementos or memory boxes (Brooten et al., 2019; Fenstermacher & Hupcey, 2019; Van & Meleis, 2003). Common sentimental items include hospital items like identification bracelets and blankets (Kavanaugh & Hershberger, 2005), and the use of transitional objects for bereaved parents is an identified best practice for hospitals (LeDuff et al., 2017). Photographs of the baby are also valued (Brooten et al., 2016; Van & Meleis, 2003), with parents of live born infants wanting pictures of the baby with minimal medical equipment visible (Kavanaugh & Hershberger, 2005). Holidays and important dates, while sometimes described as stressful, can also serve as a positive way of remembering the baby (Brooten et al., 2016; Kavanaugh & Hershberger, 2005).

Holding the deceased baby can be a part of the memory-making process for bereaved parents. Allowing parents to hold their stillborn babies is controversial among healthcare professionals, as there is sparse quantitative research with mixed results on the impact of doing so on the parent's mental health (Hennegan et al., 2015). Some research suggests that mothers who hold the stillborn baby experience increased rates of anxiety and PTSD, while other studies suggest that holding the baby has no impact or even a positive impact on mental health and wellbeing. The most common identified best practice is to offer, but not force, parents to hold the stillborn baby (Bakhbakhi et al., 2017). In broad qualitative research parents often state that they are satisfied with their decision to hold the baby (Gold et al., 2007; Ryninks et al., 2014), a theme echoed in research with Black women specifically (Fenstermacher, 2014; Van & Meleis, 2003).

Conclusion

In sum, Black mothers' experiences with perinatal loss are heavily influenced by the various stressors they experience and the coping activities they engage in. Stressors can stem

from relationships with family, friends, intimate partners, and professional relationships at work, with negative reactions from these individuals amplifying feelings of disenfranchised grief. Financial stressors can include both medical costs or lost wages as well as funeral and burial expenses. Funerals and other post-death decisions can be another common stressor, with cultural beliefs about death and service availability impacting the decision-making process. Concurrent losses of other family members or friends as well as concerns about future pregnancies were also identified as stressful. Finally, the broader category of race-related stressors including both interpersonal racism and structural racism can be an added stressor for Black women, with barriers to housing, employment, education, and medical care all contributing to Black perinatal mortality rates.

Common coping activities can include engaging in social relationships by talking to others about the loss or utilizing practical or financial help from others. Religious and spiritual coping is common, with activities like prayers, church attendance, and belief in an afterlife being described as helpful. Professional mental health care or support groups are often not sought out by Black women, with access and stigma being possible barriers to access. Finally, remembering the baby through sentimental items and photographs or reminiscing on memories can be a source of comfort for post-perinatal loss Black women.

Using the Dual Process Model of Coping with Bereavement as a guiding theoretical framework, the purpose of this study was to explore stressors and coping activities common among Black families who have experienced perinatal loss. This study was guided by the following research questions:

1. What stressors are associated with perinatal loss among Black mothers?
2. What coping strategies do Black mothers utilize after experiencing perinatal loss?

CHAPTER 3: METHODOLOGY

Methodological Approach

This study is a qualitative inquiry into Black women's experiences with perinatal loss. The purpose of qualitative research differs fundamentally from quantitative research in that the primary purpose is not to measure how often or how common a given event occurs, but rather to examine the first-hand accounts of those who have experienced the event and analyze the meaning they attribute to the experience (Merriam & Tisdell, 2016). Qualitative studies aim to understand the lived experiences of individuals by using words as data and the interviewer as the primary data collection instrument.

The interview style selected for this study was semi-structured interviewing. Semi-structured interviews allow for a more natural, conversational interviewing style than procedures with a strict question protocol (Merriam & Tisdell, 2016). Due to the sensitive nature of perinatal loss, this flexible protocol allowed the interviewer to respond to the themes most prominently emerging in the interview and ask relevant probing questions to solicit more information. Additionally, the researcher was able to adjust the research questions as more interviews were conducted. The question "Are there any questions you feel I should have asked?" was included at the end to invite participant suggestions for subsequent interviews.

Using a phenomenological approach, this study used individual interviews to explore the stressors and coping experiences of Black women who have experienced perinatal loss. Phenomenology is a qualitative methodological approach that posits that shared lived experiences all have an "essence" (Patton, 2015, p. 116) that can be identified. The purpose of this approach is to capture this essence and describe these lived experiences in a way that gives the reader a better understanding of what it is like to live through that experience (Creswell,

2013). Phenomenology describes the experience through the interviewee's perspective, allowing for a unique insight into deeply personal moments. Therefore, phenomenology is useful for research centered on intense and emotional human experiences (Merriam & Tisdell, 2016) such as perinatal loss.

Finally, Colaizzi's (1978) phenomenological analysis framework guided the data analysis process. This method involves several rounds of reading and familiarizing oneself with the data, identifying themes within and between interviews, and creating a written description of the phenomena incorporating all the identified themes. This method is appropriate for descriptive phenomenological studies intending to develop a rich description of the experience being researched as well as a concise overview, both of which are confirmed through obtaining feedback from the participants themselves.

Sampling and Recruitment

Following approval from the university's institutional review board (IRB; Appendix A), a purposive sample of five participants was recruited. Purposive sampling intends to select a sample from which the most can be learned (Merriam & Tisdell, 2016), and is often used for hard-to-reach populations (Bhattacharya, 2017). As the parameters for inclusion are narrow, purposive sampling was the most appropriate for this study.

The inclusion criteria required that participants (a) self-identify as Black, (b) be at least 18 years old at the time of the interview, (c) speak English at least conversationally, and (d) have experienced a fetal or infant loss between 20 weeks gestation and 28 days born within the family more than one year ago. This parameter of perinatal loss as defined by Barfield (2016) was chosen as it is the broadest, yet still commonly recognized, definition of perinatal loss. A minimum time frame of one year between the loss event and interview was chosen as research

points to parent grieving following pregnancy loss to most sharply decline after one year (Lin & Lasker, 1996), suggesting that parents at this point may have found coping strategies that ease the pain of the grief. No maximum time frame was placed because of the DPM's (Stroebe & Schut, 1999) lack of sequential phases and ongoing oscillation process, which allow for a similar interpretation of short-term and long-term grieving experiences. The inclusion criteria intentionally expanded beyond mothers to gain the perspective of other family members. However, no family members outside of mothers were successfully recruited.

The sample was recruited in two ways. The first was by collaborating with a local hospital's perinatal nurse navigator and other professional contacts. These collaborators emailed a flyer (see Appendix B) to their contacts and email lists relaying information about the study and the Primary Investigator (PI)'s contact information. The second way was through social media. The research flier was posted on Facebook, Instagram, and TikTok and sent personally to individuals who engaged in online advocacy work for Black perinatal loss. Upon contact, the PI screened potential participants for eligibility. If eligible, the PI sent the informed consent document (see Appendix C) to the participants and scheduled a time for an interview. The final three participants were also provided with the interview protocol prior to scheduling to assist them in making a decision to participate in the study.

The target sample size was six to ten, reflective of other phenomenological qualitative studies related to Black women's perinatal loss experiences (Brown et al., 2017; Fenstermacher & Hupcey, 2019; Jones et al., 2021), with several indicating data saturation occurring around six or seven interviews. Data saturation is achieved when additional data collection will not solicit any new information (Patton, 2015). While this target was not reached with five eligible participants completing an interview, data saturation was still achieved. With hard-to-reach

populations and under-researched areas of research, small sample sizes are often highly valuable (Bhattacharya, 2017). This sample size allowed for a more detailed description of each participant's unique story to be told. Additionally, the initial sampling plan intended for family members of the participants to be recruited via snowball sampling, but no family members were able to be recruited.

Participants

All participants in the study were women who had experienced the perinatal loss firsthand ranging in age from 27 to 40 years (*M*=33). Gestational age ranged from 20-36 weeks (M=25), and time removed from loss ranged from 14 to 60 months (*M*=26). This demographic information is further described in Table 1.

Table 1

Participant Demographics

	Denise	**Courtney**	**Nicole**	**Gabrielle**	**Erika**
Age	27	37	40	32	29
Race	Black	Black	Black	Black	Biracial
Education Level	Some college	Master's degree	Bachelor's degree	Bachelor's degree	Bachelor's degree
Employment Status	Full-time	Full-time	Full-time	Full-time	Homemaker
Religion	Christian	Christian	Spiritual	Spiritual	Agnostic
Gestational Age of Baby at Death	20 weeks	24 weeks	23 weeks	21 weeks	36 weeks
Time Removed from Loss	14 months	14 months	5 years	22 months	18 months

Note. All demographic information was self-identified by participants.

Procedure

Data collection consisted of virtual semi-structured interviews. Both in-person and virtual interview options were offered, but all participants opted for a virtual video interview. Interviews were recorded with a digital recorder and lasted between 25 and 90 minutes. At the beginning of the meeting, the PI provided each participant with a $40 virtual gift card as a token of appreciation. Then, the PI reviewed the informed consent and answered any participant questions. After review of the informed consent materials, the PI orally administered the demographic questionnaire (Appendix E).

Interviews began with the grand-tour prompt, "Tell me about the experience of losing your baby". This was followed by a series of open-ended questions aimed at obtaining meaningful insight into the stressors and coping strategies employed by the participants following the loss, including:

- In what ways did this experience impact your family?
- What did you find stressful after losing your baby?
- What did you find most helpful after losing your baby?
- Based on what you have found most beneficial following the loss of the baby, what would you tell other Black families who have experienced perinatal loss?

The list of interview questions is available in Appendix D.

All interview recordings were transcribed with Rev, an artificial intelligence transcription service, and then reviewed and edited by the PI to ensure the transcription was verbatim. Recordings were transcribed verbatim with pseudonyms assigned to protect participant privacy. To further protect participant privacy, all audio recordings and typed transcriptions were stored on a password-protected computer only accessible by the PI.

Analysis

Data analysis was conducted using Colaizzi's (1978) phenomenological analysis framework. This framework details a meticulous series of seven steps that result in concise yet rich description of the participants' experiences. Additionally, this framework is intended for descriptive phenomenological studies that attempt to realize a thorough illustration of the phenomena at hand.

The PI conducted the analysis following Colaizzi's (1978) guidelines. In the first step, familiarization, the PI read the transcripts three times to become well-acquainted with the data and to understand the participant's overall experience. Then, the PI identified significant statements that were directly related to the research questions. In the third step, formulating meanings, the PI carefully evaluated the significant statements to create more general restatements or broader meanings.

Once these first three steps were completed for each transcript, the formulated meanings from each interview were compared to each other to create clusters of themes (Colaizzi, 1978). Upon the completion of this step, the identified themes were compared with the overall transcripts and significant statements to ensure that the themes were congruent with them. At this point, the primary investigator reviewed the identified themes with two members of the thesis committee with extensive experience in qualitative research and obtained critical feedback to increase the trustworthiness of the data analysis. Then, these theme clusters were condensed into broader emergent themes. Upon determining that the emergent themes, theme clusters, and transcripts were in agreement, a comprehensive description of the phenomena including all formulated meanings, thematic clusters, and emergent themes was written to complete step five

(Colaizzi, 1978). In the sixth step the exhaustive description was reduced to a concise yet all-encompassing description of the phenomenon.

The final step was member checking (Colaizzi, 1978). Member checking consists of collecting participant feedback on the results to see if participants resonate with the researcher's interpretation of their experiences (Merriam & Tisdell, 2016). Participants were asked for permission to contact them at a later date to review the study's findings. Of the five participants, four agreed to schedule a member checking call. Feedback solicited from participants was then used to revise the findings to better reflect the participants' lived experiences.

Data Trustworthiness

For this study, the researcher utilized the techniques emphasized by Colaizzi's (1978) analysis method, including bracketing and member checking. Colaizzi (1978) emphasized the importance of bracketing, or the act of setting aside preconceived notions or personal beliefs to avoid misinterpretation of the participant's experience. While Colaizzi notes that complete bracketing is not possible, this practice can increase the trustworthiness of the data. As part of the bracketing process, the PI engaged in reflexive notetaking after each interview. Reflexive notetaking helps the researcher recognize their own biases and assumptions as well as record contextual information about the interview itself that may impact the results (Olmos-Vega et al., 2023). As mentioned, the PI completed a member checking process to increase the trustworthiness of the results. These member-checks allowed participants to clarify, correct, and contextualize any portion of the findings that did not align with their lived experience. Four of the five participants participated in a member-checking session.

Positionality Statement

Before presenting my findings, I would like to discuss my positionality. The semester I began my thesis writing process, I read the work of Evans and colleagues (2023) for a graduate course. While initially reading this article, I thought that the sample consisted of Black women who had either a miscarriage, a stillbirth, or an infant death. Upon my realization that all participants had experienced one of each, I had the pressing thought, "Someone should do something about this." I am aware that I hold a considerable amount of privilege as a White, college-educated woman in academia and felt it was irresponsible to be in my position and push this urgent issue to a nebulous "someone." Instead, I wanted to offer my thesis as a platform to uplift the voices of Black women who have experienced the unimaginable pain of losing their babies at the hands of an unjust medical system that was built to serve people who look like me.

Through this work, I have offered a space for the five women who were featured in this study to tell their stories in an academic setting. As noted above, complete bracketing of the researcher's beliefs and experiences is not possible. Thus, I am cognizant of the fact that my social location and experiences inevitably contributed to my analysis and interpretation of the participants' responses.

CHAPTER 4: RESULTS

This study's findings are heavily influenced by the unique nature of each mother's story, which are presented prior to the presentation of the identified themes and clusters. The analysis process resulted in three emergent themes that further divide into seven thematic clusters. These emergent themes were medical negligence, social stressors, and transformation.

Participant Descriptions

The smaller sample size of this project allows for a more thorough description of each participant's unique story. Thus, it is essential to illustrate the context in which each of these stories reside. The following paragraphs include a summary of the participant's pregnancy and loss story and any additional context that may aid in the understanding of their responses.

Denise

Denise's interview was the shortest of the five. At 26 years old, she was 20 weeks pregnant when she began to experience intense pelvic pain and was unable to sit correctly. She went to the emergency room and was told that she was going into preterm delivery. Her baby was the only one born alive among the five women, and her experience carries the unique pain of watching her son's breathing weaken as he slowly died in her arms. She also experienced intense physical manifestations of grief after returning home, culminating in her passing out and having to seek medical attention. She was told that her symptoms stemmed from grief. She indicated that she is not comfortable with speaking about her son in-depth as it can make her too emotional. While single at the time of the interview, Denise was in a stressful romantic relationship with the baby's father at the time of the loss.

Courtney

Courtney works as a school counselor. She enjoys staying at home, relaxing, and spending time with her mom, nephew, and niece. She described herself as "not the relationship type," choosing to conceive her baby using intrauterine insemination (IUI) treatment and a donor when she was 36. When her cervix began to open around 12 weeks into her pregnancy, her doctors placed her on progesterone and said they would "keep an eye on it." A few months later, a new doctor at the practice noted that her cervix was continuing to open and referred her to a high-risk doctor. This doctor questioned her primary provider for not placing a cerclage or implementing preventative measures against preeclampsia. Her primary then gave her an antenatal corticosteroid shot to accelerate the baby's development in the event of preterm labor. However, at her next appointment, the ultrasound technician informed her that her baby had no heartbeat. Courtney chose to deliver at the hospital immediately.

Courtney noted how her background in the mental health field heavily impacted how she viewed help-seeking after the loss and mentioned that a miscarriage she experienced several years before her perinatal loss impacted her perception of the experience. At the time of the interview, she was five months pregnant. She was the only participant to indicate significant financial stress, primarily stemming from being taken out of work right after signing her mortgage on her home. Finally, Courtney has a strong connection to her Christian faith and said that her faith in God was her biggest source of coping, saying, "I still love and trust God. I did before, I still do." She described praying frequently and striving to keep her relationship with God as strong as possible.

Nicole

Nicole's interview was heavily influenced by her identity as a maternal health advocate. Nicole had a history of reproductive issues, including having fibroid removal surgery and

difficulty conceiving. She became pregnant at age 35 with her son after five years of trying. During her pregnancy, she experienced other complications including preeclampsia, gestational diabetes, pain, and loss of cervical length requiring a cerclage to be placed. At a routine appointment 23 weeks into her pregnancy, she was told by her doctor that her son no longer had a heartbeat. This was the first prenatal care appointment she attended without a support person, meaning she was alone when she was told the news. She opted for a dilation and evacuation (D&E) as she did not want to go through labor and delivery. Once at the hospital, she began to hemorrhage. She later found out when attempting to conceive her second son that the hospital had left behind pieces of her placenta, forcing her to have an additional procedure.

In the nearly five years since her loss, the participant began working as a maternal health advocate, stating that this is her passion. She gave birth to her second son two years after her first, using in-vitro fertilization (IVF) treatment to conceive. While married at the time of her two pregnancies, at the time of the interview the participant was separated.

Gabrielle

Gabrielle works as an administrative assistant at a university and enjoys crafts, relaxing at home, and spending time with family. She was diagnosed with pre-eclampsia early in the pregnancy. At age 30, she was around 21 weeks pregnant when she experienced intense vaginal bleeding. She went to the emergency room and was monitored overnight, informed the following morning that her baby had no heartbeat. Gabrielle had a positive medical experience, and she emphasized the aftermath of the death in her interview rather than the loss experience itself. Additionally, Gabrielle was in a tumultuous relationship at the time of her loss and wondered if the stress impacted her ability to have a healthy pregnancy.

Erika

Erika is a social media content creator and posts about books, journaling, and maternal health. Her husband is an active-duty military service member and was stationed in a different state than her family at the time of her loss. She was 28 years old at the time of her loss. At a routine appointment 36 weeks into her pregnancy, an ultrasound technician made a subtle face change that made Erika question if something was wrong. A moment later, the technician relaxed and said that she sensed movement and that there was nothing to worry about. The next day, Erika noticed that she had not felt her baby move in a while, something she had been cognizant of throughout her pregnancy. She used an at-home fetal doppler and could not find a heartbeat. She went to the emergency room and was told that her baby had died. She and her husband were given the option to choose when to return to deliver and came back two days later to be inducted.

This participant's experience was heavily influenced by aspects of military life, like access to military healthcare benefits and relocation. At the time of the interview, the participant was eight months pregnant and had recently relocated due to her husband's reassignment. Finally, Erika is the only participant who identified as biracial. She does not have any connection to her dad's side of her family, and her mom's side of the family is White. She does not feel that this necessarily impacted how they responded to the loss but noted that it does play a role in her family's dynamic. She further explained that while her racial identity is not at the forefront of her mind in both familial and medical contexts, it is always in the back of her mind.

Themes

The interview data resulted in 297 significant statements, 165 formulated meaning statements, seven thematic clusters, and three emergent themes. The three emergent themes were medical negligence, social stressors, and transformation. These themes along with their thematic clusters are displayed in Table 2.

Table 2

Emergent Themes and Thematic Clusters

Emergent Themes	Thematic Clusters
Medical Negligence	Insufficient Information and Lack of Intervention
	Experiences with Subsequent Pregnancies
Social Stressors	Being Around Others
	Collective Disenfranchisement
Transformation	Symbolism
	Identity Shift
	Restoration of Normalcy and Moving Forward

These themes are broadly explained, followed by a detailed description of each thematic cluster. Finally, a summary of the exhaustive description is included.

Emergent Theme 1: Medical Negligence

The quality of participants' medical experiences was an essential part of their loss stories, with a poignant lack of information and intervention present in almost all of the women's stories. The other two emergent themes rest within the context of the medical experiences of the participants. The following thematic clusters, insufficient information and lack of intervention and experiences with subsequent pregnancies, further expand on this.

Thematic Cluster 1a: Insufficient Information and Lack of Intervention.

All participants, except for Gabrielle, expressed that their medical professionals did not provide sufficient information and failed to implement appropriate interventions. These participants were frustrated with dismissiveness from medical professionals regarding their concerns, recalling several moments throughout their care in which more could have been done

for their baby. Several mentioned concerns during the prenatal period that were not taken seriously by their care team. For example, Nicole shared:

> I remember paging the on-call doctor and being like, something doesn't feel right. "Well," she's like, "You're pregnant. That's one of the things of pregnancy, being in pain." And my son was dead six weeks later.

Similarly, Erika's doctor brushed off her questions about kick counting by being dismissive of the possibility of perinatal death:

> One doctor even told me, he was like, "Well the truth is that no matter what you do, 99.5% of all babies are gonna be born healthy and alive." And of course that's one of those things that I'm looking back on now and I'm just like, cool. So just like fuck the other 0.5% of people.

Courtney overheard a midwife and doctor at her clinic disagreeing about the severity of her condition, with a male doctor stating that he was not concerned and did not wish to pursue additional interventions. She was only referred to a high-risk doctor after a new doctor joined the practice and examined her. She expressed her frustration with her medical office for not utilizing these preventative and emergency treatments until it was too late:

> I really went in on her [doctor]. I apologized to her later on. But I went in because I was like, no one told me anything about preeclampsia, even though I had so many of the markers for preeclampsia. No one has said anything about a cerclage. And this man [high-risk doctor] said I was literally a day short of being a candidate for cerclage. Why didn't anybody here tell me that if you're supposed to be my primary?

Participants also experienced a frustrating lack of information during and after the baby's death. Erika's hospital allowed her to decide when to return for induction, but did not discuss

how long inductions can take. Nicole did not wish to deliver, but her doctor did not clarify that by choosing D&E she would not get to see her baby. For her, medical decision-making and post-death decision-making went hand-in-hand:

> I decided to discard his remains because I didn't know what else to do. [...] I felt like I was almost pressured into making a decision and, and that was super stressful in the moment. And then it's like something I had to live with, like, long term. It's a long-term stressor for me.

Denise was upset with the hospital's lack of interventions after her son was born alive:

> Them [the hospital] not trying to put him in the NICU and try to do everything they can to save him, it really frustrated me. It frustrated me a lot, even though I understood where they were coming from. But me as a first-time mother having to see my baby passing away in my arms and his breathing getting slower and slower, that was the most frustrating thing ever.

Finally, this medical negligence expanded beyond the death for Erika. There were no obvious causes of death for her son, so she and her husband requested medical testing for him:

> The genetic sample that they took wasn't large enough, and so that came back inconclusive. And then we found out six weeks after he was born that the hospital lost the autopsy request paperwork. So they never performed the autopsy before he was cremated and didn't tell us until six weeks after.

During recovery, Nicole, Gabrielle, and Erika were upset by unexpected physical changes to their body. Nicole and Gabrielle were distressed by the onset of lactation, with Gabrielle feeling that it was a "slap in the face" to have milk come in with no baby to drink it. Gabrielle said one of the worst things was feeling phantom kicks for the first few weeks, stating, "The first

time I had them, I broke down." Finally, Erika experienced postpartum anxiety related to her body and health, exacerbated by a bladder infection she contracted a few days after delivering:

> They didn't tell me that that was something that could happen, like a possibility. What, you know, what signs to watch out for? [...] And then by the second or third day, the pain was so bad. I was like, we have to go to the hospital because something's not right. So that was a whole new level of trauma.

Courtney and Nicole both described learning about racial differences in the quality of care provided by their medical staff. Courtney's obstetrician-gynecologist (OBGYN) did not provide information about preeclampsia or cerclage, only finding these things out after speaking to a White friend who was receiving care at the same clinic. Similarly, Nicole found out about resources the hospital had but did not provide through talking to other loss moms:

> You find out that it's vastly different if you're a Black woman versus White woman. The resources that you're given, the things that you're given. I remember meeting this girl a couple of years ago. She lost a baby and they gave her a certificate of life and I was just like, I'm sorry? And we had delivered at the same hospital.

Several participants expressed a desire for significant changes within the healthcare system. Suggestions included designated space for bereaved parents in hospitals, a resource connecting recently bereaved mothers with those who had experienced it before, and the inclusion of Black women's voices within the field of gynecology and obstetrics. Nicole expressed great concern regarding leadership within the field:

> I never could understand how they were gonna make changes if patients weren't the center of that. Like, these are the people that are experiencing this, or the people that have experienced it and are telling you, "Hey, you're doing this wrong and this is what you

need to do to fix it." But again, like I told you, the OBGYN world is a predominantly White male area. And it's the weirdest thing to me. Absolutely insane.

Thematic Cluster 1b: Experiences with Subsequent Pregnancies.

Of the five women interviewed, two were pregnant at the time of the interview and one had a toddler-aged son. All of the women who had subsequent pregnancies described anxiety about their pregnancy and the health of the baby. Erika found the process of trying to conceive again more stressful than the actual pregnancy:

> It was just like, knowing how far away I was from bringing a baby home and also just like, you know, even if this does work, something could still happen and then I have to go back to square one. So there's a lot of anxiety with that.

Erika and Nicole had a difficult time finding care providers for their second pregnancies. Nicole attempted to return to the same practice but had a panic attack after being placed in the same room they told her about her son's death in. The doctor's response was, "If this is how you're going to be, I can't care for you like this."

Nicole said her excitement was short-lived when learning about her second son and that she experienced doubts about his safety, adding, "I didn't believe that I was gonna bring a baby home. I didn't believe that I was going to actually have a human. And even sometimes now with him being here, I'm always like, hmm. All the 'what ifs'." Courtney also experienced this anxiety but has been able to calm this with help from her therapist:

> She helps me to kind of calm down and understand that there's no point in stressing, because at the end of the day, what's going to happen is going to happen. And we are going to, you know, pray our way through, we're going to get through it.

These feelings directly impacted how participants approached their subsequent pregnancies. Nicole recounted a desire to make decisions in her second pregnancy entirely differently than her first:

> When I got pregnant with [second son], I tried to do everything vastly different than how I did it with [first son]. I had eaten the morning that I had, like, found out that he didn't have a heartbeat and that was one of the things that delayed us doing anything because I had to be free of food. And I wouldn't eat until after my doctor's appointment. I didn't care how hungry I was, I was like, oh, well we're not eating

Similarly, Erika's grief impacted how she approached her second pregnancy emotionally:

> I was also very aware that the pregnancy could be the only time I get to spend with this baby. And I was like, if something does happen, I don't want to look back on it in the future and be like, well I was just anxious the whole time. Like I didn't enjoy any part of that or like, make any sort of connection.

Participants also felt an additional onus of responsibility for the health of their baby, with Nicole saying, "I had to participate in my pregnancy. Like, I couldn't just be pregnant." Erika had a doula for her first and second pregnancy and Nicole hired one for her second.

Finally, all three women noted that they received additional monitoring with their second pregnancy. Courtney's doctor reassured her she could come in at any time, saying, "They kind of offered me a level of comfort I didn't have before." Courtney appreciated this reassurance and felt that the doctor recognized that she deserved better treatment than she received the first time. While Nicole and Erika also received additional care, they resented the reason behind it, with Erika asking, "Why did I have to lose my first baby to be getting care like this?"

Emergent Theme 2: Social Stressors

All five participants described stress stemming from social interactions. These stressors included being around other people in general and specific experiences that invalidated their experience with loss. The following thematic clusters expand on these elements of social stress.

Thematic Cluster 2a: Being Around Others.

Participants described stress when interacting with others manifesting in a variety of ways, including total self-isolation, anxiety around infants, and difficulties returning to work. Four participants described self-isolating after the loss of their baby. Denise said:

> I was very antisocial. I didn't want to speak to anyone, like anything someone said to me just, it aggravated me right after I had my son. So I didn't have a social life at all after I had my son. I was more to myself. I didn't speak to anyone.

Courtney, Nicole, and Gabrielle avoided leaving their homes entirely in the time immediately following the deaths of their babies, keeping to themselves during this intense period of mourning. Gabrielle said during her maternity leave, there were often weeks in which she would not leave the house except to let her dog outside. Courtney's mother moved in with her while she was mourning. She experienced intense separation anxiety related to her mother's whereabouts, saying, "I developed a severe anxiety. When my mother left the house, I had to know when she left, I had to know when she arrived at her destination, I had to know when she was leaving her destination."

All participants experienced distress being around infants, with babies often serving as a painful reminder that their own baby was not present. Courtney's brother and his fiancée had recently had a baby when she experienced her loss, stating, "My brother FaceTimed my mom, and the baby was crying in the background. I ended up having a panic attack. And, you know, it is just, it literally threw me through like this whole loop or whatever." Sounds and items

associated with babies were also distressing. A particularly painful example for Nicole occurred after she was placed in the labor and delivery unit immediately following the death:

> You hear babies crying, you hear a bell that goes off every time a baby is born. Like there's all of these things. And I remember when I finally got home, I used to hear that bell in my sleep because it was so triggering for me.

Gabrielle and Nicole also cited baby showers as particularly difficult, opting not to attend showers for others. Nicole chose not to have one for her second son:

> I went to my cousin's baby shower and I had a panic attack and I was like, hmm. Can't do this anymore, my answer will be no. I didn't have my own baby shower. I had something after my son was born. I think I get stressed out about them because I know what could happen.

For Erika, watching others give attention to babies was difficult, saying "They should also be like talking about my baby." Increased comfortability around babies over time varied, with some saying that they are now able to be around babies and others saying that they still experience discomfort around them. Nicole now does not have a hard time with babies but does have a hard time with children who are the age her son would be. For Gabrielle, only baby girls are difficult to be around. Denise said that for her, emotional reactions to babies wax and wane, saying "I'm just taking it day by day. Day by day. I just saw a baby at Walmart Sunday, and I just got in the car and just started crying, but it just comes and goes."

All four participants who worked at the time of their loss mentioned hesitancy to return to work and feeling overwhelmed. These participants worked jobs that required high levels of interpersonal contact, described as especially stressful. Gabrielle worked at a retail store that offered baby registries and found it difficult to assist customers with creating them. Denise,

Nicole, and Gabrielle discussed feeling overwhelmed by coworker questions and condolences upon their return. Denise explained:

> When I went back to work, that's all I heard was, ‘Are you okay?’ ‘What happened?’ You know, questions like that. It aggravated me when that happened. They asked the same questions the whole week. [The] whole first week I got back was very frustrating, to the point where people just stopped talking to me because I just walked off and wouldn't reply to anyone.

Nicole’s workplace did not share with her coworkers that her baby died when she took leave, leading to an awkward moment with a coworker. She shared, “This woman walked up to me, she's like, how's the baby? And I was just like, he's dead. And I walked away. Because at that moment, that's all I couldn't say.” When she later apologized, her coworker acknowledged that it shouldn’t have been her responsibility to tell everyone. Courtney did not feel ready to return to her position as a school counselor and cried driving to work for a few weeks upon her return. She expanded by saying, “I went through a phase of feeling like, if I can’t take care of my baby, how can I take care of somebody else’s?”

All mothers who had expressed difficulties being around people described slowly rebuilding their social lives over time. Denise said she now feels less irritated with people, saying, “I have a social life now. It doesn’t bother me when people talk to me.” Similarly, Nicole developed more understanding with others as time has gone on:

> I've ruined some really good relationships because I just, I had like zero patience for people and their stuff. And now I come from a place of like, you don't know any better. Like, you don't know. You only know what you know.

Courtney noted that she could be in public more over time but still experiences anxiety around crowds. She said this normally doesn't impact going to work as a school counselor for a 160-student high school, but noted one specific exception:

> When they found out about this pregnancy, they wanted to do a gender reveal at school. That created severe anxiety for me. They were all gathered. They were just there and it was just like, oh, it's a lot of y'all. Let's pop this thing and let me go back to my office.

Thematic Cluster 2b: Collective Disenfranchisement.

This thematic cluster encompassed the way that participants described social disenfranchisement of perinatal loss experienced by themselves, their families, and Black women in general. All participants highlighted the stress of disenfranchisement, with their grief, pain, and identity as mothers were invalidated. Descriptions of social invalidation included individual experiences, experiences of family members, and discussion of the overarching denial of Black women's pain and experiences within maternal healthcare.

Firsthand experiences of disenfranchisement included instances in which others treated their grief as unjustified, minimized their pain, denied their identity as a mother. Nicole's ex-husband's trivializing attitude towards her grief ultimately led to their divorce, stating, "I was grieving, and I was grieving in a household with someone that didn't believe that like, I should be grieving. He was just like, alright, like, wrap this show up." Gabrielle said that her family had a "why are we talking about this?" attitude towards her grief, becoming visibly uncomfortable whenever she opened up about her loss. Similarly, Erika noted how her family members treated this loss differently from other losses:

> My uncle came up to me who's also super religious and was like, [...] "We always pray about you and you know, your situation." But it was just like, the way he just said, "your situation," like, I stubbed my toe or something. <laugh>

Insensitive questions about future children minimized the severity of participant's pain. Gabrielle said, "There was one family member who I saw within days [who] asked me, you know, if I was gonna have another kid. Like, it wasn't even a full week." Erika, Nicole, and Gabrielle felt that religious condolences were dismissive. Nicole and Gabrielle both disliked others saying their baby is in a better place, but Gabrielle later found comfort in this sentiment. Another example Erika gave was, "'Oh, you have like a beautiful little angel watching over you.' [...] My baby's not supposed to be the one watching over me. Like, that doesn't bring me comfort." Finally, participants described difficulty with social experiences that invalidated their identity as mothers. For example, Nicole said, "I remember someone saying to me, 'oh, someday you'll be a mom' and I was just like, what? What do you mean someday?"

These experiences were exacerbated by the social expectation of Black women to conceal their pain for the comfort of others. Nicole and Courtney both touched on feeling this pressure to be "strong" in the midst of their intense grief. Nicole said:

> We have to be strong all the time. And like, that was the weakest point of my life. Outside of getting divorced, that was like the weakest point of my life. And I felt so helpless, and I felt like, how are people supposed to navigate this and be able to function after this? Like, how are you supposed to live life after this?

For Courtney, emotional strength was a mutual effort between her and her mother. She said, "My mom was my support system, has always been my support system. She was devastated, but she

was trying to be strong for me. [...] She was my support system, but I was trying to stay strong for her."

While all participants noticed grieving within their families, Erika, Nicole, and Gabrielle indicated that they could not be attuned to their family member's needs while grieving themselves. Nicole said, "My mother had a very difficult time and I mean, I could talk to her more about it now. I couldn't talk to her about it then because I was piecing myself back together." She then addressed the disenfranchisement experienced by family members, saying:

> But no one talks about like, the parents that are in these situations, the moms and the dads of the pregnant person. They lose a grandchild and then they have a child that they're potentially on the verge of losing.

Participants' family members also experienced emotional distress. Mothers in particular were deeply affected. Courtney said her mom was "Devastated. Like, she was absolutely devastated." Her other family members were also impacted, including her niece and nephew. Denise's mother was also profoundly affected by the death, saying, "You know, it was her first grandchild and she actually was holding him at the time he took his last breath when I was in the bathroom. So, yeah. It hit me and my mother really, really hard."

Some feelings of invalidation stemmed from the social taboo surrounding perinatal loss. Courtney, Nicole, and Erika noted that this silence is especially loud in the Black community and spoke to the collective disenfranchisement experienced by Black women. Courtney was motivated to participate in the study in part due to the silence surrounding Black perinatal loss:

> I jumped at this opportunity because it needs to be addressed. [...] A lot of Black women don't talk about losing children and it has to be okay to talk about. Like, talk about it. It doesn't have to be a taboo conversation. It's okay to talk about.

These participants linked this silence to the importance of self-advocacy for Black women within the healthcare system, encouraging them to ask questions and push for quality care for themselves and their families. For example, Erika shared:

> We are really like the bottom of the rung [...] Healthcare is already not great in America, but then if you're a woman it's even less so. And then if you're like a woman of color, it's just like, we're literally last on the rung. Like, you do really have to know what you want and be in tune with your body and make sure people hear you.

Courtney's message was similar, urging families to advocate for themselves:

> As far as feeling like there's some medical issue or neglect, ask questions. Advocate for yourself. Know and understand that even though the world is what it is, you have to advocate for yourself and understand that certain things happen to Black and brown people that don't happen to others.

Erika and Nicole added the importance of sharing your story. Nicole has shared on social media and spoke at a national maternal health conference, saying, "You can't mess up because it's your story. You can't make a mistake because this is something that you lived and it's your story. It's your story alone." As a final statement for her interview, she reflected on hope for the future of Black maternal health, saying, "I'm hoping that 10 years from now we're having a different conversation and we're just like, oh, women aren't dying as much in childbirth because we've done the work."

Emergent Theme 3: Transformation

The final emergent theme, transformation, encapsulates how participants have noticed a change within themselves and their lives since experiencing perinatal loss. Symbolism, efforts to restore normalcy and move forward, and shifts in identity are expanded upon below.

Thematic Cluster 3a: Symbolism.

All participants attached meaning to the loss through symbolism, most prominently through memorial items and activities and spirituality. Memorial items were a symbol of the baby's presence and the mothers' connection to their babies. These items included photographs, blankets, onesies, jewelry, and stuffed animals. Some participants were provided a box of items by the hospital containing things like handprints and footprints, poems, hats, and other mementos. Feelings towards the hospital-provided items were mixed, with some finding them touching and comforting and others finding them impersonal. Personalized memorial items were more meaningful for participants who had them. These items included a stuffed animal made to match the weight and size of the baby and jewelry with significant meaning. For example, Denise, Courtney, and Gabrielle all had necklaces containing their babies' ashes they wear frequently. Other jewelry included charms with meaningful symbols, pieces featuring the baby's birthstone or date of birth, and breast milk jewelry. Two participants had or intended to get memorial tattoos for their baby.

None of the mothers had traditional memorial services and all but Nicole opted for cremation. Nicole said she would have considered burial if she had been fully informed of her options after her son's death. Courtney and Denise explicitly mentioned the desire for their baby to be within the home as a reason for cremation, with Denise explaining, "For my baby and I, I didn't want him buried. I wanted him there in my room with me." Courtney said this was especially important for her as she had purchased a house during her pregnancy and wanted him to come home to it.

While none of the mothers engaged in traditional memorial rituals, most described symbolic acts of remembrance. Courtney engaged in activities with her family to help her young

nephew cope, including potting flowers and allowing him to hang a memorial wind chime outside of her home. She also mentioned a daily routine in which she goes to her baby's room to tell him good morning. Gabrielle says hello to her daughter whenever she sees a red cardinal bird or a yellow butterfly. For Nicole, acts of remembrance rooted in giving back to her community were a way for her to memorialize her son. This year, she chose to host a book drive to commemorate what would have been his first year of school, stating, "Even though [son] is not here, I still keep his legacy alive and I'm still mothering him."

Discussion of spirituality was present in all five interviews. Denise, Nicole, and Gabrielle all experienced some form of spiritual distress. Denise said, "I blamed God for a moment. [...] That's pretty much the only spiritual thing. I just, I was very, very upset with God." Nicole also expressed feeling anger with God and became upset when someone bought her a Bible as a gift after the loss. Gabrielle felt angry with God for depriving her of watching her daughter grow up, saying, "I just felt like God just robbed me of seeing her first birthday, seeing her go to kindergarten." Over time, the hope of reuniting in the afterlife helped Gabrielle transform her spiritual distress into spiritual comfort, stating, "I see it as him, you know, just bringing her back to the other side. I'm just waiting to catch up with her, you know?" She noted that this process was lengthy, adding, "It took a while. It really took a while for me to get to that point." This imagery of the afterlife was also comforting for Courtney and Erika. While their views of the afterlife differed, both mentioned their baby being with loved ones. Courtney described a spiritual experience she had after grandmother died a few months after her baby:

> One of the reasons I wanted to go ahead and have him was because I wanted him to be in her arms. That was one of my biggest things. I wanted him to be held by her the way that she held me when I was a baby. And at that point it was something that hit me. I don't

know if it was, I don't know, I can't say, but I walked by [a copy of] her obituary one day and I said, “Hey, grandma.” And the response was, “I got him.”

Erika also found solace in the idea of her son being cared for by her deceased grandma:

> When we were in the hospital and they first told us that he had died, one of the first things I said to [husband] was like, “At least my grandma [is] taking care of him.” Because I just could not bear the idea. Like, babies just are not supposed to be alone. [...] That was always a very comforting image for me of her just taking care of him.

Thematic Cluster 3b: Identity Shift.

Participants also described change within themselves over time, experiencing a shift in their identity as they worked through their grief. Courtney’s decision to go to therapy was heavily influenced by this transition, saying, “I would never be the same. And so, I needed to learn that this new me was gonna be okay and was heading in a particular direction.” She noted that the “new her” was not healed, but coping, and that she will never be fully healed from the experience. Similarly, Gabrielle’s therapist’s advice was influential in helping her grow around her grief:

> When it comes to grief, it's always gonna be there. It's always gonna be the same. She told me to picture it as a ball that's inside of you, and it's gonna be the same size. But how you grow around it can change, you know? And I often think about that. And since I'm seeing my therapist, I've noticed how there's been more room for me.

All participants engaged in individual therapy after losing their baby, with varying degrees of satisfaction. For Courtney, Nicole, and Gabrielle, therapy was a necessary and crucial part of their grief journey. Nicole had been in therapy previously and chose to return, “I was just like, oh, I need to get back into therapy. And I don't know what it's gonna look like, but I did. And it

was pivotal for me to be able to survive." Gabrielle delayed therapy, stating, "It was something I put off for a while, but I, I needed it. And it took me a while to realize that I needed it. And my therapist, she's helped me, you know, find ways to cope well." Courtney, a counselor herself, said that being an active participant in therapy with a Black maternal health therapist was important for her healing journey. She noted that while she did not have racial preference for doctors, racial concordance was important for her within mental healthcare specifically. Gabrielle had both a racial and gender preference, while Nicole had a gender preference but liked having a different cultural perspective from a non-Black therapist.

Two participants described negative experiences with therapy, one with individual counseling and another with couple's counseling. Denise said, "I wasn't interested, but I did speak to a therapist. We had like two sessions and then it was just too much for me, so I just stopped it." She said she did not feel emotionally ready to return to therapy and did not plan to in the future. Erika attended couple's counseling with her husband after they decided to try to conceive following the death of her son, but was unsatisfied with the therapist's approach:

> She's just constantly telling us like, "Oh, you guys are doing a great job." Like, "You guys are like the ideal couple after loss, blah, blah, blah." And it's just like, that's nice to hear. But also like, I'm not always doing well. Like I don't care if I'm doing better than your, you know, other clients. Like, I am still struggling sometimes and that's what I'm here for you to help me with.

Participants noticed changes in identity outside of the therapy room as well. For Nicole, her loss helped her discover her passion for Black maternal health. Through her advocacy work, she said, "I found purpose in my pain." She added that she is no longer a "people pleaser" and is

more vocal about her boundaries. Erika described how she has noticed a shift in how she approaches confrontation:

> I have definitely been a lot more assertive since he died and have a lot less hesitations about advocating for myself. [...] Once you have a kid, you just have this different energy to like, protect them or whatever. And that just didn't go away from me just because he wasn't here.

She also noted an increase in emotional intelligence within her relationship with her husband, feeling like the experience made them grow closer. Courtney felt similarly about her relationship with her family in the time immediately after the death, adding, "It drew us closer. We're not a very touchy-feely family. We're not super, you know, 'I love you' type. We're just not that kind of family. But it did bring us closer." She noted that her relationship with them has essentially returned to how it was before the death as time as gone on.

Thematic Cluster 3c: Restoring Normalcy and Moving Forward.

Most participants described a process of restoring equilibrium, both in the short and long term. All five participants described feeling intense emotions immediately following the loss of their baby. Gabrielle said the beginning was particularly painful, saying, "First going through it, it was some of the roughest, rough days that I've had." Nicole also experienced intense emotional distress, going mute during the period immediately after the loss. Denise was especially bothered by her feelings of anger towards her son:

> I hated how I was so upset that I kind of blamed my son. [...] I was so upset. Like why did you, why he had to come so early? Why couldn't he hold on a little longer? Just one more week and he would've been fine. And it brought me up when I started blaming my son for, you know, him passing and coming early.

During this period of mourning, several participants described utilizing routines to establish a sense of normalcy following the death. Nicole found these integral to her survival, stating, “You have routines and things that you are just like, okay, so I have to do this. This is like a part of me being able to survive all of this.” Courtney was very intentional in her routines:

> I opened my front door and I opened my blinds every day. That was a must. I got up and I got dressed every day. That was a must. That was intentional because I had a miscarriage when I was like 30. And I went into severe depression. I mean, I didn't open blinds, I didn't open doors, none of that. But this time I wanted to make sure that I didn't completely cut myself off from the world.

Erika got into the routine of pumping breast milk as it helped her both establish a routine and feel connected with motherhood, stating, “It was just kind of something to like, help me get out of bed and take care of my body and [it] just made me feel more like a mom, I guess.”

All five participants discussed the ongoing nature of grief, experiencing fluctuations in intensity of grief and emotional reactions as time went on. Denise opened her interview by describing these experiences, stating, “I think about him every day. I live every day. I take it day by day. Sometimes I just have a meltdown out of nowhere. [...] It’s not an easy process trying to get through it.” Others also experienced these random grief triggers, with Nicole adding, “You're always triggered in like the weirdest ways. Like I don't have them as often now. I'm like five years into this, but when they do happen, they are very, very weird.” The mothers described a dynamic relationship with grief, with some days being easier than others. Gabrielle stated, “One thing I can say about grief is definitely not linear. you know, every day it's not gonna be the same.”

While social relationships served as a large source of stress for all participants, they also played a large role in the process of navigating their grief. All five women gave examples of both practical and emotional support that others provided. Practical support included cooking meals, cleaning, assisting with self-care tasks, and helping with post-death arrangements. Nicole stated that her sister supporting her basic care needs was one of the most helpful things for her after losing her son, saying, "She slept on a cot and she worked from the hospital and she would come to my house every day and make sure I took a shower. Like, little things like that." Taking over responsibilities was another form of helpful practical support. For example, Erika's brother assisted with making cremation arrangements:

> He actually called a bunch of places and made a spreadsheet for us of like, if they had availability and how much they charge for infant cremation and their options for urns or whatever. [...] So that was super, super helpful that he did that, because I was just not in a place to be making those calls.

Family and friends provided emotional support by allowing participants to express their grief, offering distraction, and by simply acknowledging their pain. Participants valued the ability to express their grief and talk about their baby to others. Gabrielle said, "I did have some people that just let me talk about it. Like, they didn't offer any advice or tell me how I should think about it. They just let me let it out. And that I appreciate." Erika desired similar support from her husband:

> When I was crying, he would kind of try to talk me out of it or help me feel better. And I had to tell him like, sometimes I just need you to hold me or give me a hug. And like, you know, you can't fix this. You can't make our child undead.

Two participants highlighted children within their families as helpful. Courtney's nephew was eight at the time of her loss and had no prior experiences with death or grief, leading to many conversations to help him understand what happened. She said, "He made it okay to talk about. He made it okay for it to have happened." For Erika, her cousin's daughter's acknowledgement of her baby was meaningful:

> She came up to me and was like, "Hey, I'm really sorry this happened to you. Like, I wish that hadn't happened." And so that was really sweet. But then I was also like, wow, a six-year-old can do this, but none of the adults really can.

Erika's story was strongly influenced by emotional support she found through social media:

> I had so much support from people, like totally random strangers who I have hardly interacted with. Like, they were sending me gifts or sending me sweet messages or reaching out to me often. You know, reading my blog posts and leaving comments and stuff like that. So, like, I also got a lot of support socially that I was not expecting and that I absolutely would not have had if I weren't like, public about my feelings.

Three of the participants noted support from support groups, both virtual and in-person. Both Nicole and her mom began individually attending a healing circle and support group, which she described as helpful. She noted that her mother's support group used to be exclusively for women of color but has since become majority White women. Erika was involved in a virtual support group and attended a weekend-long grief conference after her loss. The virtual support groups described were private groups on social media. Gabrielle noted that the way she engages in online support has changed over time:

> When I first started off, I was commenting and I made a few posts and it helped because it was just that immediate space that, you know, I was able to let it out. Since then I've

been a lurker. I think I started being a lurker because I did start to get a bit triggered. [...] I do go back to it from time to time because it's nice to still, you know, connect when I'm able to have, you know, that mental strength to do so.

In the long term, the establishment of equilibrium was often defined by acceptance and moving forward after loss. Courtney said that life feels, for the most part, "normal" for her now, saying, "I've been able to adjust to what life is now. I understand that, you know, life was what it was and life is this now, and I have to be okay with that." For Gabrielle, moving forward was defined by "being able to learn how to live with that grief." One of the most important ways she did this was through practicing self-compassion, adding, "I've been able to cope as I give myself grace. I just need to remind myself that it's normal to react that way and to not get upset with myself." Participants also noted that their grief would always be within them, even as time passed. Courtney acknowledged this when speaking a friend and later a former student who experienced perinatal losses after hers, telling them, "This isn't something you heal from, it's something you cope with." Other methods of moving forward were avoiding dwelling on regrets and "what-ifs" and an emphasis on being in the moment.

Each participant was asked to share advice they had for other Black women and families who have experienced perinatal loss. Denise suggested practicing empathy for others, saying, "Even though you're hurting, try not to take it out on everyone else [...] Especially like your parents, your family members, because they're experiencing the loss as well as you." Gabrielle said, "Don't give up. Just keep going."

Exhaustive Description

Black women's perinatal loss experiences are shaped by various external and internal stressors and coping methods. Medical negligence plays a key role in Black women's perinatal

loss experiences, with many experiencing insufficient information and a frustrating lack of intervention. Medical care for subsequent pregnancies is also affected. Black women who have experienced perinatal loss experience social stress, both through being around others and through collective disenfranchisement. Black women's perinatal loss experiences are marked by a profound sense of transformation characterized by restoration of normalcy and moving forward, the use of symbolism, and a permanent shift in identity.

CHAPTER 5: DISCUSSION

This study aimed to further examine the lived experience of Black women who have experienced perinatal loss by exploring the associated stressors and coping methods using the following research questions:

1. What stressors are associated with perinatal loss among Black families?
2. What coping strategies do Black families utilize after experiencing perinatal loss?

While the study's original intention of introducing a holistic familial perspective was unattainable due to the lack of non-mother family figures within the sample, this study contributes to the existing literature by conceptualizing Black perinatal loss within the Strobe and Schut's (1999) Dual Process Model of Coping with Bereavement. Prior to this study, no research on Black women's experiences with perinatal loss used the DPM.

The study answered the first research question by identifying a variety of social and emotional stressors as well as the stress of medical negligence. The second research question was answered through the emergent theme of transformation. These emergent themes outline how Black women's experiences in the aftermath of perinatal loss are largely shaped by their treatment within an inherently racist medical system, interpersonal and cultural social stress, and the act of navigating their newfound identities in the midst of their intense pain during bereavement. The stressors outlined by the five participants in this study contain frustrating parallels to studies conducted decades prior, confirming that work towards positive maternal and infant health outcomes for Black women in the United States is far from done.

Medical Negligence

Medical negligence was prominent in four of the five participants' stories. These participants were not given sufficient information regarding their care and what would happen to

them both during and after labor and delivery, experienced dismissive attitudes from medical providers, and expressed frustration with medical providers' neglect to implement or outright refusal to implement potentially life-saving interventions.

Some aspects of the women's stories were strikingly similar to those in the work of Kavanaugh and Hershberger (2005) and Fenstermacher (2014), with parallels in even the smallest details of the women's stories. For example, both Courtney and a woman in Kavanaugh and Hershberger's (2005) study had doctors who questioned other medical professional's neglect to attempt a cerclage. Another emotional parallel rests in the detailed description of watching the baby's breath slow and then cease in both Denise's story and a woman interviewed by Fenstermacher and Hupcey (2019). These similarities are especially concerning when considering the 19-year gap between 2005 and 2024, driving home the point that despite recent initiatives to address issues within the world of maternal and infant healthcare, the field continues to traumatize Black women the way it has for decades.

Four participants described situations in which they wished that medical staff had shared more information with them. Medical staff failed to provide information about several different things within the women's stories, such as precautions to prevent preeclampsia, options for disposal of fetal remains, and possible complications after delivery. This lack of transparency was also found within the literature (Kavanaugh & Hershberger, 2005), and may contribute to feelings of distrust towards medical professionals. Additionally, Courtney and Nicole noted that they later learned from White women who had received care at the same places they had received better care, open communication, and additional resources. This clear-cut medical racism is present in both of their stories despite their losses occurring four years apart in entirely

different geographic locations, further exemplifying how medical racism is structural in nature and persists across the medical system as a whole.

While the overall medical experience was negative for all but one participant, a few positive medical experiences were highlighted. These experiences showcased medical professionals who were receptive, proactive, and respected the participant's medical autonomy. It is troubling that several participants could only describe one doctor who met this bare minimum expectation of care out of the dozens of healthcare professionals they encountered across their pregnancy and loss experience. This alarming pattern raises serious questions regarding the medical educational system's ability to prepare medical professionals to care for Black women and infants in a way that preserves their dignity, their autonomy, and most importantly, their lives.

Two participants discussed preference for continuity of care with their preferred care providers, congruent with past findings (Kavanaugh and Hershberger, 2005). Importance of racial concordance, as with past work (Kemet et al., 2022), was mixed. Several participants mentioned that they would have preferred Black care providers, but that these providers were either not available, difficult to access, or did not align with their care needs. However, almost all participants indicated that they had strong preference for female care providers. This reveals an urgent need for OBGYNs across racial lines to adopt anti-racist philosophies into their care practice.

Inconsistent with past research, all but one participant said they did not experience much financial stress after their loss. None of the participants had extensive medical costs, with several having their medical bills cleared entirely by medical facilities or insurance. This lack of financial stress may reflect the sample's demographic qualities, with all participants having

completed at least some college. Additionally, two participants noted their ability to get medical costs forgiven by their care providers or insurance and one had benefits through the military that included both coverage for the medical costs and a life insurance payout for the baby. The demographics of the sample directly challenge the assumption that socioeconomic status is the key cause behind disproportional rates of perinatal death in Black women. This point is further emphasized by the maternal health experiences of high-wealth Black women like Serena Williams and Beyoncé. In other words, no amount of wealth or socioeconomic privilege can exempt Black women from medical racism.

Finally, three women detailed their experiences with pregnancy after loss. As established in previous work (Hunter et al., 2017; Van & Meleis, 2003), the three participants in this study who experienced a subsequent pregnancy experienced increased prenatal anxiety. Van and Meleis (2003) found that their participants had lower levels of attachment of the fetus and some level of denial about the pregnancy, a sentiment echoed in Nicole's comment that she doubted that she would bring home a baby even when she became visibly pregnant with her second son. Conversely, Erika made an extra effort to attach to her daughter in her second pregnancy due to the heightened awareness of the possibility of fetal loss. Similarly, all three noted that their loss influenced their prenatal decision-making, like increased frequency of appointments or change in appointment-day routines. Erika and Nicole both mentioned how helpful having a doula was. While the racial identity of these doulas were not discussed, this is reminiscent of the historical significance of Black midwifery and non-medical birthing assistance (Bonaparte, 2014). Erika and Nicole were frustrated with the fact that care providers gave them better quality care during their second pregnancies. These professionals' adoption of comprehensive and compassionate

care only after perinatal loss is a call for concern, implying that quality care for Black women is only accessible after traumatic experiences have already occurred.

These anxieties occurred at various points in their pregnancy and centered not only on the health and safety of the baby, but on the ability to get pregnant in general and the process of conceiving. Interestingly, two of the women who experienced pregnancies after loss utilized fertility treatments. Nicole conceived her first son after five years of trying, leaving her to wonder how long it would take for her to get pregnant again while using IVF the second time. While Erika did not use fertility treatment, her anxiety surrounding conceiving was also rooted in concerns about if and when she would become pregnant again. This concern over the ability to become pregnant again is present within the existing literature (Evans et al., 2023; Van & Meleis, 2003). Among the two who had not experienced a subsequent pregnancy, only Gabrielle mentioned having children in the future. She said she was interested but hesitant, an opinion shared with others in the general perinatal loss literature (Dyer et al., 2019).

Social Stressors

Social stressors were found to be an emergent theme in this study, strongly reflective of previous work on Black perinatal loss. Consistent with previous research, social stress occurred across a variety of interpersonal relationships and contexts, including family, friends, and colleagues (Evans, et al., 2023; Fenstermacher, 2014; Fenstermacher & Hupcey, 2019; Jones et al., 2021; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). While some of the social stressors highlighted in other studies included adjacent concepts to self-isolation like disconnectedness from others (Jones et al., 2021) and feelings of loneliness (Kavanaugh & Hershberger, 2005), the intense period of lone grieving described by participants in this study was different than those identified in previous literature. Three participants in this study

described complete isolation from others, avoiding talking to people and not leaving their homes when possible. Returning to work following the loss was also difficult due to tiring inquiries about the baby from colleagues, reminiscent of the experiences women in previous literature, in both studies focused on Black women (Van & Meleis, 2003) and studies with several racial identities represented (Hazen, 2003). The participants in this study described rebuilding and restructuring their social lives moving forward, a restoration-oriented activity under Stroebe and Schut's (1999) model.

One particular aspect of social interaction that proved to be difficult was being around babies and infants, echoed in the work of Fenstermacher (2014) and Fenstermacher and Hupcey (2019). However, while those women experienced sadness, anger, and jealousy when around reminders of pregnancy and babies, the women in the present study often added an aspect of anxiety and panic not described in prior research. Additionally, three of the women experienced these negative feelings when encountering anything having to do with babies, including baby showers and baby items. These encounters with babies and items with babies served as a painful reminder that the women's own babies were not present, causing feelings of distress.

As discussed by Shannon and Wilkinson (2020), bereaved parents often experience disenfranchised grief following perinatal loss, expressed by participants within this study as feelings of invalidation. All participants experienced some form of social invalidation of their grief, their identities as mothers, or their baby's very existence. Four participants felt hurt by comments that downplayed the severity of their pain, with many of these comments belittling their connection with their baby. These comments were reminiscent of comments made to women interviewed in previous studies (Evans et al., 2023; Kavanaugh et al., 2004; Van & Meleis, 2003). Some of the unintended messages hidden within these comments were that the

baby was replaceable with other children, that their first experience with motherhood didn't count as mothering, and that their grief was an overreaction. While the women in the present study did not deflect these hurtful comments through prayer as the women within Van and Meleis's (2003) study did, women in the current study still chose to either ignore or brush off these comments.

Nicole and Erika expressed distaste for religious platitudes, describing them as annoying. Both women acknowledged that these comments were from others whose religion did not align with their own. This finding is not present in the existing research and suggests that the alignment of religious condolences with the mother's religious affiliation is an important factor in the distinction between "helpful" and "hurtful." Additionally, it highlights the importance of verifying religious preference with mothers for care providers.

Another aspect of invalidation lies within language. As described previously by Van and Meleis (2003), the participants in this study referred to their experiences as the death of a baby over the loss of a pregnancy, emphasizing the way in which language can validate the individual's perception of their loss. Two women criticized the way that family members and others spoke of the death, using vague terms and avoiding the topic. As recognized by participants both within this study and others (Kavanaugh et al., 2004; Van & Meleis, 2003), these family members often intended to avoid hurting the mother by bringing up the death or offering well-intentioned comments, but unintentionally hurt them by implying that their grief was unnecessary.

This disenfranchisement was felt on the individual, familial, and societal level. Family members of participants also experienced mental and emotional distress, especially participants' parents. Mothers were the most common family members described as having a difficult time

after the loss. Three described their mothers as a pillar of support throughout their own grieving process, suggesting that these mothers may push their own grief aside to support their daughters. This rejection of personal grief is reminiscent of both the historical disenfranchisement of Black mothers' grief (William & Bonner, 2023) and the "strong Black woman" stereotype, the assertion that Black women are meant to carry the pain of others while denying their own needs (Carter & Rossi, 2019). Courtney mentioned that she and her mother were strong for each other, indicating that this feeling of responsibility to serve as a source of emotional stability is bidirectional within mother-daughter relationships.

Societally, several women acknowledged how Black women are the least heard, least cared for, and least considered within maternal health. These women emphasized the importance of sharing their story and advocating for themselves and others, expressing concern for other Black women who will experience perinatal loss in the future. This highlights the collective nature of disenfranchisement and how important the role of community care is in maternal health.

There were few examples of concurrent losses or stressors discussed by participants, unlike in previous literature (Fenstermacher & Hupcey, 2019; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). One participant's grandmother died after her loss, but this was not described in detail or discussed as a major stressor. This may be due to the interview question wording, with participants focusing on addressing the stressors directly associated with the loss event.

Transformation

The theme of transformation emerged, encapsulating experiences like the use of symbolism, the restoration of normalcy and moving forward, and changes in personal identity.

These themes are key aspects of restoration-oriented coping, with all of the women discussing their adjustment to life after loss. Similar themes appear in existing literature, with past work discussing meaning-making, the adoption of a new perspective on life, and internal reflection (Fenstermacher, 2014; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003).

Restoration of normalcy was a process that appeared to be two-fold, with short-term actions focused on the implementation of day-to-day routines and long-term actions focused on acceptance of the loss and the ability to push forward. Both short and long-term examples of restoration of normalcy carried an overarching desire for a sense of emotional equilibrium. This resiliency is present in past work, particularly Fenstermacher's (2014) description of the adoption of a new perspective on life following perinatal loss.

Consistent with the DPM (Stroebe & Schut, 1999), the coping process described by these participants was a fluid, dynamic process that shifted over time. All five participants described struggling emotionally in the aftermath of their baby's death. Participants experienced a range of emotions, including sadness, depression, anxiety, fear, anger, and apathy. These emotions were all present in women within the existing literature (Fenstermacher, 2014; Jones et al., 2021; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Descriptions of coping with these emotions are relatively consistent with that of previous work. Congruent with the DPM (Stroebe & Schut, 1999) participants engaged in both loss-oriented and restoration-oriented coping activities. When asked about coping, participants primarily responded with examples of loss-oriented coping such as reminiscing about the baby, going to therapy, and talking about the baby with others. Restoration-oriented responses such as rebuilding their social lives and stepping into new identities appeared later when asked about how their coping has changed over time. This pattern is consistent with Stroebe and Schut's (1999) assertion that the emphasis on loss-oriented

coping wanes over time, leading to a more balanced oscillation between loss and restoration-oriented coping.

As seen in previous studies, participants found comfort in memory items and rituals (Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). In addition to traditional memory items recognized in prior studies like photographs and items from the hospital, all five participants described personalized memory items obtained after the death. Additionally, participants discussed hospital-provided boxes with resources and memory items, suggesting that several hospitals have integrated this identified best practice for bereaved parents (LeDuff et al., 2017). It should be noted that one participant noticed that items within her box were meant to be personalized by hospital staff and they were not, demonstrating the need for clear procedures within hospital settings for perinatal loss patients. Finally, memories of time with the baby were also cherished.

The use of social interaction as a means of coping corresponds with prior literature, particularly the importance of practical support (Kavanaugh et al., 2004) and emotional support (Jones et al., 2021; Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Participants who mentioned acts of practical support emphasized their impact and how helpful they were, suggesting that at times this form of social support was more beneficial than emotional support for these participants. Participants indicated that emotional support was most effective when the person providing it allowed them to express their grief freely, a description in alignment with Jones et al.'s (2021) description of "authentic presence" (p. 417). Appreciation of the openness and honesty surrounding death from children reflected this value of authenticity, and experience found both within this study and the work of Van and Meleis (2003).

Several also found the ability to speak freely about their loss through social media, both in posting to their personal social media pages or by sharing in private groups. The private groups described were virtual support groups. This comfort discussing the loss with those who had also experienced it reflects the experiences of women in past studies who found comfort by talking to others with similar experiences (Jones et al., 2021; Kavanaugh et al., 2004). These women used social media for information, social support, and advocacy work. For them, social media became a way to be heard within a culture of silence regarding Black perinatal loss.

A key difference from prior work concerning memorial activities was the lack of desire within participants for traditional funeral or burial services. None of the women chose to have a formal burial service, though Nicole said that she feels that if she had gotten to meet her son she would have wanted one. While prior work on cultural differences in death rituals suggests that Black Americans are less likely to opt for cremation (Buchanan & Gabriel, 2015; Lobar et al., 2006), four of the participants in this study chose cremation. This preference may be reflective of the ambiguity and disenfranchisement of perinatal grief, with the lack of acknowledgement of perinatal losses as "legitimate" losses leading bereaved families to make different post-death arrangement decisions than they would for other individuals. Additionally, two participants mentioned cremation being offered for free to them by the hospital, which could have been a factor in their decision-making. Finally, two participants explicitly stated that they wanted their babies to be home with them, highlighting the importance of maintaining a semblance of the baby's presence for the coping process.

One interesting difference from previous literature on Black perinatal loss is that all participants in this study tried therapy, with most remaining in therapy for extended periods of time. This finding, while inconsistent with work on Black women after perinatal loss, does

reflect the interest in mental health services expressed by postpartum Black women in newer research (Bodnar-Deren et al., 2017; House et al., 2020). The three participants who had positive experiences with therapy expressed appreciation for therapy that was engaging, holistic in nature, and addressed other areas of their lives. Of the negative experiences with therapy, Denise did not feel emotionally ready to talk about her baby and Erika did not like her counselor's approach, feeling it was too surface level. While she had a good experience while in therapy, Nicole described difficulty getting healthcare providers to help her access mental healthcare and felt that if she were White, her mental wellbeing would have been held to a higher standard. Both Erika and Nicole's experiences are reminiscent of the women in the work of Kemet and colleagues (2022) who described feeling like they had to escalate their symptoms for their distress to be addressed, being forced to conform to the "angry Black woman" stereotype to be taken seriously. This again calls into question the ability of healthcare professionals to care for Black women in a way that is respectful of their autonomy, dignity, and safety.

In contrast to this apparent increase in interest in therapy, discussion of religion was less present in this study compared to previous research. While not all participants mentioned religion as a coping strategy, those who did leaned on their faith heavily through their grief experience. Additionally, two participants expressed a connection to spirituality outside of religion. Three participants found solace in the idea of their baby in the afterlife surrounded by loved ones, a sentiment echoed in the work of Van (2001). None of the participants mentioned receiving social support from a church community, unlike in other studies (Jones et al., 2021). This is likely reflective of the religious demographics of the participants.

All five participants described shifts in identity, detailing a variety of ways their baby's death had affected their behaviors and decision-making moving forward. These discussions

carried themes of identity as participants examined their experience moving from the version of themselves before loss and the version of them after. This message of being permanently changed following loss corresponds with past research (Fenstermacher, 2014; Fenstermacher et al., 2019; Jones et al. 2021), but one difference is that several women directly credited therapy with their ability to step into this new identity. This theme highlights the permanent impact that perinatal loss has on Black women, with the intense personal mourning process combined with disenfranchisement of grief forcing these women to rediscover who they are to themselves, to others, and society at large.

Limitations

All the participants were mothers of the lost babies, meaning the intended evaluation of the family as a whole is missing the perspective of other family members. This paired with the study's small sample size means that the results cannot be applied to all Black families who have experienced perinatal loss. The topic of perinatal loss and grief is sensitive, which could be one reason that recruiting was difficult. However, this only further proves the need for additional research as those having difficulty coping were potentially less inclined to participate. Finally, the researcher's White racial identity could have served as a barrier to participant comfortability with sharing their stories, with other similar studies noting the success of using "sister-to-sister talk" (Few et al., 2003, p. 205) and the noted comfortability with racial concordance in healthcare that may translate into the research setting.

Future Directions

As Black maternal healthcare and infant mortality continue to be researched, future research may go in many ways. More research is needed with direct interviews with family members of Black women who have experienced perinatal loss to better understand their unique

needs and strengths as they grieve while supporting the grieving mother. Work investigating generational differences in response to loss could reveal a valuable look at the role of intergenerational trauma in perinatal death experiences. Interestingly, two participants used fertility treatment for their subsequent pregnancy. Further inquiry into the connection between fertility treatment experiences and perinatal loss could reveal helpful insight into best practices for providing fertility treatment following perinatal death.

Finally, one participant's experience was distinctly unique in that her husband is an active-duty military personnel. Recent research affirms that racial healthcare disparities are also present within the Military Health System regardless of socioeconomic status (Vereen et al., 2023), calling for further examination of the experiences of Black families experiencing perinatal loss within the United States military. Additional examination of the role that military-exclusive risk and protective factors play on maternal health outcomes is also needed.

Implications

The purpose of this study was to examine the stressors and coping methods associated with perinatal loss among Black mothers. The experiences of these participants offer meaningful insight into future work aimed at improving Black maternal and infant health. For example, the identified stressors and coping mechanisms could be useful starting points for the development of interventions for Black mothers experiencing perinatal loss. Certified family life educators should consider methods of increasing their presence within maternal health, using their knowledge of family risk and resiliency to create strengths-based systems for Black families experiencing perinatal loss. Their expertise in the ten family life education content areas, particularly families and individuals in societal contexts, interpersonal relationships, and family

law and public policy (National Council on Family Relations, 2020), positions them to be excellent advocates for Black women experiencing loss and their families.

However, the strongest implication of this work rests within the healthcare field. There are many examples of actions that individual practitioners can implement to address some of the problems faced by Black women within the field of healthcare, such as emphasizing education and informed consent or improving access to resources for bereaved parents. However, the results of this study reveal an urgent need for substantial action to address racism rooted deep within the overarching healthcare system, calling practitioners and researchers alike to take responsibility for dismantling these racist structures within their fields. Rather than attempt to summarize the existing literature on examples of anti-racism work, and as actionable steps towards anti-racist care and practice can vary from discipline to discipline, I feel it most appropriate to refer to academic literature from Black lead authors outlining methods of decolonizing Black maternal health within fields such as nursing (Canty, 2023), mental healthcare (Estriplet et al., 2022; Morris & Barrera, 2024), education and research (Iradukunda & Canty, 2023), and health policy reform (Barlow & Johnson, 2021). However, practitioners must not limit themselves to the often-inaccessible world of academic literature when educating themselves. Iradukunda and Canty (2023) underline the importance of community knowledge in the decolonization of healthcare:

> As long as Black women have been oppressed, exploited and denied reproductive rights, they have found ways to resist. A major part of this resistance is building knowledge and protective community practices. Racialized communities understand the existing structural issues and have developed their own solutions. Their lived experiences can contribute to the development of nursing knowledge. Therefore, academia must value this

knowledge and invite communities to partner in educating the next generation of nurses and midwives.

In other words, the value of Black women's stories is not dependent on their inclusion in maternal health literature, but rather, the value of maternal health literature is dependent on the inclusion of Black women's stories.

Conclusion

In summary, the experiences of Black mothers who have experienced perinatal loss are largely shaped by the stressors they encounter, coping strategies they employ, medical experiences, and an overarching theme of transformation within their lives. Generally, stressors and coping methods described by participants aligned closely with those discussed in previous literature. However, due to the highly personal nature of perinatal loss, each individual story told through this story carries unique insight into the experience of perinatal loss for Black women and their families. The inclusion of stories like these within the literature is important for the future of anti-racist work within the field of maternal and infant healthcare.

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APPENDIX A: IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
Willis Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** ·
rede.ecu.edu/umcirb/

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB
To: Annagrace Saufley
CC: Sandra Triebenbacher
Date: 3/25/2024
Re: UMCIRB 24-000073
Perinatal Loss Among Black Families

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) occurred on 3/25/2024. The research study is eligible for review under expedited category # 6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

As the Principal Investigator you are explicitly responsible for the conduct of all aspects of this study and must adhere to all reporting requirements for the study. Your responsibilities include but are not limited to:

1. Ensuring changes to the approved research (including the UMCIRB approved consent document) are initiated only after UMCIRB review and approval except when necessary to eliminate an apparent immediate hazard to the participant. All changes (e.g. a change in procedure, number of participants, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the UMCIRB before they are implemented;

2. Where informed consent has not been waived by the UMCIRB, ensuring that only valid versions of the UMCIRB approved, date-stamped informed consent document(s) are used for obtaining informed consent (consent documents with the IRB approval date stamp are found under the Documents tab in the ePIRATE study workspace);

3. Promptly reporting to the UMCIRB all unanticipated problems involving risks to participants and others;

4. Submission of a final report application to the UMICRB prior to the expected end date provided in the IRB application in order to document human research activity has ended and to provide a timepoint in which to base document retention; and

5. Submission of an amendment to extend the expected end date if the study is not expected to be completed by that date. The amendment should be submitted 30 days prior to the UMCIRB approved expected end date or as soon as the Investigator is aware that the study will not be completed by that date.

The approval includes the following items:

Name	Description
Demographic Survey.pdf	Surveys and Questionnaires
Demographic Survey.pdf	Data Collection Sheet
Hospital Approval Email	Additional Items
Interview Guide.docx	Interview/Focus Group Scripts/Questions
Saufley Thesis (1).pdf	Study Protocol or Grant Application
Thesis Informed Consent 3_5_24.pdf	Consent Forms
Thesis Recruitment Flyer (1).pdf	Recruitment Documents/Scripts

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

—

Study.PI Name:
Study.Co-Investigators:

APPENDIX B: RECRUITMENT FLYER

Exploring Black Families' Experiences with Perinatal Loss, Grief, and Coping

Research Study Participants Wanted

The aim of this research study is to learn how Black families cope with perinatal loss and the associated stress.

Eligibility

To qualify for this study, you must:

- Be at least 18 years old
- More than one year ago, have experienced a perinatal loss between 20 weeks pregnant and 28 days after birth
- Identify as Black

Participation Involves

- A 45-60 minute one-on-one interview either virtually through Zoom or on campus at East Carolina University
- A $40 Visa gift card for your time

Contact Annagrace Saufley at saufleya18@students.ecu.edu for more information

APPENDIX C: INFORMED CONSENT

Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Exploring Black Families' Experiences with Perinatal Loss, Grief, and Coping

Principal Investigator: Annagrace Saufley (Person in Charge of this Study)
Institution, Department or Division: ECU College of Health and Human Performance, Department of Human Development and Family Science
Address: 112 Rivers, East Carolina University, Greenville, NC 27858, Mail Stop 505
Telephone #: 252-917-1220

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

Why am I being invited to take part in this research?
The purpose of this research is to better understand the lived experiences of Black individuals who have experienced perinatal loss within their family. You are being invited to take part in this research because you have indicated that you identify as Black and have experienced perinatal loss within your family beyond the past year. The decision to take part in this research is yours to make. By doing this research, we hope to learn how Black families go through perinatal loss, stressors and challenges that they face after perinatal loss, and how they cope with the experience.

If you volunteer to take part in this research, you will be one of about 10 people to do so.

Are there reasons I should not take part in this research?
You should not take part in this study if you are under 18 years of age, if you have not experienced a perinatal loss within the family, or if you do not identify as Black.

What other choices do I have if I do not take part in this research?
You can choose not to participate. Participation in this research project is entirely voluntary.

Where is the research going to take place and how long will it last?

The research will be conducted virtually, or in the Rivers building at East Carolina University. You will need to come to this location one time during the study. The total amount of time you will be asked to volunteer for this study is 2 hours over the next 2 months.

What will I be asked to do?

You will be asked to do the following:

Complete a short demographic survey that will ask about basic information such as age, relationship status, and gender.

Complete an in-depth interview that will be audio recorded. The interview will include questions about your experience with perinatal loss, stressors related to the loss, how you coped with the loss, and how this loss impacted your family. I will type up your audio-recorded interview for analysis. The typed transcript and recorded file will be kept in a password-protected file. Only those involved in the research study (the principal investigator and the faculty investigator) will have access to the documents. The tapes and documents will be kept for, at most, seven years and then they will be deleted at the end of this time period. Any accompanying documents will also be shredded at that time.

If you are willing to be involved in the process of double checking the results ("member checking"), I will contact you and discuss the results with you. This will give you an opportunity to give feedback or make corrections.

What might I experience if I take part in the research?

We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. Potential risks may include, but are not limited to, recalling and disclosing past events that may cause you to become emotionally distressed. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you but the information gained by doing this research may help others in the future. In the instance that you experience distress while taking part in the study, you will be provided contact information about mental health services to receive further support.

Will I be paid for taking part in this research?

We will not be able to pay you for the time you volunteer while being in this study. However, each participant will be given a $40 gift card as a token of appreciation.

Will it cost me to take part in this research?

It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:
Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

How will you keep the information you collect about me secure? How long will you keep it?
You will be given a pseudonym and a code number. All documents and audio files will be password-protected and stored on ECU's encrypted server. Data will be kept for 7 years following the study when it will be deleted and any accompanying documents will be destroyed.

What if I decide I don't want to continue in this research?
You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?
The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at (252) 917-1220 (Mondays, Wednesdays, and Thursdays, between 9am and 2pm).

If you have questions about your rights as someone taking part in research, you may call the ECU University and Medical Center Institutional Review Board (UMCIRB) at phone number 252-744-2914 (Monday-Friday, between 8am and 5pm). If you would like to report a complaint or concern about this research study, you may call the Director for Human Research Protections, at 252-744-2914.

Is there anything else I should know?
Identifiers might be removed from the identifiable private information and, after such removal, the information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you or your Legally Authorized Representative (LAR). However, there still may be a chance that someone could figure out the information is about you.

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

I have read (or had read to me) all of the above information.
I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
I know that I can stop taking part in this study at any time.
By signing this informed consent form, I am not giving up any of my rights.
I have been given a copy of this consent document, and it is mine to keep.

Participant's Name (PRINT) **Signature** **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT) **Signature** **Date**

APPENDIX D: INTERVIEW GUIDE

Interview Guide

Rapport

- Tell me a little bit about yourself
  Where are you from? What do you do for work? What are your interests or hobbies?

Grand tour question: Tell me about the experience of losing your [baby/grandchild/family member's baby]

In what ways did this experience impact your family?

What did you find stressful about losing the baby?

- Social? Emotional? Financial? Spiritual?
- How have these stressors changed over time?

What did you find most helpful after losing the baby?

- Social? Mental health services? Spirituality?
- How have these changed over time?

Based on what you have found most beneficial following the loss of your baby, what would you tell other Black families who have experienced perinatal loss?

Are there any questions you feel I should have asked?

APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE

Code _____

Gender

- Man
- Woman
- Nonbinary
- Prefer not to say
- Prefer to self-describe _____

Race (Check all that apply)

- White
- Black/African American
- American Indian/Alaskan Native
- Asian
- Native Hawaiian/Pacific Islander
- Other _____

Are you of Hispanic, Latino, or Spanish origin?

- No
- Yes

What is your highest level of education?

- Less than high school education
- High school diploma/GED
- Some college
- Associate degree
- Bachelor's degree
- Master's degree or more

What is your current age? _____

Do you have any other children?

- No
- Yes

If yes, how many? _____

What is your employment status?

- Employed full-time
- Employed part-time
- Self-employed
- Out of work
- Homemaker
- Student
- Retired
- Other

What is your relationship status?

- Single
- Committed relationship
- Married
- Separated
- Divorced
- Widowed

What is your religious or spiritual affiliation? _____

What is your relationship to the baby? _____

How long ago did the loss event occur? _____