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**PERINATAL LOSS AND BEREAVEMENT
IN NON-HISPANIC BLACK ADOLESCENTS**

A Dissertation in

Nursing

by

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Abstract

Background: Perinatal loss is one of the most stressful events a person can experience in life. The experience of perinatal loss is different from other types of loss through death because it represents the loss of future hopes, dreams, and parenthood. The period that follows perinatal loss is referred to as perinatal bereavement. Despite an overall decline in infant and fetal mortality, non-Hispanic Black adolescents continue to experience rates of perinatal loss that are higher than any other racial or ethnic group. Adolescents are at higher risk for complicated grieving after perinatal loss due to the sudden nature of the loss and the potential negative stigma associated with the pregnancy. Numerous research studies have focused on the experience of perinatal loss and bereavement, however, most research has concentrated on the experience of middle-class, adult White women. Consequently, there is limited scientific literature available to describe the experience of perinatal loss and bereavement in African American adolescents.

Purpose: The overarching goal of this study was to build an understanding of the experience of perinatal bereavement in non-Hispanic Black (African American) adolescent females after perinatal loss. There were two specific aims: To generate a disclosive theory of perinatal bereavement in non-Hispanic Black adolescent females and to identify critical transitions in the perinatal bereavement process that may signal a need for well-targeted, culturally sensitive bereavement support services.

Methods: This study used qualitative methods of grounded theory to explore the experience of perinatal bereavement in eight non-Hispanic Black adolescents (ages 18-

21) who had experienced recent perinatal loss. IRB approval was obtained from six urban hospitals with a high-risk perinatal population. Potential participants were approached by the perinatal bereavement coordinator at each hospital using a script for recruitment. Upon obtaining verbal consent, participants were followed with interviews at three points in time over 12 weeks following their loss. Data were analyzed using constant comparative methods.

Results: The outcome of this research is a grounded theory, “Enduring to gain new perspective” which discloses the main theoretical concepts of the experience, grounded in the data from the thick, rich descriptions of the participants. Analysis of the data revealed the following theoretical categories: Life before pregnancy; Reacting to the pregnancy (sub-categories: accepting and attaching); Living through the loss event (sub-categories: emotional response and physical response); Seeking and receiving support; Maintaining relationship; Searching for meaning; and Gaining new perspective. The core conceptual theme was “Enduring the loss”.

Conclusions: The theoretical concepts of the theory correspond in many ways to what other perinatal bereavement researchers have found, yet the manifestations of the experience within the non-Hispanic Black adolescents in this study were different, mostly attributed to age and culture. This study offers new knowledge and suggestions for interventions that add to the perinatal bereavement science. Perinatal bereavement is an interpretive process that is lived out in relation to the meaning that the adolescents ascribe to their pregnancy. Young African American women in late adolescence attribute

meaning to the experience of perinatal loss and bereavement in interaction with partners, family and friends, taking cues from their cultural norms and inherent value systems.

Over time, as they endured the loss, these adolescents gained new perspective on how they have changed from the experience and how the experience will shape their future.

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DEDICATION

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Chapter 1

Introduction

Perinatal loss is reportedly one of the most stressful events a person can experience in life (Flenady & Wilson, 2008). The experience of perinatal loss is different from other types of loss through death because it represents the loss of future hopes, dreams, and parenthood (Bartellas & Van Aerde, 2003). The sudden and unexpected nature of perinatal loss often triggers profound grief in response to the traumatic event (Gold, Dalton, & Schwenk, 2007). The grieving period that follows the loss of an infant is referred to as perinatal bereavement (Chan et al., 2008).

Perinatal loss includes miscarriage, stillbirth, and neonatal death within the first 28 days of life (DiMarco, Renker, Medas, Bertosa, & Goranitis, 2002). Despite an overall decline in infant and fetal mortality, African Americans continue to experience rates of perinatal loss that are higher than any other racial or ethnic group, and more than twice the Caucasian fetal mortality rate (Price, 2006). Likewise, the infant mortality rate for non-Hispanic Black adolescents is higher than any other racial and ethnic group (U.S. Department of Health and Human Services [DHHS], 2006). Birth outcome statistics are reported by the U.S. DHHS according to race and Hispanic origin, thus for the purposes of this research study, non-Hispanic Black and African American are used interchangeably. Adolescents are at higher risk for complicated grieving after perinatal loss due to the sudden nature of the loss and the potential negative stigma associated with the pregnancy (Sefton, 2007). Complicated grieving is defined as a group of symptoms including longing for the deceased, purposelessness about the future, anger, bitterness, and a lost sense of security (Melhem, Moritz, Walker, Shear, & Brent, 2007).

The focus of this dissertation is the phenomenon of perinatal bereavement as experienced by non-Hispanic Black adolescents after perinatal loss. In this chapter, the scope of the problem of perinatal loss in non-Hispanic Black adolescents is described, the purpose of the study is presented, and the conceptual framework for the study is introduced. Two research aims are presented, as well as theoretical definitions for the concepts that are salient to the phenomenon of perinatal bereavement. The underlying assumptions that support and guide the inquiry are delineated. Lastly, a discussion to support the significance of the study of perinatal bereavement in non-Hispanic Black adolescents is offered. A brief definition of perinatal loss is provided for clarity and consistency.

Statement of the Problem

Perinatal Bereavement Research

A significant and unique bereavement response follows a perinatal loss (Wallerstadt & Higgins, 1996). Non-Hispanic Black teenage girls experience the highest rates of perinatal loss compared to other racial and ethnic groups, yet very little is known about the bereavement experience for this population. In fact, while teenage pregnancy has received much attention from researchers, the research in the area of adolescent bereavement after pregnancy loss has been sporadic (Chesterton, 1996). Numerous research studies and review articles have focused on the experience of perinatal loss and bereavement, however, most research has concentrated on the experience of middle-class, adult White women (Kavanaugh & Hershberger, 2005). Consequently, there is limited scientific literature available to describe the experience of perinatal loss and bereavement in African American women (Kavanaugh & Hershberger, 2005; Van, 2001; Van &

Meleis, 2003) and inadequate literature to describe the experience in non-Hispanic Black adolescents despite the incidence of perinatal loss in this vulnerable population.

Definition of Perinatal Loss

There are several definitions of perinatal loss in the scientific literature. For example, some authors define perinatal loss as a wide range of losses associated with pregnancy: miscarriage, ectopic pregnancy, stillbirth, neonatal death, loss of a twin, and giving up a child for adoption (Callister, 2006). Elective termination of pregnancy for fetal anomalies has also been considered perinatal loss as the grief experience that follows the death of the infant has been shown to be similar in intensity and expression to other types of perinatal loss (Keefe-Cooperman, 2005; Lorenzen & Holzgreve, 1995; Zeanah, Dailey, Rosenblatt, & Saller, 1993). Other researchers offer a more limited definition of perinatal loss to include pregnancy loss after 20 weeks gestation and up to the first 28 days of life (Chan et al., 2007). Some suggest that perinatal loss is defined as involuntary loss of pregnancy by miscarriage, early loss (less than 20 weeks), stillbirth, or neonatal loss (newborn through 28 days of life) (DiMarco et al., 2002; Robinson, Baker, & Nackerud, 1999). The latter definition is used to define perinatal loss for the purposes of this dissertation. The definition by Callister (2006) is considered too broad through its inclusion of adoption and the definition offered by Chan and colleagues (2007) excludes the experience of miscarriage as a perinatal loss. Although the researcher acknowledges elective termination for fetopathic reasons as a type of perinatal loss, for the purposes of this dissertation study, the definition reported by DiMarco et al. (2002) and Robinson et al. (1999) is chosen as it encompasses the range of loss before 20 weeks up to and including loss within the first 28 days of life.

Perinatal Mortality Rates

In order to present the broad scope of the problem of perinatal loss in non-Hispanic Black adolescents, the most recently available U.S. Department of Health and Human Services perinatal mortality rates are reviewed. Perinatal mortality is defined as the combined rates of neonatal deaths within the first 28 days of life and fetal deaths with a gestation period of 20 weeks or more per 1000 live births and fetal deaths (MacDorman, Hoyert, Martin, Munson, & Hamilton, 2007). Although perinatal mortality in the United States has demonstrated a steady decrease over the past 20 years, a wide gap persists between birth outcomes for non-Hispanic Black women and women of all other racial and ethnic backgrounds (MacDorman et al., 2007). As noted above, perinatal mortality data includes both fetal and neonatal mortality statistics. The disparity in birth outcomes is illustrated by Table 1 which compares fetal, neonatal, and perinatal mortality rates between non-Hispanic Black women and women of other racial and ethnic backgrounds.

Table 1. Comparison of Fetal, Neonatal, and Perinatal mortality, United States 2005 (per 1000 live births)

	Non-Hispanic Black	American Indian or Alaska Native	Hispanic	Non-Hispanic White	Asian or Pacific Islander	Total
Fetal Mortality	11.13	6.17	5.44	4.79	4.78	6.22
Neonatal Mortality	9.13	4.04	3.86	3.71	3.37	4.54
Perinatal Mortality	20.17	10.18	9.27	8.48	8.13	10.73

Fetal Mortality = fetal death of 20 weeks gestation or more

Neonatal Mortality = infant deaths less than 28 days

Perinatal Mortality = Combined infant deaths of less than 28 days and fetal deaths of 20 weeks or more (MacDorman & Kirmeyer, 2009)

Reviewing the perinatal mortality statistics by age and race combined reveals that the neonatal mortality rate (infant deaths within the first 28 days of life) experienced by non-Hispanic Black women under age 20 is 9.3 per 1000 births compared to 3.9 for non-

Hispanic Whites and 3.8 for Hispanics (DHHS, 2006). Likewise, teenagers experience stillbirth more often than women over the age of 20 (Chesterton, 1996). In brief, these data illustrate the disparity in occurrence of perinatal loss in non-Hispanic Black women and Black adolescent females compared to other racial and ethnic groups.

Disparities in Birth Outcomes and Social Determinants of Health

The risk factors associated with disparities in poor birth outcomes are linked to the racial and ethnic trends in perinatal mortality rates. Late or no prenatal care, drug abuse, stress, depression, and bacterial vaginosis are all risk factors for preterm birth and are more prevalent in Blacks (DHHS, 2006). Social determinants of health, such as race, low socioeconomic status, and age have been linked to disparities in health status and pregnancy outcomes (Price, 2006). Other social determinants of health include education, social support, employment, and environment (Wuest, Merrit-Gray, Berman, & Ford-Gilboe, 2002). These factors are considered in relationship to non-Hispanic Black adolescent females in order to explicate the disparities, vulnerabilities, and health risks associated with this population. Examples of the social determinants of health relative to what is known about perinatal outcomes and perinatal mortality are described as follows: race and ethnicity, income, social support, education, and age.

Race and ethnicity.

Race is a socially derived construct and a chief contributor to health disparities (Fiscella & Williams, 2004). Even despite improved access to early prenatal care for the economically disadvantaged, racial and ethnic disparities in perinatal morbidity and mortality persist. For example, in a study that examined pregnancy outcomes for more than 35,000 singleton pregnancies with adequate prenatal care, the Black population

experienced the highest frequency of perinatal mortality compared to all other ethnic and racial groups (Healy et al., 2006).

Income, social support, education, and age.

Low income and lack of social support have also been linked to poor birth outcomes (Carter, Misri, & Tomfohr, 2007). Years of education and age are related to perinatal mortality, placing teenage mothers at higher risk for poor birth outcomes. According to a report by Singh and Kogan (2007), in 2001, the relative risk of infant mortality for mothers with less than 12 years of education was 41% higher than for mothers with ≥ 16 years of education. Low maternal age is also associated with neonatal survival. Salihu, Emusu, Aliyu, Kirby, and Alexander (2004) found that there was an elevated risk of neonatal death among extremely preterm twins born to teenaged mothers. Thus, adolescent mothers are among those with the highest rates of infant mortality (Mathews & MacDorman, 2007).

Purpose of the Study

The overarching goal of this study was to build an understanding of the experience of perinatal bereavement in non-Hispanic Black adolescent females after perinatal loss. To that end, there were two specific aims:

- 1) To generate a disclosive theory of perinatal bereavement in non-Hispanic Black adolescent females.
- 2) To identify critical transitions in the perinatal bereavement process that may signal a need for well-targeted, culturally sensitive bereavement support services.

Disclosive theory is a product of qualitative research emerging from grounded theory that exposes the linkages between concepts and delimits the stages and phases of a

process (Morse, 1997). In this study, the process of interest is perinatal bereavement and the method of inquiry is grounded theory.

As noted above, the experience of perinatal bereavement in the lives of non-Hispanic Black adolescents has not been well described in the literature. This study describes the experience of perinatal bereavement in non-Hispanic Black adolescent mothers after perinatal loss. Results from this study provide a foundation to inform nurses and other healthcare professionals about the experience of perinatal bereavement in non-Hispanic Black adolescents and offer direction to develop culturally and developmentally appropriate bereavement support interventions for this population.

Conceptual Framework

Symbolic Interactionism

Symbolic interactionism is an approach to interpreting the actions of human beings in response to one another, based upon the meaning that is attached to actions, as actions are mediated through the use of symbols (Blumer, 1969). As such, this framework provides an appropriate lens through which to interpret data from a grounded theory study on perinatal bereavement in non-Hispanic Black adolescents. Symbolic interactionism provides the foundation and theoretical underpinnings for the methods of grounded theory in qualitative research. Symbolic interactionism guides a grounded theory research study by informing the underlying assumption that the participants in the research study share a common problem in the domain being studied (Wuest, 2007). Grounded theory provides a conceptual rendering of the data to explain the phenomenon under study (Charmaz, 2003).

Assumptions of symbolic interactionism.

The three major assumptions of symbolic interactionism espoused by Blumer (1969) are as follows:

- 1) Human beings act toward things and people according to the meaning that things and people hold for them.
- 2) Meaning is derived from social interaction.
- 3) People modify the meanings of things through an interpretative process as they respond to things that are encountered in the human experience (Benzies & Allen, 2001). The word “things” is used to refer to objects, other human beings, as well as categories of people, institutions, ideals, activities, and situations (Blumer, 1969).

In symbolic interactionism, meaning grows out of how a person acts towards another person in regard to the thing, or situation. For example, the notion of ascribing meaning to an experience of perinatal loss can be understood through the tenets of symbolic interactionism. Swanson (1999) discovered that a woman’s way of thinking about perinatal loss could only be interpreted in the context of what the pregnancy and loss meant to the individual woman. Most importantly, women made meaning about the loss from how they perceived the pregnancy. Through a symbolic interactionism lens, the “thing”, or situation, in this dissertation research is perinatal loss and bereavement. According to symbolic interactionism, the meaning ascribed to the experience of perinatal loss and bereavement is established through an interpretive process, which is influenced by the human experience or cultural interactions.

Symbolic interactionism posits that meaning is ascribed through social

interaction; hence, an association to the cultural influences imparted to the experience of perinatal bereavement can be made. Fletcher (2002) makes the connection to culture and the perception of life events, such as perinatal loss, by asserting that all humans experience the same types of problems, but the influence of culture significantly impacts how the problems are perceived. Consequently, individuals respond to loss and bereavement in part according to their cultural influences. Researchers have noted the differences in the grief response during bereavement in relation to culture and ethnicity, (Laurie & Neimeyer, 2008; Sefton, 2007) suggesting the importance of considering how these factors influence perinatal bereavement in non-Hispanic Black adolescents. Laurie and Neimeyer (2008) found that African American college students who had experienced the loss of a family member reported higher levels of complicated grief symptoms than Caucasian students. Likewise, African Americans are likely to appear stoic and not show an emotional response to loss until they have the opportunity to interact with someone from their culture (Hardy-Bougere, 2008). Symbolic interactionism presents a framework that is suitable to consider cultural influences within the phenomenon of perinatal bereavement. In relation to the aims of this study, symbolic interactionism offers a viable way to guide the analysis and interpretation of data as the researcher looks for the ways in which culture influences how meaning is ascribed to perinatal bereavement.

Research Questions

This research aimed to describe and explain the process of perinatal bereavement in non-Hispanic Black adolescents using grounded theory methods, thus the research

questions were process-oriented as opposed to cause and effect oriented. The following research questions guided this study:

- 1) What is the process of perinatal bereavement in non-Hispanic Black adolescents who have experienced perinatal loss?
- 2) How do non-Hispanic Black adolescents describe the meaning of the experience of perinatal bereavement after perinatal loss?
- 3) What are the critical transition points during the process of perinatal bereavement for which interventions may be helpful?
- 4) What factors influenced, helped, or hindered the process of perinatal bereavement?

Theoretical Definitions

It is important to differentiate bereavement from other related concepts, such as loss, grief, and mourning. Theoretical definitions of each of these terms are offered for clarity and consistency. In addition, clarifications of the types of perinatal loss are set forth.

Bereavement has been defined as a process or a state of having experienced the death of someone significant (Corless, 2006) or having been deprived by death (Bartellas & Van Aerde, 2003). The process and meaning of bereavement is influenced by gender, ethnicity, culture, education, and socio-economic status (Ferrell & Coyle, 2006).

Loss is considered the act or instance of losing a physical object or a symbolic object that may or may not be apparent to others (Bartellas & Van Aerde, 2003).

Grief is considered to be a response to bereavement, but not the only response to bereavement (Kastenbaum, 2007); the emotional reaction that follows the loss of a valued

other (Brier, 2008); or a normal response characterized by intense and deep sorrow that may be manifested in psychological, physical, behavioral, or social ways (Bartellas & Van Aerde, 2003).

Mourning is the manifestation of culturally patterned behaviors during bereavement (Kastenbaum, 2007) that incorporates the experience of the loss into the outward expression as life is lived (Ferrell & Coyle, 2006).

The concepts of bereavement, loss, grief, and mourning are particularly blurred in the scientific literature. Only two explicit definitions of perinatal bereavement were found in the review of 144 articles in the Pub Med database searching with the terms “perinatal bereavement”, English language, and no time limits (Fenstermacher, 2011, unpublished manuscript). Callister (2006) defines perinatal bereavement as a “unique mourning situation”. Krone and Harris (1998) propose a broad assessment of perinatal bereavement as a “significant situational crisis”. Neither of these definitions provides the conceptual clarity needed as a theoretical foundation for scientific study. Thus, a principle-based concept analysis as described by Penrod and Hupcey (2005) was performed by the researcher to discern the epistemological, pragmatic, linguistic, and logical properties of the concept of perinatal bereavement as a theoretical foundation for this research. The end product of a principle-based concept analysis is a theoretical definition that is reflective of the state of the science (Penrod & Hupcey, 2005). Findings from the principle-based concept analysis are described in greater detail in Chapter Three. Therefore, the definition of perinatal bereavement that guided this study is as follows:

Perinatal bereavement is the experience of parents that begins immediately following the death of an infant by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies. Perinatal bereavement is characterized by a complex emotional response, most commonly manifested by grief in both the mother and father, but often expressed differently and in varying degrees of intensity and duration between males and females. The grief response of perinatal bereavement is manifested as both psychological and psychosomatic responses, and is modified by contextual factors that influence grief intensity, duration of bereavement, and the ability to ascribe meaning to the experience. Contextual factors include, but are not limited to, timing of the loss during pregnancy, type of loss, cumulative stressful life events, and cultural influences. Mourning occurs during perinatal bereavement as an expression of the process to resolve the bereavement and is influenced by culture, religion, and tradition. There is no prescribed timeframe for perinatal bereavement, although bereavement support interventions such as creating mementos, naming the baby, holding the baby, and having a funeral service have been shown to decrease the intensity and duration of the grief response (Fenstermacher, 2011, unpublished manuscript).

The following terms are used throughout this dissertation to denote types of perinatal loss, therefore definitions are offered to aid in conceptual clarity.

Miscarriage is the lay term that has been given to the medical term of spontaneous abortion. It is the common term to describe involuntary early pregnancy loss in the perinatal bereavement literature. Spontaneous abortion, or miscarriage, is an involuntary pregnancy loss of a fetus prior to viability or before 20 weeks gestation (Olds, London, & Ladewig, 2000).

Stillbirth typically refers to a fetus born dead after 20 weeks gestation (Olds et al., 2000). In the state of Pennsylvania, where this research originated, physicians are required to issue a certificate of death for any fetal death at 16 weeks gestation or greater (Pennsylvania Department of Health [DOH], 2011). Moreover, the remains of any fetus born at 16 weeks or greater must be cremated or buried so that parents have to make a decision concerning the disposition of the baby's remains. Thus, for the purposes of this study, the cut-off for defining stillbirth loss was a gestational age of 16 weeks or greater. *Neonatal loss* is a loss that occurs within the neonatal period defined as the first 28 days of life (Olds et al., 2000).

Assumptions

The major assumptions that guided this inquiry are as follows:

- 1) All participants shared the common experience of perinatal loss.
- 2) There is variability in the response to perinatal loss and bereavement, therefore an interpretive approach was used to study the phenomenon.
- 3) The bereavement experience is influenced by the gender, culture, socioeconomic status, and ethnicity of the bereaved (Sefton, 2007).
- 4) The degree of attachment to the unborn baby has an impact on the intensity of grief expressed during bereavement.

Significance of the Study

The experience of perinatal loss is a profound life event, often preceded by a stressful and emotional end of life experience in the hospital setting (Gold, Dalton, & Schwenk, 2007). Researchers have studied perinatal bereavement extensively through both quantitative and qualitative paradigmatic perspectives; however, the majority of

studies have focused on the experience of bereavement in White, middle class adult women (Kavanaugh & Hershberger, 2005). Non-Hispanic Black adolescents experience perinatal loss at rates higher than any other racial or ethnic group and yet, little is known about the perinatal bereavement experience in this group.

Adolescence is a particularly vulnerable time of the life span experience. Physiological changes, cognitive differences, puberty, and a lack of practice in coping with stress all contribute to the tumultuous, and often stressful, experience of adolescence (LaRue & Herrman, 2008). Uniquely characterizing the developmental period of adolescence is a strong desire for independence coupled with an increasing need for peer group social support (Hall-Lande, Eisenberg, Christenson, & Neumark-Sztainer, 2007). Among the other factors that influence adolescent development are gender, age, and socio-economic factors, such as family structure and the school environment (Wright & Fitzpatrick, 2004). The adolescent years are formative, challenging, and potentially stressful years. Moreover, adolescents are at risk for rapid repeat pregnancy following a perinatal loss (Bright, 1987). Thus, the experience of perinatal bereavement after the loss of a pregnancy merits investigation in the context of the experience of adolescence and in particular, from the perspective of non-Hispanic Black adolescents.

Culture also informs the bereavement experience (Laurie & Neimeyer, 2008), and cultures have varied norms around the expectations to have children, the meaning of parenting, and the interpretation of death (Bennett, Litz, Lee, & Maguen, 2005). In addition, the unique perspectives and beliefs of others in the context of culture must be considered in order to address health disparities (Airhihenbuwa & Liburd, 2006).

Therefore, there is a need to understand perinatal bereavement from the perspective of the African American culture as experienced by non-Hispanic Black adolescents.

The disparity in perinatal mortality rates between non-Hispanic Black mothers and White mothers is significant, yet very few published studies have addressed the perinatal bereavement support needs for this vulnerable population. The paucity of information available in the literature about the bereavement support needs appropriate for non-Hispanic Black adolescents is problematic for nurses seeking to provide evidence-based care. Nurses have reported that caring for parents who have lost an infant is stressful, demanding, and challenging (Chan et al., 2008; Foster, 1996). Some nurses have expertise in providing perinatal bereavement care, while other nurses find the experience to be so emotionally overwhelming that they are not able to deliver quality care (Roehrs, Masterson, Alles, Witt, & Rutt, 2008). Likewise, negative attitudes of nurses towards bereaved parents can affect the quality of care (Chan et al., 2008). For these reasons, perinatal bereavement is an important area for nursing research and the need to understand this phenomenon as it is experienced by non-Hispanic Black adolescents is paramount.

Summary

In summary, the overarching goal of this study was to build an understanding of the experience of perinatal bereavement in non-Hispanic Black adolescent females. Using a qualitative approach and grounded theory methods, the data yielded rich description of the experience of perinatal bereavement over time in order to build a disclosive theory of perinatal bereavement in non-Hispanic Black adolescent females. In addition, critical transitions were identified that denote a need to offer culturally sensitive bereavement

support interventions. There is a gap in the existing literature and therefore a need to study the perinatal bereavement experience in non-Hispanic Black adolescents. This research makes a significant contribution to nursing science by addressing the critical need to better understand the perinatal bereavement experience and identify bereavement support interventions for non-Hispanic Black adolescent mothers experiencing perinatal loss.

Chapter 2

Literature Review

The purpose of this chapter is to present both a theoretical discussion and a conceptual discussion of the concept of perinatal bereavement. First, a discussion of a relevant, rival theoretical framework with potential application to this study of perinatal bereavement is presented. Secondly, the rationale and approach for using Symbolic Interactionism as a theoretical framework to guide this research is discussed. Finally, as part of the conceptual discussion, a literature review of the concept of perinatal bereavement and its related concepts is set forth to explain how perinatal bereavement is different from other types of bereavement, to reveal the state of the science regarding perinatal bereavement, and to highlight the gaps in knowledge about this phenomenon in non-Hispanic Black adolescents. A discussion of adolescent development, culture, and current modes of bereavement support is presented as important background to this research study.

Theoretical Discussion

Theories of Bereavement: Historical Perspectives

Grief as work.

Bereavement is a widely studied phenomenon among scientists in the disciplines of psychology, sociology, medicine, and nursing. Since the 1950's, bereavement research has contributed theoretical perspectives to cultivate a deeper understanding of the experience of loss and bereavement, as well as provided a means to study interventions and outcomes, guide practice, and raise awareness of the human vulnerability to loss (Benoliel, 1999). An historical review of the major theoretical insights about

bereavement is highlighted here to explain the evolution and scientific progressions of bereavement theory.

Bonanno and Kaltman (1999) identified Freud as being among the first to describe the bereavement experience as “grief work” and to introduce the notion of complicated or pathological mourning as a potential outcome of bereavement. According to Davies (2004), Freud contended that bereaved persons must work through their grief, detach from the deceased, and restructure life by reviewing the past and confronting the reality of the loss. While Freud’s ideas were mainly concerned with depression rather than grief, this conception of bereavement to include detachment from the deceased dominated the bereavement literature for many years (Bonanno & Kaltman, 1999).

In 1944, guided by Freud’s psychodynamic model of grief, Lindemann concluded that unresolved grief resulted in preoccupation with the deceased and failure to successfully conclude the final step of breaking the bonds with the deceased (Davies, 2004). Therefore, bereavement interventions during this time were aimed at helping a person sever their ties to the deceased. Bowlby (1980) challenged the belief that a bereaved person must break the connection to the deceased when he first introduced the idea that the pain of grief stimulates a reorganization of the relationship to the deceased, resulting in continued bonds or a persistent relationship to the deceased. Although originally intended to describe the mother-infant attachment, Bowlby extended his theory of attachment as a means to understand the response of an adult or older child to the loss of a loved one (Davies, 2004). Bowlby noted that the continued bonds help a person to preserve their identity and to find meaning in life (Bonanno & Kaltman, 1999). These insights led to the conception of grief during bereavement as a process instead of “work”.

Grief as a process.

With grief conceptualized as a process, bereavement researchers began to introduce theoretical models of grief as proceeding in phases. The Integrative Theory of Bereavement is an example of a phase theory that was developed to explain bereavement as a process (Sanders, 1999). This theory includes five phases that mark the progression of bereavement through the onset of bereavement to resolution. Three categories of possible outcomes are considered: personal growth, no change, or adverse effects to health. The Integrative Theory of Bereavement has been criticized for lacking a systematic process analysis and for not describing the process in terms of cognitive appraisal or coping (Stroebe, Folkman, Hansson, & Schut, 2006). A major criticism of presenting grief as a process with delineated phases is that this view portrays grief as a problem to be resolved and implies resolution to indicate that there is recovery from grief as a person moves through the phases (Greenstreet, 2004).

Current Theoretical Perspectives of Bereavement

People exhibit a wide variety of responses after the death of a loved one, in terms of intensity of expression, amount of distress, and length of time of bereavement (Fraley & Bonanno, 2004). Classic theories on grief and bereavement centered on the resolution of grief and detachment from the deceased loved one (Davies, 2004). To understand the complexities of the experience, bereavement researchers have studied the phenomenon of bereavement through the various theoretical lenses of stress, trauma, crisis, attachment, spirituality, and social-emotional response (Balk, 1999; Bonanno & Kaltman, 1999). The current theoretical perspectives of bereavement reflect a changing paradigm away from the view that a person breaks all ties with the deceased in order to resolve bereavement.

Rather, researchers now consider bereavement to be an intersubjective process that is unique to each person and includes maintaining connectedness to the lost person as the meaning of the experience persists, yet changes continually (Florczak, 2008). The former thinking about grief as “work” or as phases leading to resolution has shifted to consider grief as meaningful and enriching (Lindstrom, 2002). Bereavement researchers are now considering grief that follows a loss as a catalyst for personal change leading to self-transformation, a reframing of the experience, or a new way of being (Paletti, 2008). Balk (2008) suggests that while not every person experiences a transformation or growth during bereavement, those who are challenged to recover grow spiritually, cognitively, interpersonally and emotionally. In other words, most bereaved people do not return to baseline after losing a loved one; they are in some way transformed by the experience.

As noted thus far, multiple conceptual frameworks have been developed to describe the universal phenomenon of bereavement. The theoretical stance and focus of these models have evolved over time as research has contributed new insights and fresh perspectives about bereavement. Despite the incidence of perinatal loss and the recognition of the phenomenon of perinatal bereavement, no theoretical models were found to be specific to the phenomenon of perinatal bereavement. Therefore, current bereavement theoretical models were considered as background for this research study as a means to articulate the nature of relationships between concepts and suggest propositions that may be appropriate for future testing.

Integrative Risk Factor Framework.

One such model that sets forth several assumptions and propositions about the phenomenon of bereavement and reflects the current worldview about bereavement is the

Integrative Risk Factor Framework (Stroebe et al., 2006). While this framework does not provide the theoretical base for this study on the phenomenon of perinatal bereavement, it does inform the research by suggesting the relationship of certain constructs as possible influences to bereavement outcomes. For this reason, a discussion of the Integrative Risk Factor Framework is presented here.

The Integrative Risk Factor Framework is a theory-based, empirically derived model that builds upon the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999) and the Stress, Appraisal and Coping Model (Lazarus & Folkman, 1984). While the framework was not developed to describe perinatal bereavement specifically, the precipitating event or stressor in the model is bereavement, initiated by the death of a close other. Therefore, the framework is particularly salient to this study of perinatal bereavement. According to Stroebe et al. (2006), the model was conceived to build on what is known about bereavement and to address the weaknesses and shortcomings in other theoretical models of bereavement, namely, those which espouse stages of grief or bereavement and those which fail to include the presence of risk factors. The Integrative Risk Factor Framework holds the following assumptions: that there is variability in a person's response to a loss, that it is important to establish who is at risk for detrimental outcomes related to the bereavement, and that it is not only the type of loss that is important, but the nature of the loss as well (Stroebe et al., 2006).

One of the major strengths of the Integrative Risk Factor Framework is that it considers the impact of both loss-oriented stressors and restoration-oriented stressors on the appraisal of bereavement and coping, as well as predicts outcomes of bereavement. Loss-oriented stressors include the type of loss, the quality of the relationship with the

deceased, and the presence of multiple concurrent losses. Restoration-oriented stressors are deemed secondary consequences of the bereavement, such as work or legal problems, caregiver burden that preceded the loved one's death, and economic hardships related to lost income (Stroebe et al., 2006). The Integrative Risk Factor Framework posits that both interpersonal risk factors, such as culture, religious practices, and family dynamics, as well as intrapersonal risk factors, namely gender, socioeconomic status, and personality, influence a person's appraisal and coping of the bereavement experience, subsequently impacting bereavement outcomes (Stroebe et al., 2006).

There is a dynamic, interactive relationship depicted between the appraisal of bereavement and the prediction of bereavement outcomes. Notably, the bereavement outcomes include grief intensity, exacerbation of the stressors, psychological and physical health, cognitive ability, and social engagement (Stroebe et al., 2006). Another strength and unique feature of this framework is the inclusion of a wide-range of possible outcomes of bereavement to include concepts other than grief. Overall, the Integrative Risk Factor Framework aided in the conceptualization of this study of perinatal bereavement in non-Hispanic Black adolescents by describing the potential of culture, religion, social support, gender, age, nature of the relationship, and socio-economic status as influential on the appraisal and outcomes of the bereavement experience.

No research studies were found that have used the Integrative Risk Factor Framework to guide inquiry. However, this is not considered to be a weakness since the framework was only recently introduced in 2006 and was empirically developed by well-known and respected theorists (Stroebe et al., 2006). Despite the strengths and predictive potential of the Integrative Risk Factor Framework, there are limitations to its application to the

qualitative approach to study perinatal bereavement in non-Hispanic Black adolescents. The model is broad in scope and considers bereavement without differentiation, yet the phenomenon of perinatal bereavement has been set apart from other types of bereavement (Bennett et al., 2005). In addition, the framework suggests outcomes of bereavement, yet the few measurement tools that have been used in the perinatal bereavement literature do not measure bereavement outcomes with consistency and conceptual clarity. A discussion of the tools used to measure perinatal bereavement is presented later in this chapter.

Furthermore, this study aimed to build theory as opposed to test theory, and therefore a predictive theoretical framework would be an inappropriate choice for this qualitative study. Likewise, in terms of considering bereavement interventions for non-Hispanic Black adolescents, there is a risk of being overly prescriptive such that theory takes precedence over individual needs (Sandler, Wolchik, & Ayers, 2008). This investigation intended to describe the experience of perinatal bereavement from the perspectives of non-Hispanic Black adolescents. This paradigmatic stance requires a more interpretive theoretical framework that considers the exploration of how people ascribe meaning to situations and others around them. Current bereavement research suggests that despite the contextual and cultural factors, bereavement is a transformational experience that results in a new way of seeing the world as a person makes meaning of the loss (Paletti, 2008). Finding meaning in the bereavement experience is an interpersonal and intrapersonal process that is rooted in cultural belief systems, individual roles, and family interaction (Sandler et al., 2008). Therefore, symbolic interactionism was used as a theoretical framework to undergird this study of the experience of perinatal bereavement

in non-Hispanic Black adolescents.

Symbolic Interactionism

Historical and disciplinary roots.

As noted in Chapter One, symbolic interactionism provides the theoretical underpinnings for grounded theory methods in qualitative inquiry. While Herbert Blumer is credited with actually coining the term “symbolic interactionism” in 1937, the foundational work of this theory has its roots in a philosophy professor and social psychologist named George Herbert Mead. Mead taught the precepts of symbolic interactionism at the University of Chicago for nearly 40 years, yet published very little on the topic. After Mead’s death in 1931, his lecture notes were found and converted into a theory that was later published by Blumer in 1969 (Benzies & Allen, 2001).

Symbolic interactionism guides a grounded theory research study by informing the underlying assumption that the participants in the research study share a common problem in the domain being studied (Wuest, 2007). In the case of this study, the domain is perinatal loss and bereavement. Grounded theory, in turn, provides a conceptual rendering of the data to explain the phenomenon under study and to explain collected data through the use of systematic inductive strategies to construct middle-range theoretical frameworks (Charmaz, 2003). According to Morse (1997), theory generated from grounded theory methods may be ready for implementation to clinical practice if the methodology was sound. Since one of the aims of this study was to develop a disclosive theory of perinatal bereavement in non-Hispanic Black adolescents, symbolic interactionism as the theoretical underpinnings for grounded theory methods was most appropriate for this research.

Major concepts.

The following paragraphs describe the tenets of symbolic interactionism as described by Blumer (1969). The major concepts of symbolic interactionism center on the human attribute of “self” and how self is developed, conceptualized, and reconceptualized through social interaction (Crooks, 2001). Meaning is derived as one becomes an object of his or her own action. Therefore, self cannot be considered in isolation because the self is constantly changing. That is, self is the subjective “I” which is the spontaneous and natural self as a reflection of what others see, and the objective “me” which sees self as a reflection of what others see (Jeon, 2004). It can also be said that the “I” is how a person really is and the “me” represents the expectations of others. As one has capacity to reflect upon the self through the “I” and “me” constantly communicating with each other, human beings develop a concept of “social self”. A person’s actions are a result of these inner conversations and reflections.

According to Bielkiewicz (2007), Mead first synthesized symbolic interactionism to include the concepts of self, mind, and society as a whole, believing that humans adapt to their environment by sharing common symbols. Through the act of role-taking, interactions occur whereby humans envision themselves in other roles and take on the attitudes, values, and norms of the social group. How human beings respond in the environment is based upon symbols, both verbal and non-verbal, or shared meanings and interactions. Symbolic interactionism focuses on the relationship between symbols and the interactions. Role-taking is the basic cognitive process in which interactions occur as people put themselves in the role of another person and try to anticipate responses. Mead described these interactions as the structure of society (Bielkiewicz, 2007).

Assumptions.

Building upon Mead's work, the three major assumptions of symbolic interactionism espoused by Blumer are as follows: 1) human beings act toward things and people according to the meaning that things and people hold for them, 2) meaning is derived from social interaction, 3) people modify the meanings of things through an interpretative process as they respond to things that are encountered in the human experience (Benzies & Allen, 2001). In the first assumption, the use of the word "things" is used to refer to objects, other human beings, categories of people, institutions, ideals, activities, and situations (Blumer, 1969).

In the second assumption, meaning is said to arise from the process of social interaction between human beings. Blumer (1969) claimed that it is the unique interpretation of the concept of "meaning" in the tenets of the theory that gives symbolic interactionism distinction. According to Blumer (1969), the assertion that meaning arises from social interaction is in sharp contrast to how psychological and social sciences regard meaning as a product of outside factors that influence behavior, such as attitudes, social pressures, and status. In symbolic interactionism, meaning grows out of how a person acts towards another person in regard to the thing, or symbol. How people act, therefore, defines the thing for that person, and therefore gives it meaning. Meaning is a social product formed in and through human beings as they interact.

According to the third assumption, meaning is modified through an interpretative process that has two separate steps. First, a person engages in communication with self to determine the things that have meaning and the things toward which he is acting. Secondly, he selects, regroups, and transforms meaning in light of the situation and the

direction of action (Blumer, 1969). Again, Blumer declared that the interpretative process to assign meaning in social context through self-interaction distinguishes symbolic interaction from other approaches that assign meaning based upon a fixed, established application.

Root images.

In addition to the three major tenets as described above, there are six root images that are foundational to symbolic interactionism as explicated by Blumer (1969). These root images depict the way in which symbolic interactionism relates to human society and conduct (Blumer, 1969). Each of the root images is described briefly.

The first root image is described by Blumer (1969) as the nature of human society or human group life. Because human groups and society exist in action as they engage in the multitude of activities performed in life, people must be seen in terms of action. Human society consists of the activities of its members fitting together in a complex organization. Blumer asserts that the root image of viewing human society as people engaging in action is a fundamental principle of symbolic interactionism.

The second root image is the nature of social interaction, which is recognized as a process that forms the conduct of people as they interact with each other based upon how the other person is acting toward them. Actions are adjusted, therefore, based upon the interpretation of the indications, gestures, or symbols made by others. Therefore, Blumer (1969) states that symbolic interaction includes social interaction as a formative process that results from people fitting their actions to one another, and not as a result of pre-existing psychological factors or social organization.

The nature of objects is the third root image described by Blumer (1969) as significant to symbolic interactionism. Objects are the product of symbolic interaction and can be anything that can be pointed to or referred to, such as a physical object, a social object or an abstract object. The meaning of objects arises from the way in which the definitions of objects are explained by others and through the social process. From the standpoint of symbolic interactionism, human beings form and transform objects as they give meaning to objects through social process.

The human being as an acting organism, or as an actor, is the fourth root image of symbolic interactionism that recognizes the human being as having a self and acting towards self (Blumer, 1969). Human beings engage in social interaction with self and respond through a process of self-interpretation. The notion of self is best seen by a person looking in from the outside and seeing himself as others see him, engaging in self-interaction and then taking on a role by directing his action according to the meaning ascribed to the object of self.

The fifth root image of symbolic interactionism is that of the nature of human action. This refers to the ability of human beings to confront objects in the world and act based upon interpretation of the world, as opposed to the notion that is espoused by scholars in psychology and sociology that human beings simply act in response to the influences of their environment (Blumer, 1969). Human action is both individual and collective action such that whether as individuals or corporations, human beings act on situations according to the meaning of the actions of others and then allow the interpretation of the actions to guide behavior. As one understands the indication and interpretive process of the actor, one can understand the action (Blumer, 1969).

Lastly, Blumer (1969) reports the interlinkage of action as the sixth root image that is foundational to symbolic interactionism. The interlinkage of action refers to the joint action, or social action of a group as a result of the interlinkages of the separate acts of the individual participants. Joint action has three main components. First, according to Blumer, the joint action has a character of its own and may be spoken of without breaking it down into separate acts. Examples of joint actions are those actions found in society, such as marriage, war, or a church service. Even though many of these joint actions involve repetitive and pre-established processes, Blumer (1969) asserts that it is the social process in group life that creates the rules for interaction, not the rules that create group life. Secondly, the interlinkage of joint action exists because of the actions of people at different points and how people define the situation in which they must act. Thirdly, Blumer (1969) states that joint action arises out of the previous actions of participants as they bring a set of meanings and interpretations that influence how they will interpret new situations. Therefore, joint action has a horizontal component of the linkages among all participants and the vertical linkage that is connected to previous joint action.

The use of symbolic interactionism in previous research.

Symbolic interactionism, originating within the tradition of sociology, provides the underpinnings for the grounded theory method of qualitative research (Speziale & Carpenter, 2007). Influenced by the philosophical thinking of both Mead and Blumer, sociologists Barney Glaser and Anselm Strauss are credited with originally developing the method of grounded theory (Strauss & Corbin, 1998). According to Glaser (1978), grounded theory is the process of discovering what is really happening, rather than

making assumptions about what is expected to happen. It is this precept that Glaser asserts makes grounded theory and the theoretical framework of symbolic interactionism attractive to scientists from the social science disciplines. Thus, it is helpful to understand the application of grounded theory methods using symbolic interactionism in nursing research in order to understand the influence of this theoretical framework in nursing science.

Hutchinson (1993) reports the use of symbolic interactionism in nursing science as a foundation for grounded theory research in its usefulness to guide research questions, develop interview questions, select data collection strategies and choose methods of data analysis. One area of nursing science where symbolic interactionism has been used significantly to guide grounded theory methods research is in women's health (Crooks, 2001; Marcellus, 2005). Citing limitations in the biomedical model of research to capture the meaning of health experiences, Crooks (2001) asserts that as nurse researchers gain an understanding of women's experiences through the principles of symbolic interactionism, nurses can provide meaningful evidence-based care to women. For example, O'Brien, Evans, and White-McDonald (2002) studied coping in women with severe nausea and vomiting during pregnancy using grounded theory methods with symbolic interactionism as the theoretical approach. Their goal was to describe the meaning ascribed to the nausea and vomiting in order to understand how women cope during pregnancy. Because the researchers sought to understand behavior in both natural settings and social settings from the patients' perspectives, symbolic interaction provided an appropriate framework.

Symbolic interactionism has also been used to frame nursing research in end-of-life issues. For instance, Mok, Chan, Chan, & Yeung, (2003) applied symbolic interactionism in the context of culture and end of life in their study of families caring for terminally ill patients with cancer in Hong Kong. Using symbolic interactionism as a framework, grounded theory methods were applied to describe the caregiving process in the context of caring for a dying relative. The use of symbolic interactionism in this study demonstrates the utility of the framework to guide research that explores the meaning of symbols to reveal a significant need for culturally sensitive interventions at every phase of caregiving in end of life.

In a study of oncology nurses' experiences with patients and families, Jezewski and Finnell (1998) used symbolic interactionism to frame a grounded theory method approach to understand the meaning of "do not resuscitate" (DNR) status. Through exploration of how nurses assigned meaning to DNR status, the researchers came to understand how the nurse mediates conflict with families and physicians to arrive at a shared meaning of DNR status. Findings from this study inform practice as the authors outline strategies used by nurses in the study to mediate the conversations between physicians and family members with regard to DNR status. Communication emerged as the major strategy for arriving at shared meaning.

Symbolic interactionism has been used to guide nursing research aimed at understanding the process of nurse-client interaction in the care of depressed older adults in the community setting. Jeon (2004) used symbolic interactionism as the theoretical framework to study the process of community health nurses working with caregivers of older adults with depression. One of the purposes of the study was to understand the

interaction of community psychiatric nurses and family caregivers in order to inform nursing education.

In a study of Thai women living with HIV/AIDS, Klunklin and Greenwood (2006) used symbolic interactionism to explain rather than merely describe the relationships of the strategies used by participants to avoid hurtful discrimination. Symbolic interactionism explained that symbolic meaning is important in social life and that meaning is attached to societal value systems. The application of symbolic interactionism in this study reveals the utility of this framework in marginalized groups where there is a possible stigma associated with the situation, such as adolescent pregnancy.

Link between symbolic interactionism and perinatal bereavement.

Symbolic interactionism provides the theoretical underpinnings of grounded theory methods, which allow for an interpretive approach to the study of perinatal bereavement from the perspectives of those who are experiencing the phenomenon. The focus of this study is the experience of perinatal bereavement in non-Hispanic Black adolescents. The tenets of symbolic interactionism provide a framework from which to approach this research through the assumption that human beings act toward things and people according to the meaning that things and people hold for them. Each participant in the research study shared the common problem of perinatal bereavement, yet how they ascribed meaning to the experience was influenced by their interactions with society and those around them.

According to Crooks (2001), symbolic interactionism has great utility for the study of women's health issues because it attends to contextual variables, relationships,

caring responsibilities, and how women ascribe meaning to their situations. In the case of this research study, symbolic interactionism was used to understand the actions and experience of perinatal bereavement in relation to the meaning of the loss for each participant. Symbolic interactionism provides a way to look at process rather than causation and to acknowledge change in perceptions and understandings over time as new information is integrated into the experience (Crooks, 2001). The application of symbolic interactionism requires direct observation of the empirical world through “first hand observation” (Blumer, 1969, p. 38). The use of symbolic interactionism provides a wide lens to understand how the participants react to the experience, how they make meaning from the circumstances, and how the meaning they construe directs their actions and responses (Crooks, 2001).

Conceptual Discussion

Historical Overview of Perinatal Bereavement

The loss of an infant through miscarriage, stillbirth or neonatal death is recognized as a profound event for parents (Gold et al., 2007). Researchers studying the experience after a perinatal loss are in agreement that a significant time of bereavement follows the loss of an infant (Barr & Cacciatore, 2007; McCreight, 2008; Widger & Picot, 2008). An historical review of the literature reveals the evolution of the attitudes of the medical community towards perinatal bereavement and the way in which perinatal loss has been both perceived and approached scientifically over the past 30 years. Such a perspective is helpful in considering the current understanding, use, and application of the concept of perinatal bereavement and is therefore included as important background information.

While perinatal loss is now recognized as a significant loss event in the lives of parents and families, according to Badenhorst and Hughes (2007), several decades ago mothers of stillborn babies were told by physicians to forget about the loss and have another baby. During the decade of the 1970's, however, there were three major influences on perinatal bereavement research: the emergence of attachment theory to understand maternal bonding during pregnancy (Quirk, 1979); changing social conditions which gave voice to the suffering of women experiencing perinatal loss (Toedter, Lasker, & Janssen, 2001); and technological advances in neonatal care (Hughes & Riches, 2003), including regionalization of neonatal intensive care (Sahu, 1981).

Prior to the 1970's, the death of a baby, whether by miscarriage, stillbirth, or neonatal death, was not viewed by the medical community as a significant loss (DiMarco, Menke, & McNamara, 2001). In fact, women experiencing a perinatal loss were not encouraged to view and hold their deceased infants (Rand, Kellner, Revak-Lutz, & Massey, 1998). The seminal work of Kennel, Slyter, and Klaus (1970) on the mourning response to pregnancy loss produced the first documented empirical evidence that women experience a significant mourning response following the death of an infant. The surge of literature on the topics of perinatal loss, grief, and bereavement during the decade of the 1980's is testimony to the change in attitude and attention that was given to the newly recognized phenomenon of perinatal bereavement (Bourne & Lewis, 1991).

Definitions

The following section will address the paucity of clear conceptual definitions of perinatal bereavement in the scientific literature, as well as related problems that ensue because the concept is not consistently and explicitly defined.

Explicit definitions of perinatal bereavement.

Although many researchers have studied the response to perinatal loss, a clear, explicit definition of perinatal bereavement is rarely set forth in the literature. In a review of 140 articles retrieved from Pub Med purporting to examine perinatal loss and bereavement, only two explicit, albeit brief, definitions of perinatal bereavement were found as follows: “Perinatal bereavement is a unique mourning situation” (Callister, 2006, p. 227); and “Perinatal bereavement is a significant situational crisis for the family and its social network.” (Krone & Harris, 1988, p.1). The primary antecedent to perinatal bereavement is the sudden, unexpected loss of an infant through death from miscarriage, stillbirth, or neonatal death (Barr & Cacciatore, 2007), or by elective termination for fetal anomalies (Van Putte, 1988). Furthermore, Hammersley and Drinkwater (1997) assert “bereavement from perinatal death differs from ‘conventional’ bereavement because of the unusual attributes of the lost subject and sociocultural attitudes surrounding pregnancy and its perceived ‘failure’” (p. 53).

Some researchers have argued that the concept of bereavement is not the right label for the phenomenon that follows perinatal loss, specifically for miscarriage because it does not allow for the conceptualization of the experience to be a transitional experience with myriad feelings other than grief (Murphy & Merrell, 2009). They suggest that changing the paradigm to that of viewing miscarriage as a transition allows

for the incorporation of the response to manifest in ways that may include feelings of ambivalence, anxiety, distress, anger, and depression without calling it bereavement. Thus, women who do not grieve after miscarriage would feel legitimate in their response.

The bereavement response to perinatal loss is unique (Wallerstedt & Higgins, 1996). In perinatal loss there is no prior knowledge, history or reference point of life to reflect upon during the bereavement. This distinguishes perinatal loss from other types of loss (Bennett et al., 2005). In the case of a miscarriage, there is no body to bury, no customary ritual of mourning, and often no opportunity to express emotions freely if the pregnancy had not yet been announced (Brier, 2008). Perinatal loss represents not only the loss of the pregnancy, but also lost hopes and dreams, (Smith, 1999), loss of the perfect baby, and loss of future roles as parents (Reed, 2003). Perinatal bereavement is uniquely experienced by parents (Chan et al., 2008) and has no prescribed ending point. It is an interpretive experience, often varying with the ebb and flow of life events (Uren & Wastell, 2002). One significant outcome of perinatal bereavement is the ability of parents to ascribe meaning to the experience of loss (Kirk, 1984). These assertions and insights distinguish perinatal bereavement as a separate, unique phenomenon and serve as compelling evidence to study the phenomenon of perinatal bereavement qualitatively.

Bereavement.

While few explicit definitions exist for perinatal bereavement, the term “bereavement” is well defined in the scientific literature. Bereavement follows the death of a close relative or friend and includes the entire process of loss, grief, and mourning (Bartellas & Van Aerde, 2003). Bereavement is considered the termination of an attachment (Ritsher & Neugebauer, 2002) and the objective situation of having lost

someone or something significant (Conway & Russell, 2000). In comparing these examples, the concept of bereavement is closely associated with death, loss, grief, and mourning.

In order for a concept to be considered “epistemologically mature” (Penrod & Hupcey, 2005, p. 405), it must be well defined and distinguishable within a discipline’s knowledge base. The concept of perinatal bereavement has not been clearly and consistently defined in the literature, nor is it well differentiated from other concepts in the scientific literature, such as loss, grief, and mourning. Comparing the definitions of bereavement to “perinatal bereavement” it is notable that neither of the two explicit definitions of perinatal bereavement found in the literature includes a clear notion that perinatal bereavement follows death, nor the death of an infant. This lack of a concise and consistent definition of perinatal bereavement threatens the concept’s distinction from other related concepts in the literature. As the next section will present, the concept of perinatal bereavement is often blurred with the concepts of loss, grief, and mourning. Such inconsistency in conceptual meaning threatens the validity of tools designed to measure the phenomenon of perinatal bereavement, and contributes to a potential for incongruency in theoretical assumptions.

Related concepts: loss, grief, and mourning.

Few researchers make clear and crisp distinctions to separate the concepts of perinatal bereavement, loss, grief, and mourning. Loss has been defined by Corless (2006) as the absence of an object or person, while the significance of the loss is determined by the strength of the relationship between the owner and the object or person that was lost. Kennell, Slyter, and Klaus (1970) were the first to characterize the

perinatal bereavement experience as mourning, although they admit to using grief and mourning interchangeably. Others have also used grief and mourning interchangeably in describing perinatal bereavement (Gordon, 1989). Mourning and grief have been cited as expressions of bereavement (Ryan, Cote-Arsenault, & Sugarman, 1991), hinting at the individualism of the grief response (Janssen, Cuisinier, Graauw, & Hooduin, 1997). Definitions of grief and mourning vary. Grief has been defined as a reaction to loss (Brier, 2008), “the emotion or emotions one feels when one suffers a loss”, (Menke & McClead, 1990, p. 262) and “the characteristic response of sadness and sorrow to loss of a valued object” (Gardner & Merenstein, 1986, p. 8). Grief, once thought of as a pathologic response (Kirk, 1984), is considered “a normal, healthy response to the death of a loved one” (Bruhn & Bruhn, 1984, p. 108) and a symptom of bereavement (Flenady & Wilson, 2008).

Mourning has been defined as “the painful process of detaching from a significant person and reinvesting energy in others” (Theut, Zaslow, Rabinovich, Bartko, & Morihisa, 1990, p. 523). On the contrary, Brost and Kenney (1992) differentiate grief as an ongoing interpersonal process, and mourning as a public expression of grief that is time limited. Mourning has been described as dynamic, differing from person to person and over time (LaRoche et al., 1982) and as painful and “necessary for recovery from bereavement” (Bourne & Lewis, 1984, p. 148). As evident in the preceding examples, the lines that conceptually differentiate bereavement, grief, loss, and mourning in the scientific literature are particularly blurred. This lack of conceptual clarity about what constitutes perinatal bereavement poses difficulties related to the measurement of the concept. Measurement tools for perinatal bereavement exist, yet the lack of an explicit

definition has presented difficulties in synthesizing the outcomes of quantitative research efforts.

Measurement of the Concept of Perinatal Bereavement

The concept of perinatal bereavement is a practice-based concept that traverses the disciplines of nursing, medicine, and psychology. As previously noted, Kennell and colleagues (1970) were the first to study and measure the reactions of mothers who had lost an infant to neonatal death. They operationalized perinatal bereavement by assessing the “mourning score” of each participant on a scale of zero to 24. Researchers have commonly measured grief as the emotional reaction to loss during bereavement (Corless, 2006). The grief experienced during perinatal bereavement is different from other types of grief in that it is a complex phenomenon, mediated by many variables, such as previous losses, length of gestation, and demographic characteristics (Toedter et al., 1988). Although there is consensus in the literature that grief is present during perinatal bereavement, the concept is often inadequately or inconsistently defined across measurement tools, at times including constructs such as yearning and depression as indicators of grief (Brier, 2008). In addition to yearning and depression, perinatal grief has been described to include a wide variety of psychological and psychosomatic expressions such as sadness, irritability, anger, and crying (Badenhorst & Hughes, 2007).

Researchers from various disciplines have devised multiple tools purported to measure perinatal bereavement, and have in some cases even used the words “perinatal bereavement” in the name of the tool. One of the most frequently used measurement tools in the perinatal bereavement literature is the Perinatal Grief Scale (PGS) which was developed by Toedter et al. (1988) to measure the “many different dimensions of grief

mentioned in the literature” (p. 514). In this tool, three subscales measure active grief, difficulty coping, and despair, the scores of which are combined for a total PGS score with a higher score predictive of more severe grief. According to Toedter et al. (1988) the Active Grief Scale rates sadness, crying, and missing the baby. The Difficulty Coping Scale includes items to rate how a subject deals with people and normal activities in order to determine withdrawal or depression. The Despair Scale elicits the degree of hopelessness a subject feels. The authors assert that perinatal grief can be acute, (normal), or chronic (pathologic), with pathologic grief indicated by high scores on the Difficulty Coping Scale and the Despair Scale. They base their convictions on the bereavement literature in existence at the time of tool development.

Multiple researchers have used the PGS to measure perinatal grief during bereavement following a pregnancy loss in concert with other tools to produce correlations of grief after perinatal loss with variables such as depression (Burgoine et al., 2005; Swanson, Pearsall-Jones, & Hay, 2002; Zeanah et al., 1993), marital satisfaction (Lin & Lasker, 1996), impact of other life events (Hunfeld, Wladimiroff, & Passchier, 1994; Hunfeld, Wladimiroff, & Passchier, 1997a; Johnson & Puddifoot, 1996; Kroth et al., 2004; Serrano & Lima, 2006), and social support (Kroth et al., 2004; Lin & Lasker, 1996). These findings suggest that perinatal bereavement is a complex phenomenon, influenced by multiple variables that are not captured in a single measurement tool.

The Perinatal Bereavement Scale (PBS) was designed to measure the bereavement of parents who have experienced a perinatal loss through miscarriage, stillbirth, or neonatal death (Theut et al., 1989). The scale was initially intended to measure perinatal bereavement in couples after the birth of a subsequent child in order to evaluate

unresolved grief from a prior perinatal loss. The 26-item PBS measures bereavement using a Likert scale of questions that focus on thoughts and feelings such as sadness, guilt, preoccupation with the loss, and anger. According to Theut et al. (1989), the scale can differentiate between parents who are bereaved from an early perinatal loss and those with a late perinatal loss. Despite the authors' assertion that the tool measures perinatal bereavement, they refer to the results as "grief scores" and they do not explicitly define the concept of perinatal bereavement (Theut et al., 1990).

Hutti, dePacheco, and Smith (1998) presented the Perinatal Grief Intensity Scale as a "theoretically based instrument to measure and predict intensity of perinatal grief after early pregnancy loss" (p. 547). The authors assert that grief is influenced by how people perceive events, rather than the facts that surround the event. Subsequently, this scale is designed to interpret the reality of the event of the miscarriage to the person and the congruence between the actual experience and the standard of the desirable. The subscales of the tool rate the perception of reality, the ability to confront others, and the congruence of the actual experience of early pregnancy loss to the desired experience (Hutti et al., 1998). None of the 14 items on the scale rate the respondent's grief in terms of sadness, crying, anger, or yearning as manifestations of grief. The incongruency between the name of the tool (Perinatal Grief Intensity Scale), its purported use to measure perceptions of the experience, and the lack of actual conceptions of grief differentiate this tool from other tools that claim to measure perinatal bereavement.

Wheeler and Austin (2000) developed a Loss Response List to measure and compare the psychosomatic grief response in adolescents who had experienced a pregnancy loss to the psychosomatic grief response in those who had never been pregnant

or were currently pregnant. They concluded that this tool could be used to measure changes in the grief response over time in response to multiple types of loss, therefore suggesting that the loss response in perinatal bereavement shares similar characteristics to other types of loss. This notion is in sharp contrast to the assertions of other perinatal bereavement researchers who emphasize that the grief experienced in perinatal bereavement is different from other types of grief (Hammersley & Drinkwater, 1997; Toedter et al., 1988), therefore requiring a unique tool for measurement. Characteristics that set perinatal bereavement apart from other types of grief include the social and cultural attitudes associated with pregnancy as well as the possibility that a pregnancy loss may be a perceived failure (Hammersley & Drinkwater, 1997). The grief of perinatal bereavement is also mediated by factors that are unique to pregnancy, such as length of pregnancy and previous pregnancy losses (Toedter et al., 1988).

Another example of a measurement tool for perinatal bereavement is the Perinatal Bereavement Grief Scale (PBGS), which was developed to investigate the reactions to perinatal bereavement after miscarriage by measuring grief, yearning, and preoccupation with the loss (Ritsher & Neugebauer, 2002). Ritsher and Neugebauer (2002) determined that higher PBGS scores equaled higher grief and yearning. Furthermore, they assert that yearning is a key psychological response to bereavement.

Some researchers have adopted adult bereavement measurement tools and applied these measures to the experience of perinatal bereavement (DiMarco et al., 2001; Lilford, Stratton, Godsil, & Prasad, 1994; Lindberg, 1992), while others have measured perinatal bereavement by assessing psychiatric symptoms such as depression and anxiety (Forrest, Standish, & Baum, 1982; Vance, Boyle, Najman, & Thearle, 1995). While results from

these studies show appreciable levels of grief, allowing researchers to compare the intensity of grief to those who have lost an older family member, these data do little to differentiate the grief expressed in perinatal bereavement as unique.

As presented thus far, the tools used to evaluate perinatal bereavement vary in the constructs that are measured and the contexts in which they are applied. For instance, contexts vary across the spectrum of perinatal loss: miscarriage, stillbirth, neonatal loss, or elective termination for anomalies. Tools that purport to measure perinatal bereavement are in fact, measuring grief, while a tool that intends to predict grief intensity, measures perception of events. The multiple variables that are often measured in concert with the bereavement measures give evidence of the complex nature of perinatal bereavement. No single tool captures the essence or complexity of the experience.

Context of Previous Perinatal Bereavement Research

The next section will address the impact of context to the study of the phenomenon of perinatal bereavement. Research endeavors to study the experience of perinatal bereavement have been fraught with difficulties related to the contextual variable of time, such as gestation at the time of the loss and duration of bereavement (Flenady & Wilson, 2008; Toedter et al., 2001). For instance, the concept of perinatal bereavement has been applied to both early loss by miscarriage and later losses to stillbirth or neonatal death (Barr & Cacciatore, 2007; McCreight, 2008). However, there is evidence to suggest that the timing of the loss impacts the bereavement response.

While some research has shown that early loss, such as miscarriage, results in high grief scores during bereavement, other studies have shown that the length of

gestation at the time of loss is a predictor of intensity of grief (Theut et al. 1989; Toedter et al., 1988). According to Theut et al. (1989), losses that occur later in pregnancy, such as stillbirth or neonatal losses, result in greater intensity of grief compared to the experience of early loss. The researchers assert that the longer the pregnancy duration, the more intense the physical and emotional attachment becomes, and therefore the greater intensity of grief. Likewise, according to Hutti (2005), grief follows the death of a baby when there was an attachment to the unborn baby. The presence of attachment increases the intensity of the grieving process. Kowalski (1991) strongly asserts “without attachment or bonding, there can be no sense of loss or bereavement; the two are irrevocably intertwined” (p. 369). Attachment is strengthened by quickening or feeling the baby move (Robinson et al., 1999) and by viewing the baby on ultrasound or listening to the fetal heartbeat (Furlong & Hobbins, 1983). Still others claim that it is the significance of the pregnancy, not the gestational age at the time of the loss, that determines the grief response (Hammersley & Drinkwater, 1997).

Perinatal bereavement has also been studied in the context of pregnancy after perinatal loss. Patterns of grief in subsequent pregnancy following a perinatal loss are impacted and appear to be different between early losses (miscarriage) and late losses (stillbirth after 20 weeks). When the loss occurs late in the pregnancy, such as stillbirth and neonatal loss, grief and anxiety are heightened in future pregnancies (Robertson & Kavanaugh, 1998; Theut et al., 1990). Other contextual factors that appear to impact grief during perinatal bereavement are the number of living children (Janssen et al. 1997), parenting a surviving twin (Swanson et al., 2002; Van der Zalm, 1995), recurrent perinatal loss (Serrano & Lima, 2006), subsequent pregnancies (Cote-Arsenault &

Mahlangu, 1999), or stressful life events (Kavanaugh & Hershberger, 2005). Over the past decade, research has revealed gender differences in grief response during perinatal bereavement, concluding that men and women grieve differently following perinatal loss (Armstrong, 2001; Conway & Russell, 2000; DiMarco et al., 2001; Franche, 2001; O'Leary & Thorwick, 2006).

There are conflicting reports about the duration of perinatal bereavement. For instance, according to some researchers, perinatal bereavement has no precise end point (Theut et al., 1990), lasting months to years and even extending into future pregnancies (Hutti, 2005). Others assert that perinatal bereavement lasts a lifetime (Capitulo, 2005). Duration of perinatal bereavement has been studied at various intervals, such as one year after miscarriage (Swanson, Connor, Jolley, Pettinato, & Wang, 2007), four months after miscarriage (Adolfsson, Bertero, & Larsson, 2006), and even years after the death of an infant (Hunfeld, Wladimiroff, & Passchier, 1997b; Schaap, Wolf, Bruinse, Barkhof-vande Lande, & Treffers, 1997; Swanson et al., 2002). The duration of perinatal bereavement has been limited to one year by Kowalski (1991), while Badenhorst and Hughes (2007) suggest that bereavement is prolonged if there is no improvement in the manifestation of grief after six months.

The previous discussion has revealed several important concerns related to the concept analysis of perinatal bereavement. First, the concept of perinatal bereavement has not been consistently and clearly defined in the nursing literature. The conceptual boundaries of perinatal bereavement are blurred with related concepts such as grief, loss, and mourning. In turn, the measurement tools devised to measure the phenomenon of perinatal bereavement actually measure related concepts such as grief, mourning,

yearning, and stress. Additionally, contextual factors such as timing of the loss in the course of the pregnancy, type of loss, gender, and factors such as the presence of previous losses impact the outcome of bereavement after perinatal loss.

Conceptual Clarification of Perinatal Bereavement

It is important to establish the state of the science, or “the best estimate of probable truth” (Hupcey & Penrod, 2005, p. 205) surrounding the concept of perinatal bereavement in order to understand the current use and meaning of the concept and to determine the best methods for advancing the concept. The conceptual components of perinatal bereavement consist of antecedents, attributes, and outcomes and are considered in the development of a theoretical definition of the concept. These conceptual components, or characteristics of perinatal bereavement, are best determined through an analysis of implicit meanings of the concept of perinatal bereavement. The primary antecedent to perinatal bereavement is the sudden, unexpected loss of an infant through death from miscarriage, stillbirth, or neonatal death (Barr & Cacciatore, 2007), or by elective termination for fetal anomalies (Van Putte, 1988). Perinatal bereavement is unique to parents (Chan et al., 2008). While attachment, or forming a relationship or bond with the unborn baby, occurs prior to the loss, its effect can be considered a modifying factor to the attributes of perinatal bereavement.

The main attribute of perinatal bereavement is an emotional response that is most commonly manifested as grief. The grief that follows perinatal death is different than the grief of bereavement from losing an older significant other (Hunfeld et al., 1997a) and is unique because of the relationship of the deceased to the bereaved (Stierman, 1987). Perinatal grief is complex and is manifested in a wide variety of psychological and

psychosomatic expressions such as sadness, irritability, depression, yearning, anger, and crying (Badenhorst & Hughes, 2007).

Theoretical definition of perinatal bereavement.

A theoretical definition is presented based upon what is known about perinatal bereavement from a synthesis and integration of the findings of the concept analysis. This definition represents the best estimate of probable truth as revealed by the scientific literature and it is the final product of principle-based concept analysis (Hupcey & Penrod, 2005). Perinatal bereavement is the experience of parents that begins immediately following the loss of an infant through death by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies and is characterized by a complex emotional response, most commonly manifested as grief in both the mother and father, but often expressed differently between males and females, both in intensity and duration. Perinatal bereavement is manifested by both psychological and psychosomatic responses, and is mediated by situational, internal and external factors. Mourning occurs during perinatal bereavement as an expression of the bereavement and is influenced by culture, religion, and tradition (Fenstermacher, 2011, unpublished manuscript).

Non-Hispanic Black Adolescents and Perinatal Bereavement

Despite the higher rate of infant mortality in non-Hispanic Black adolescents, no studies were found that provide detail about the perinatal loss and bereavement experience for this specific population. Three studies were found that focused on a total African American sample and are described as follows. Van (2001) interviewed ten African American women, all over the age of 18, to determine healing strategies after pregnancy loss. Van and Meleis (2003) studied adult African American women three

years after an involuntary pregnancy loss to determine coping strategies during bereavement. Kavanaugh and Hershberger (2005) examined the experience of perinatal loss in African American parents with an age range of 19 to 34 years. Only one study on pregnancy loss included a diverse sample of low-income, never married teenage girls ages 13-19 with 54.4% of the sample noted to be African American (Wheeler & Austin, 2000). Thus, little is known about the phenomenon of perinatal bereavement in non-Hispanic Black adolescents.

This study aimed to describe the perinatal bereavement experience in non-Hispanic Black adolescents after perinatal loss. A synthesis of the literature regarding the general experience of loss in adolescents is presented to demonstrate what is known about the responses of adolescents after the death of a parent, friend, or relative and to inform this research study with regard to the developmental epoch of adolescence. This discussion about adolescents, loss, and bereavement is presented to illuminate the potential influence of age, developmental stage, education, and socioeconomic status on the experience of perinatal bereavement.

Adolescent Development and Loss

The process of bereavement is impacted by age, gender, education, culture, and socioeconomic status (Corless, 2006). Low-income urban adolescents experience a higher incidence of negative life events, including the experience of the death of parents, friends, or relatives. For instance, in a study of bereaved inner city adolescents who had lost a parent or other relative to death, Vann Epps, Opie, and Goodwin (1997) found that the major themes in the lives of the adolescents were chaos, stress, lack of family and social support, avoidance, fear of the future, and isolation. Melhem et al., (2007) report

that following the loss of a peer to suicide, adolescents experience depression and posttraumatic stress disorder, suggesting a profound response to the death a close significant other. Balk (1996) notes that older adolescents aged 17 to 19 responded in more anger than younger adolescents after the death of a sibling, while the death of a parent overwhelms an adolescent with fear, confusion, anger, and despair. Balk (1996) concludes that an important fundamental task during adolescent bereavement is to maintain a sense of self-efficacy and self-image. These studies suggest that the bereavement response to loss in adolescence is a significant process and worthy of deeper investigation.

Because of the developmental changes and challenges during the teenage years, the needs and expressed emotions of an adolescent experiencing perinatal loss and bereavement may not be the same as those experienced by an adult. Two studies were found that report the impact of pregnancy loss in adolescents. Wheeler and Austin (2001) conducted a study of 164 adolescent girls to determine the impact of early pregnancy loss on self-esteem, depression, family relationships, grief responses and perception of life changes. The findings revealed that adolescents who experience early pregnancy loss may be at increased risk for depressive symptoms and display significant physical, emotional, social, and cognitive grief responses. Sefton (2007) examined the perinatal bereavement experiences of 14 Latina adolescents after a miscarriage and reports that the bereavement response ranged from minimal to long-term, unresolved grief.

According to Chesterton (1996), adolescents are neither socially or reproductively mature, making their experience of perinatal bereavement uniquely different from that of

an adult. The developmental challenges during adolescence, such as the emotional separation from parents and finding a sense of belonging with one's peer group, impact the adolescent's experience of bereavement (Balk, 1996). A study by Bartlett, Holditch-Davis, Belyea, Halpern, and Beeber (2006) reports that adolescent girls have a need for self-esteem enhancement during a time of moving away from parents and toward their peer group for support. From a developmental perspective, adolescents are more prone to socially disruptive problem behaviors such as substance abuse, risky sexual behaviors, and violence (Bartlett, Holditch-Davis, & Belyea, 2007). Because adolescents from marginalized groups assume adult responsibilities at an earlier age in addition to school and work responsibilities, the adequacy of family resources, emotional closeness, and relationships must be considered in assessing the bereavement response in adolescents (Servaty-Seib & Pistole, 2006). Adolescents with religious beliefs have been found to have less depression after the death of a loved one than those with no religious beliefs, suggesting that assessing religious beliefs is also an important consideration in evaluating the bereavement experience (Balk, 1996).

Cultural Influence on Bereavement

In addition to the influence of age and developmental stage at the time of the perinatal loss and bereavement, culture impacts the interpretation and expression of the bereavement experience (Bennett et al., 2005). The following section presents an overview of the importance of considering the influence of culture on the experience of perinatal bereavement, particularly as pertaining to the African American community. The perception of perinatal loss and the manifestations of bereavement are informed by culture, faith, and tradition, (Callister, 2006; Chichester, 2005; Mehta & Verma, 1990)

which in turn, influence the expression of grief. For example, in India, a later pregnancy loss is more distressing than an early loss and mothers are discouraged from attaching to the baby since the death is considered a misfortune (Mehta & Verma, 1990). In the Muslim culture, the bereavement period lasts three days followed by 40 days of mourning (Hebert, 1998). The cultural context of the perinatal bereavement experience has also been studied in African Americans (Kavanaugh & Hershberger, 2005), in Thai women (Prommanart, Phatharayuttawatt, Boriboonhirunsarn, & Sunsaneevithayakul, 2004) in Dutch women (Janssen et al., 1997), and in German parents (Lorenzen & Holzgreve, 1995). All of these studies report specific individual cultural nuances that are unique and meaningful. Because the manifestations of perinatal bereavement vary across culture and time, bereavement support interventions must be culturally sensitive, age appropriate, and respective of intercultural differences and diversity.

Copeland (2005) suggests that health care providers must be aware of the cultural influences on African Americans that have impacted their functioning in society where class, gender, and race have strongly influenced their social support networks and health beliefs. For example, African Americans traditionally depend on the family unit for support after the death of a loved one (Clements, Virgil, Manno, & Henry, 2003).

Likewise, in a study of bereavement and grief in African Americans, Laurie and Neimeyer (2008) report that African American participants relied heavily on the strength of kinship rather than professional support. Van and Meleis (2003) report that adult African American women who had experienced an involuntary pregnancy loss want to talk with women of their own culture, their family, and their close friends following a loss. It was noted in the interview data that few African American women attend formal

bereavement support groups because they perceive support groups are meant for wealthier White women and therefore they felt constrained to share their feelings about pregnancy loss in that setting. The women also reported using spiritual beliefs as a strategy to cope with the pregnancy loss. Van (2001) conducted a qualitative pilot study in which she interviewed 10 African American women about their healing strategies after perinatal loss. Spirituality, avoidance, an inner voice of comfort, and finding purpose in the loss were reported as healing strategies. These studies suggest that family support and spirituality appear to be important in offering bereavement support to African American women.

Bereavement Support

Since the late 1970's bereavement support has been offered to parents experiencing perinatal loss (Ilse & Furrh, 1988). Using Walker and Avant's methods of concept analysis, Nallen (2004) presents the following four essential elements to define bereavement support: effective communication skills; individualized care; facilitation of the grief process; and sensitivity to patients' needs. Likewise, Hutti (1988) suggests interventions for bereaved parents following perinatal loss should include reducing the trauma of hospitalization through open communication and empathetic care, validation of the loss, making the loss real, and offering follow-up counseling.

Bereavement support, such as counseling, (Lilford et al., 1994), creating mementos, encouraging the parents to view and hold the baby, naming the baby, and holding a funeral or memorial have been shown to decrease grief intensity and the duration of bereavement (Forrest, Standish, & Baum, 1982; Lorenzen & Holzgreve, 1995). Additionally, Forrest et al. (1982) found that support and counseling after a

perinatal loss are effective in reducing the perinatal bereavement reactions of depression and anxiety. Although the need for perinatal bereavement support is well accepted among health care professionals, perinatal bereavement support is not offered consistently and comprehensively. Nurses caring for mothers with perinatal loss are often emotionally overwhelmed and lack the knowledge and skill to provide adequate support (Modiba, 2008).

Hutti (2005) states that while perinatal loss support groups are an important referral for nurses to make, not every bereaved parent will utilize and appreciate such a service. Although it is important to provide the information to parents for future use, Hutti (2005) stresses the importance of discovering the needs of bereaved parents and avoiding the prescription of the same interventions for every person. Stroebe, Schut, and Stroebe (2007) caution against basing bereavement support interventions on data from studies of White Americans because there are differences in the cultural patterns of grief and mourning among the different societal and ethnic groups.

Very little is known about the perinatal bereavement support needs of non-Hispanic Black adolescents, consequently, there is little empirical evidence that existing modes of hospital-based and community-based perinatal bereavement support are effective for this population. Kavanaugh and Moro (2006) assert that appropriate nursing interventions can make a substantial impact on the bereavement experience of parents and the ability of parents to ascribe meaning from the experience of losing a baby. No studies were found to measure the benefit of traditional nursing interventions and modes of bereavement support among adolescent non-Hispanic Black mothers who experience the loss of a baby. Bereavement support after perinatal loss should be a significant part of the

comprehensive palliative care offered after an infant's death to provide compassionate support to families (Gale & Brooks, 2006). Widger and Wilkins (2004) explain that while bereavement care is identified as important to parents, health care professionals have not met the bereavement needs to satisfy the expectations of parents. Web-based resources might be considered one way in which teenage mothers experiencing perinatal loss could find support. However, Geller, Psaros, and Kerns (2004) report finding only one Internet bereavement support site that included teen parents in the intended audience. At the time of this dissertation submission, the website is still active (www.pregnancyloss.info), however, the site is maintained by an individual who experienced pregnancy loss, rather than by a professional organization. The site contains personal accounts of pregnancy loss and a "frequently asked question" section.

Summary

In summary, this chapter presents both a theoretical and conceptual discussion as related to the concept of interest: perinatal bereavement. The Integrative Risk Factor framework is presented as a useful and insightful model to inform the research topic, however several limitations were noted that preclude its use as a final selection to guide this particular inquiry. More appropriately, symbolic interactionism was chosen as the theoretical framework to guide this qualitative, grounded theory methods study of perinatal bereavement in non-Hispanic Black adolescents because of its paradigmatic stance and history to provide the theoretical underpinnings for grounded theory studies. The conceptual discussion reveals the state of the science of perinatal bereavement with the conclusion that the conceptual boundaries are particularly blurred with related concepts of grief, loss, and mourning. As such, the measurement tools that purport to

measure perinatal bereavement often measure grief along with other concepts.

The phenomenon of perinatal bereavement has been of interest to scientists in the disciplines of nursing, medicine, and psychology for several decades, yet few qualitative studies exist to illuminate the experience from the mother's perspective and no published studies exist to reveal the experience as perceived by non-Hispanic Black adolescents.

This paucity of research is problematic as non-Hispanic Black adolescents experience the highest rates of perinatal mortality of any racial or ethnic group in the United States (DHHS, 2006).

Chapter 3

Research Design and Methods

The purpose of this chapter is to describe the qualitative approach and methodology that was used to study perinatal bereavement in non-Hispanic Black adolescents. Specifically, this chapter will explain the historical and philosophical roots of grounded theory methods, including a discussion of the metaphysical stances of grounded theory. A discussion of the variations between Glaser and Strauss (1967) compared to Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008) is presented, along with the rationale for choosing the methods as explicated by Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008). A description of the research design, setting, sampling, data collection, data analysis, and human subjects protection is offered. Issues of validity, reliability, and transferability are discussed, along with the limitations of the study.

This was a qualitative study using grounded theory methods to explore the phenomenon of perinatal bereavement in non-Hispanic Black adolescents. In review, the overarching goal of this study was to build an understanding of the experience of perinatal bereavement in non-Hispanic Black adolescent females after perinatal loss.

Specific Aims

- 1) To generate a disclosive theory of perinatal bereavement in non-Hispanic Black adolescent females.
- 2) To identify critical transitions in the perinatal bereavement process that may signal a need for well-targeted, culturally sensitive bereavement support services.

Research Questions

- 1) What is the process of perinatal bereavement in non-Hispanic Black adolescents who have experienced perinatal loss?
- 2) How do non-Hispanic Black adolescents describe the meaning of the experience of perinatal bereavement after perinatal loss?
- 3) What are the critical transition points during the process of perinatal bereavement for which interventions may be helpful?
- 4) What factors influenced, helped, or hindered the process of perinatal bereavement?

Methodology

Grounded Theory

Rationale for qualitative approach.

This was a qualitative study, using grounded theory methods as explicated by Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008). From the time the phenomenon of perinatal bereavement was first recognized in the 1970's, quantitative methods have been used extensively by researchers to study perinatal bereavement, resulting in a range of interpretations about the experience that follows perinatal loss. Researchers purporting to measure bereavement after perinatal loss have employed various instruments to measure perinatal grief, none of which provide explicit definitions of perinatal bereavement. Likewise, as presented previously, the concept of perinatal bereavement is inadequately defined in the scientific literature. This lack of conceptual clarity is a threat to the construct validity of the existing tools that have been developed to measure perinatal bereavement. Previous research has focused largely on measuring

grief after perinatal loss in White, married women, resulting in a gap in knowledge about perinatal bereavement in other racial and ethnic groups.

According to Davies (2004), there is a shift away from the positivist approach to study bereavement towards a non-positivist stance which considers how a person experiences grief and makes meaning from the situation. In contrast to quantitative methods to study the phenomenon of bereavement, qualitative methods provide a way to explore the phenomenon through in-depth interviews with participants who have experienced perinatal loss and the bereavement which follows. Thus, rather than producing a quantified level of grief to describe the phenomenon of perinatal bereavement, qualitative research produces rich, thick descriptions of the experience from the perspectives of those living through it. Inductive examination of data produced through interviews and observations in the natural context leads to theory development in subject areas which would be difficult to access using quantitative methods (Priest, Roberts, & Woods, 2002).

Rationale for grounded theory.

Grounded theory methods were specifically chosen because very little is known about the phenomenon of perinatal bereavement in non-Hispanic Black adolescents, therefore the process and experience of perinatal bereavement over time from the perspective of this population is not well described in the literature. According to Crooks (2001), the grounded theory method is ideal for use in research to explore the social relationships and behaviors of women. Furthermore, the aim of this research was to develop theory, not to test theory. As purported by Blumer (1969), the research question should guide the method. Grounded theory methods aim to identify the nature of process,

that is, the ongoing action, interaction, and emotion in response to a problem or situation, and to build theory from the data (Corbin & Strauss, 2008). This study aimed to identify the process of perinatal bereavement and to generate a disclosive theory of perinatal bereavement in non-Hispanic Black adolescents. Thus, grounded theory methods were the most appropriate approach to study this phenomenon, under girded by the theoretical framework of symbolic interactionism.

Furthermore, grounded theory methods offer the most adequate way to address the research questions to identify critical transition points for which intervention may be most helpful, as well as to uncover specific bereavement support interventions to positively influence the process of perinatal bereavement. Through the procedures of multiple in-depth interviews with each participant, constant comparative analysis, and theoretical sampling, the researcher sought to describe the experience to build an understanding of specific factors that influence, help, or hinder the process of perinatal bereavement. Although another qualitative approach, such as phenomenology may reveal the lived experience of perinatal bereavement, grounded theory is the only approach that yields disclosive theory about a substantive process as in bereavement.

Historical and disciplinary roots of grounded theory methods.

Sociologists Barney Glaser and Anselm Strauss are credited with the original conceptualizations of grounded theory (Mills, Chapman, Bonner, & Francis, 2007). According to Charmaz (2000), it was Strauss's training with Blumer at the University of Chicago that originally linked the theoretical perspectives of symbolic interactionism to the methods of grounded theory. This educational background and association with symbolic interactionists contributed to the assumptions inherent in grounded theory

methods, such as: the need for the researcher to be in the field to understand what is going on, that people have an active role in shaping their world, and that there is a variability and complexity in the changes and processes of life (Strauss & Corbin, 1990).

In their seminal work, *The Discovery of Grounded Theory*, Glaser & Strauss (1967) asserted that theory is generated from data, or “grounded” in the research itself. The process of using constant comparative analysis to inductively discover theory that is grounded in data results in a theory that will fit the phenomenon that is researched and also work when put to use (Glaser & Strauss, 1967). A student of Glaser and Strauss, Jeanne Quint Benoliel first used grounded theory methods in nursing research in 1967 to describe the dying patient (Hutchinson, 1993). From the time when the first descriptions of grounded theory methods were described by Glaser and Strauss in 1967, the method was expounded by Glaser and then further diversified by Strauss and Corbin (1990, 1998) indicating that grounded theory methods are maturing with distinct epistemological and ontological perspectives (McCann & Clark, 2003). The next section will address the metaphysical stances of grounded theory and the philosophical differences between the approaches to developing grounded theory as explicated by Glaser and Strauss (1967) compared with Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008).

Metaphysical stances of grounded theory.

Epistemology: ways of knowing.

According to Corbin and Strauss (2008), “every method rests on the nature of knowledge and of knowing...” (p.1). The epistemology of grounded theory lies in two philosophical traditions: symbolic interactionism and pragmatism (Corbin & Strauss, 2008). The epistemological perspective of symbolic interactionism is that coming to

know involves looking for ways to understand situations from the perspective of both the individual and society (Benzies & Allen, 2001). Symbolic interactionism posits that individuals and their actions cannot be understood out of the context of their social situation (Hutchinson, 1993), therefore, the only way to know about and understand the meaning of the actions of individuals is to study the individual together with the social context. The standpoint that meaning is a social product, an interpretative process resulting from the activities of people in interaction with one another, gives symbolic interactionism its distinctive position (Blumer, 1969). That human beings interpret each other's actions based upon the meaning ascribed to such actions, rather than simply react to the actions of another is a foundational epistemological stance of grounded theory methods (Corbin & Strauss, 2008).

Pragmatists' writings by Dewey and Mead published in the early twentieth century espousing that "knowledge is created through action and interaction" also influenced the epistemological stance of grounded theory methods (Corbin & Strauss, 2008, p. 2). Pragmatists viewed knowledge as collective, emanating from the acting and interacting of self-reflection in response to resolve problematic situations (Corbin & Strauss, 2008). Pragmatists consider knowledge as useful for practice. Knowledge leads to action, which in turn sets into motion the interplay of practice and inquiry. Thus, pragmatism influences grounded theory methods through the value and inclusion of personal experience and the importance of self-reflection in relation to knowing (Corbin & Strauss, 2008).

Ontology: the nature of truth.

According to Wuest (2007), grounded theory emerges from the pragmatic paradigmatic perspective with an ontological position that truth is relative to time and place and is modified in light of new discoveries. Pragmatists uphold the philosophical view that human beings are in a continual state of adaptation in an ever-changing social world. From a symbolic interactionism lens, truth is tentative because meaning changes according to the context for the person (Benzies & Allen, 2001). For example, a change in health status or a social crisis presents an opportunity to assign a new meaning, or truth, which directs the action of the individual (Crooks, 2001). Corbin and Strauss (2008) assert that the assumptions about the nature of the universe, the complexity of phenomena, and the significance of process influence the inquiry about the nature of human responses to the events and problems encountered in life. The epistemological and ontological stances described thus far shape the methods of grounded theory.

Methodology: the relationship of the researcher to the researched.

The qualitative methodological approach of grounded theory is directly related to the theoretical stance of symbolic interactionism. This methodological approach was “discovered” by Glaser and Strauss (1967), who used the theoretical underpinnings of symbols, interactions, context, and society to further define grounded theory methods (McCann & Clark, 2003). Blumer (1969) himself asserted that the methodological position of symbolic interactionism is aligned with empirical science as it supports direct observation of the empirical social world rather than testing a model of that world. Blumer (1969) believed that to test the validity of the concepts of symbolic interactionism one must go directly to the examination of human behavior and not to a

contrived lab setting. Reality, Blumer (1969) contended, exists in the empirical world and not in the methods chosen to study the world.

The methods of grounded theory have diversified over time, indicating that the method is both maturing and expanding (McCann & Clark, 2003). Classical grounded theory as originally explicated by Glaser and Strauss (1967) is guided by a post positivistic paradigm that espouses that reality exists but cannot be completely measured by research. Originating from a more poststructuralist paradigm and constructivist ontology, Strauss and Corbin (1990), however, contend that although reality cannot be known, it can be interpreted and the role of the researcher is active and dialectic (McCann & Clark, 2003). The differences between the Glaser and Strauss approach and the Strauss and Corbin approach to grounded theory methods exist not entirely in the characteristics of the method, but in the underlying philosophical assumptions (McCann & Clark, 2003). The following paragraphs detail the divergence between the two approaches. The procedures explicated by Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008) were the tenets of grounded theory research used for this study of perinatal bereavement.

Comparison of approaches.

The methods proposed by Glaser and Strauss (1967) and Strauss and Corbin (1990) share the common procedure related elements of theoretical sensitivity, theoretical sampling, constant comparative analysis, coding, literature as a data source, integration of theory and theoretical memos (McCann & Clark, 2003). The approaches differ methodologically in the use of literature review, identification of a researchable problem,

emphasis of field work, data collection, and evaluative criteria. Each of these differences is explained as follows.

Use of literature review.

Glaser (1992) claimed that reviewing the literature prior to entering the field would contaminate the researcher's view of data and hamper the development of categories; therefore he advocated using the literature only to support emerging theory. Conversely, Strauss and Corbin (1990) recommend that a preliminary review of the literature should be conducted before the start of data collection. Moreover, a review of literature regarding a specific phenomenon may reveal gaps in existing knowledge that will help the researcher pose questions aimed at generating new knowledge and advancing conceptual clarity. In the case of this study of perinatal bereavement, the literature review indeed revealed gaps in knowledge with regard to how the phenomenon is experienced in non-Hispanic Black adolescents. Likewise, the literature review uncovered the need to further define the concept of perinatal bereavement.

Strauss and Corbin (1990) describe two types of literature, both of which are considered useful for grounded theory: technical literature (professional and disciplinary literature) and nontechnical literature (biographies, diaries, and letters). In contrast to quantitative methods, where researchers seek to test theory, thereby using the literature to identify variables for study, grounded theory researchers aim to use literature to compare emerging theory with existing theoretical models in order to develop or extend theory (Strauss & Corbin, 1990). Knowledge of the literature enhances theoretical sensitivity by revealing concepts and relationships that appear to be significant to the situation under study, as well as revealing ways to approach and interpret data based upon existing

theoretical knowledge (Strauss & Corbin, 1990). Other uses of literature suggested by Strauss and Corbin (1990) include generation of interview questions, directing theoretical sampling, and comparing or validating findings with existing literature. The literature review that preceded this study informed the researcher about current bereavement theory thereby guiding the formation of interview questions aimed at discovering specific ways to support bereaved adolescents.

Identification of a research problem.

Glaser (1992) proposed that one should not enter the field with a predetermined notion of what constituted the problem, believing that the problem would emerge during the study through theoretical sampling, open coding, and constant comparative analysis. On the contrary, Corbin and Strauss (2008) offer both practical and contemporary strategies for identifying a research problem. These suggestions include personal and professional experience, receiving suggestions from an academic advisor, considering available funding in an area of need, generating ideas derived from the literature, or consideration of problems that emerge from the research itself. In the case of this study, the professional nursing experience of the researcher, a personal desire to improve care for bereaved adolescent mothers, and ideas from the literature helped to identify the research problem for this study.

Emphasis of field work.

For Glaser (1992), field work centered on identifying symbols, interactions, and understanding the socially constructed world of the participants. This is considered a micro approach to field work, which mirrors classic symbolic interactionism methods (McCann & Clark, 2003). Strauss and Corbin (1990), however, regard field work as a

means to examine both the socially constructed world of the participant (micro) and the cultural (macro) influences on the research problem through emphasis on culture, context, symbolic, and interactional influences on participants. Aligning with the methods of Strauss and Corbin, the field work for this study focused on both the micro and macro influences on perinatal bereavement for non-Hispanic Black adolescents. In other words, the individual's perspectives, as well as the collective social and cultural influences of the world around the subjects were considered.

Data collection.

Glaser (1992) argued for a flexible approach to data collection, whereas Strauss and Corbin (1990) embrace a more structured and rule-governed tactic for collecting data. In fact, Corbin and Strauss (2008) set forth a Paradigm Model to help researchers think systematically about the data in terms of causal conditions, phenomenon, context, intervening conditions, action-interaction strategies and consequences. Such a schema helps the researcher think systematically about the data to see complex relationships between the categories.

Evaluative criteria.

In their original work, Glaser and Strauss (1967) suggested four interrelated properties to consider as prerequisites to implementation of theory in practice: fit, understandable, general, and control. In a later work, Glaser (1992) proposed four similar criteria to evaluate grounded theory. These criteria are as follows: fit (does the category directly relate to the data?); work (does the theory have explanatory power to interpret the phenomenon in the context of the theory?); relevance (is the theory relevant or is a preconceived theory imposed onto the results?); and modifiability (can the theory

be adaptable in response to a changing world?). These evaluative criteria are helpful, yet they do not address the rigor of the study itself. Corbin and Strauss (2008) assert that judgments must be made about the validity, reliability, and credibility of the data, the adequacy of the research process, and the empirical grounding of the findings. Therefore, strategies for rigor must be built into the research process to assure that the findings will hold up to scrutiny (Corbin & Strauss, 2008).

Types of theory generated by grounded theory methods.

One of the specific aims of this study was to generate a disclosive theory of perinatal bereavement in non-Hispanic Black adolescents. According to Morse (1997), qualitatively derived theory is classified according to the level of theoretical abstraction, as descriptive, interpretive, disclosive and explanatory. Disclosive theory includes both substantive and formal theory and “reveals the structure of knowledge and the intricate complexity linking concepts and delimiting stages and phases of a process” (Morse, 1997, p. 177). The theories that result from grounded theory method research may be classified as formal or substantive (Hutchinson, 1993). For example, a formal theory addresses a more conceptual level of a phenomenon, whereas a substantive theory is generated for a specific, empirical area of inquiry. Substantive theories, therefore, may be used to construct formal theories (Hutchinson, 1993). Grounded theory methods are used to develop disclosive theory that is process-bound, yet generalizable to other persons experiencing a similar phenomenon (Morse, 1997). When the methodology of the grounded theory study is sound, the resulting theory is incrementally confirmed and ready for use in the clinical setting (Morse, 1997).

Procedure

Setting

At the start of this study, three large urban hospitals in central Pennsylvania were targeted for recruitment and IRB approval was obtained at the Penn State Milton S. Hershey Medical Center; Pinnacle Health System, Harrisburg; and Hospital of the University of Pennsylvania, Philadelphia. As the study progressed, three additional urban hospital sites were added to boost recruitment: Mercy Medical Center, Baltimore, Maryland; University of Maryland Medical Center, Baltimore, Maryland; and York Hospital, York, Pennsylvania. Although IRB approval was obtained in six hospitals, in the end, only three of the six hospitals yielded participants who met the study criteria. These hospitals were selected for the number of annual births at each hospital, level of acuity for obstetric and neonatal populations, and because each of the hospitals serve an ethnically and racially diverse high risk obstetric population. Each hospital has a level III B or Level III C Neonatal Intensive Care Unit (NICU). A level III B NICU can support the care of babies requiring all types of ventilator support, as well as minor surgeries. A level III C NICU can care for babies requiring all types of ventilator support and major surgeries such as bowel resection or tracheoesophageal fistula repair (American Academy of Pediatrics, 2004). Importantly, each hospital has a perinatal bereavement support program with a perinatal bereavement nurse coordinator who could serve as a gatekeeper to identify potential research participants.

Sampling

Purposive sampling was used to recruit non-Hispanic Black adolescent females who had experienced recent perinatal loss. Research suggests that both the type of loss

and the length of gestation may impact the bereavement process (McCreight, 2008). However, others have purported that it is the meaning of the pregnancy and the presence of attachment to the baby that influences the response to perinatal loss. For example, according to Kowalski (1991) there can be no sense of loss or bereavement without the presence of attachment to the unborn baby. Moreover, the presence of attachment increases the intensity of the grieving process (Hutti, 2005). Thus, even in early losses, intense grief may be experienced when the pregnancy is perceived as real and desired (Hutti, 1992). Attachment may be strengthened by quickening or feeling the baby move (Robinson et al., 1999) and by viewing the baby on ultrasound or listening to the fetal heartbeat (Furlong & Hobbins, 1983). Quickening usually occurs between the eighteenth and twentieth week of pregnancy (Gilbert, 2011). Likewise, during the second trimester, the pregnancy begins to be recognizable in the physical symptoms of a growing abdomen. It is at this point when a pregnant teenager's friends and family may acknowledge the existence of the pregnancy and therefore, the subsequent loss of the pregnancy. Each of these variables potentially impact the dynamic of the experience of perinatal bereavement, but it is unknown how these factors influence bereavement in Black adolescents. Thus, because there is limited literature to describe the experience of perinatal loss in Black adolescents, this study included all types of perinatal loss in order to gain an understanding of the phenomenon.

Only neonatal deaths that occur in the hospital were included because the experience of a baby dying at home (such as Sudden Infant Death) was expected to be different from losing an infant in the hospital. Additionally, one of the aims of this study was to identify points in the bereavement experience, beginning in the hospital setting,

where bereavement support may be helpful.

Inclusion criteria.

Initial inclusion criteria were as follows:

- Age 16-18 years
- Non-Hispanic Black females
- Not married
- English speaking
- Able to read English and understand written material in the verbal consent document
- Experienced a recent perinatal loss
- Willingness to participate and verbal consent/assent obtainable
- Parental verbal consent obtainable if participant <18

Inclusion criteria were expanded during the data collection phase of the study to include early losses (miscarriages) and older young women in later adolescence (up to age 21) in order to boost recruitment and so that emerging concepts in the data could be further explored in participants who had experienced early loss. IRB modifications were submitted for the changes and approvals were received.

This research study aimed only to examine the experience of perinatal loss from the perspectives of the females. While it is important to understand the experience of the partners of these adolescent females, such a broad study was beyond the scope of this dissertation project. Likewise, it was difficult to predict how many of the participants would be partnered at the time of data collection, therefore, the fathers' perspectives were not the focus of this work. This research was targeted at late adolescence. There are

several reasons for this distinction. First of all, more teen pregnancies occur in the later adolescent years than the earlier years. Secondly, it was anticipated that older adolescents may be more articulate about their experiences than younger teenagers. Thirdly, the social milieu of 16 to 18 year old adolescents in high school or for those entering and attending college between the ages of 18 and 21 is different from that of the 13 to 15 year old adolescent in junior high. Older adolescents experience more independence. For example, they are old enough to drive and obtain jobs.

Recruitment

Recruitment for this study took place between April 2010 and May 2011. Participants were identified through the perinatal bereavement nurse coordinators at each hospital. Each study site has a perinatal bereavement nurse coordinator who oversees the perinatal bereavement support program. Initial contact and entry to each hospital was sought through communication with the nursing leadership at each location. The researcher worked with the nursing leadership and perinatal bereavement nurse coordinators at each of the hospitals to introduce the study design and gain support for the study prior to submitting IRB applications. Once buy-in was obtained from the perinatal bereavement nurse coordinator and the unit nursing leadership, IRB application was made and a plan for participant recruitment was discussed in advance of beginning the study. As a means of showing appreciation for the coordinators' time, the primary investigator (PI) offered to do inservice education for the staff at each hospital on the topic of perinatal bereavement or nursing research. By offering this education to the staff, the researcher hoped to convey appreciation to the staff for their willingness to support the research and also to build trust with the staff (Sutton, Erlen, Glad, and

Siminoff, 2003). Of the six hospitals, four invited the researcher to do educational presentations of the study for the unit staff and/or the Nursing Research Councils.

At each hospital, the perinatal bereavement nurse coordinators receive a referral for every patient who has experienced perinatal loss as a standard of care, thus they were an excellent source of identifying potential subjects. Recruiting in the hospital was the preferred strategy for this population as opposed to advertising in the community or trying to recruit once the subject has been discharged (K. Kavanaugh, personal communication, November 12, 2008). Each perinatal bereavement nurse received a binder with the following study information: Copies of Recruitment Scripts (Appendix A: Recruitment Script), Copies of Recruitment Letters (Appendix B: Recruitment Letter), Sample Summary Explanation of Research (Appendix C: Adult Summary Explanation of Research; Appendix D: Parent Summary Explanation of Research), Inclusion Criteria, and Researcher Contact Information. The perinatal bereavement nurse coordinators were asked to announce the study to the staff nurses at unit based staff meetings and if applicable, at their unit based Nursing Research Council meetings. Each of the study hospitals was either a Magnet® Hospital, designated for nursing excellence by the American Nurses Credentialing Center, or in the process of becoming a Magnet® hospital. Thus each of these hospitals was extremely welcoming and helpful to the researcher and a collegial relationship with each hospital was easily established.

To prevent a violation of patient privacy, potential participants who met the inclusion criteria were approached by the perinatal bereavement nurse coordinator at the hospital and were informed about the research study. Each perinatal bereavement nurse coordinator was given a recruitment script to use when speaking with potential

participants to explain the study and the background of the researcher. The perinatal bereavement nurse coordinator gave or read an invitation recruitment letter written by the researcher to the potential participant. The letter indicated that if the potential participant was willing to hear more about the research study, she would give her contact information to the perinatal bereavement nurse coordinator to pass onto the researcher. This letter did not serve as the actual consent for the study, but as a way to protect patient confidentiality during recruitment of subjects and to avoid any pretense of coercion to participate. The potential participant's contact information was forwarded to the researcher through the perinatal bereavement nurse coordinator, most often by email or telephone contact. All patients were assured in writing via the letter that their refusal to participate in the study would not influence their care in any way.

Verbal consent.

The researcher petitioned the IRB for a Waiver of Written Consent because of the difficulty to meet and consent potential participants while still hospitalized. Barriers such as shortened hospital stays, delay in bereavement referral to the nurse coordinator, and distance to the recruitment sites would delay the researcher's arrival to any identified participant prior to her discharge. Thus, consent for this study was verbal and was obtained by using a Summary Explanation of Research, written at a sixth grade level. All participants in this study were 18 or older and therefore able to give consent. However, a Parent Summary Explanation of Research was prepared in the event that any participant was under 18. Upon receiving the contact information for potential participants, interested participants were contacted by the PI by phone as soon as possible to explain the study and review the Summary Explanation of Research. The PI obtained the verbal

agreement to participate at the time of first interview but before any data were collected.

Because of the potential for a participant to be limited in her literacy, the PI offered to read the consent aloud to the participant. The Summary Explanation of Research was written at the sixth grade reading level as recommended by Erlen (2005). The research study was explained in terms of expectations of time, the nature of the study, risks, and incentive. As a means of ascertaining the understanding of the participants, the PI asked, "Tell me in your own words what this research is about."

Participants were assured that they could drop out of the study at any time for any reason and that additional counseling was available to them at any time for any reported or assessed distress. Participants were also assured of strict confidentiality by way of private interviews and data that are cleaned of all identifiers before analysis. Questions about the verbal consent process and the study itself were solicited from the participant. Copies of the Summary Explanation of Research were given or mailed to each participant to keep. All consenting procedures were done in private to protect confidentiality.

The initial recruitment discussion was structured as an opportunity to express sympathy for the loss, obtain verbal consent and create rapport between the participant and the researcher. The intent of this first contact was to establish trust and make a connection to the subject through respect and sensitivity to her loss. In this way, the researcher hoped to increase the chances for the subjects to be accessible and available at the subsequent interviews.

Demographic information.

Demographic information was collected during the first interview as follows:

- Age

- Pregnancy history: number of pregnancies/losses; age of infant/weeks gestation at time of loss
- Race and ethnicity
- Education
- Partnered or non-partnered at the time of loss
- Place of residence

Strategies for minimizing attrition.

Skepticism and trust have been cited in the literature as two barriers to research with minority populations (Sterling & Peterson, 1999). Because of these potential barriers, every effort was made to establish trust through sincere and genuine communication with the participants and their families. At the time of the first interview each participant interviewed in person was given a small gift bag containing a hand-signed card expressing sympathy and a body lotion for her personal use as an expression of thanks for her participation. Every participant was mailed a sympathy card hand-signed by the researcher shortly after the first interview. This particular strategy has been used by previous researchers to build trust, show caring and respect, and establish rapport (Kavanaugh, Moro, Savage, & Mehendale, 2006).

The PI maintained contact with the participants throughout the study through occasional reminder notes sent via the mail in order to stay in touch with participants between interviews and establish rapport, build trust, and reduce attrition (Sterling & Peterson, 1999). The PI asked the participants for more than one telephone number to maintain contact and also determined which telephone numbers were appropriate for leaving a message if there was no answer when a call was made to schedule an interview.

These strategies were intended to help both in retention and in maintaining privacy for the participants. However, most participants gave only their personal cell phone number as a means for contact.

Sample size.

Over the course of the study, recruitment efforts were managed by the perinatal bereavement coordinators at each hospital. In the early months of study recruitment, the researcher was notified by the perinatal bereavement coordinators that several potential candidates for the study were bypassed because they fell outside of the initial narrow age range of 16-18. This prompted an IRB modification to raise the age range of the participants as previously explained. Additionally, there were two potential participants who fell short of the study inclusion criteria and ethical guidelines for inclusion because of mental illness, one who was excluded because of suspicious circumstances surrounding the death of the fetus, and one who initially agreed to participate but when called by the researcher for the first interview, she refused for an undisclosed reason. Three potential participants were not identified until many weeks into the perinatal bereavement period, thereby excluding their participation based upon the timing of the referral. Additionally, three potential participants were identified by the perinatal bereavement coordinators but could not be reached at the last known phone number from the medical record. Lastly, one potential participant agreed to participate and consented to be interviewed but could not be reached by phone for the interviews, thus was not officially enrolled. Therefore a total of eleven potential participants were identified but not enrolled for a variety of reasons as outlined above.

Using the principles of grounded theory, recruitment, sampling, and data collection,

and analysis continued until saturation; that is, no new data emerged with subsequent interviews (Strauss & Corbin, 1998). Because of the sensitive nature of the topic, there was a need for intense data analysis and deep questioning in order to richly describe the experience of perinatal bereavement in the lives of the participants. As each participant in a qualitative study has the potential to generate multiple concepts, a large sample size is not needed to yield rich data and meaningful results (Starks & Trinidad, 2007). There were eight participants in this study. One participant withdrew from the study after her first interview due to illness. Four participants completed all three interviews and three participants completed the first two interviews after which the researcher was unable to reach them by phone. Reminder cards with personalized notes were sent when phone calls were an unsuccessful means of contacting these participants, but no one responded to the researcher. Thus, a total of 19 interviews were conducted to yield 19 sampling units.

Procedure for Data Collection

This study was a prospective, longitudinal study. Interviews took place at three points in time: 1) as close to the loss as possible, 2) at around six to nine weeks post-loss, and 3) at around 12 weeks post-loss. Mean time interval between the loss event and the first interview was five weeks. More than one interview for each participant was proposed to build an understanding of the bereavement response in the first few months after the pregnancy loss. According to Swanson et al. (2007), women are most able to comfortably discuss their loss and share how they are dealing with the loss at around six weeks after the loss. The 12- week interval was chosen as the ending point for this study in order to describe the immediate perinatal bereavement experience. It is within this 12-

week window of time that the participant would likely be experiencing a range of events such as telling their friends about the loss, planning the baby's funeral, and going back to school. Likewise, because this study was longitudinal from the time of the loss until 12 weeks after the loss, the PI anticipated that participants would have a fresher recall of the events than if the study was a retrospective study several years after the loss.

The first interview was done as close to the time of referral from the perinatal bereavement nurse coordinator as possible so as not to have the participant lose interest or potentially have her contact information change (such as a new cell phone number). Interviews were scheduled at a time and place convenient to the participants. The participants were given the option of being interviewed in person or over the telephone. The second and third interview was conducted in private, either by phone, or at a time and place convenient to the participants. Two of the participants in this study requested to be interviewed in their homes; all others were interviewed via telephone interview.

All interviews were digitally recorded. Interviews lasted approximately 45-50 minutes. Semi-structured interview questions were asked during the interviews. Probes were aimed at eliciting a deeper understanding of the perspectives of the participants. The PI began each interview by expressing sympathy to the participants and (if in person) asking to see any mementos of the baby (i.e. photos, footprints, etc.) that the participant may have as a way to build trust and establish rapport (Kavanaugh & Hershberger, 2005). Field notes were recorded after each interview.

Interview guide.

Initial interview questions included:

- Tell me about your pregnancy...

- What was everyday life like for you before your pregnancy?
- Tell me about your loss...
- What was this experience like for you?
- Tell me about your family, your friends...how did they respond to the news of your pregnancy/ your loss?
- How did you tell your friends and family about your loss? What was it like for you to tell your friends/family about losing the baby?

Subsequent interview questions were determined based upon constant comparative analysis, although each participant was asked the following questions:

- How are you dealing with the loss? Does talking to people help you? Talking with friends, family, partner, support group?
- Do you have any spiritual beliefs that have helped you during this time?
- Is there anything else that has helped you during this time?
- Is there anything that made it worse for you? Things people said, things people did or didn't do...?
- Tell me about going back to school/work after the baby died...what was that like for you?
- Did you hold a memorial/funeral for your baby? Tell me about that...what was that like for you?
- How did you make your decisions about cremation? Burial?
- How are you feeling now, emotionally, physically?

In the last interview, which took place at around 12 weeks after the loss, the participants were asked about any unmet needs and their future plans.

- Do you feel like you have some needs that are unmet through this experience?
- What do you hope your future will be like?
- How has this experience impacted your life?

De-briefing questions.

Because of the sensitive nature of this topic, the PI understood that it may be painful for the participants to talk about their experience. Due to the risk of distress, a series of de-briefing questions was asked at the conclusion of each interview. These questions are based upon research strategies of Kavanaugh and Hershberger (2005) and Kavanaugh et al., (2006).

- What was it like for you to talk with me today about your loss?
- How are you feeling now?
- Do you feel the need to talk further about this with anyone else?

There were adequate resources for referral at each study location for instances of depression, domestic violence, abuse or psychological distress that may have arisen. More detail about the referral plan is given in the Human Subjects Protection section.

Data Analysis

Theoretical sensitivity.

In qualitative research, the researcher brings perspectives, training, knowledge, and aspects of self into the analysis of data. This process is called theoretical sensitivity and it refers to the characteristics of the researcher that enable the researcher to have insight, give meaning to the data, and understand the difference between what is pertinent in the data from what is not pertinent (Strauss & Corbin, 1990). Sensitivity is in contrast to objectivity and requires the researcher to be in tune to relevant issues in the data to foster

interplay between the researcher and the data. According to Corbin and Strauss (2008), the researcher's "background and past experiences provide the mental capacity to respond to and receive the messages contained in the data...the findings are a product of data *plus* what the researcher brings to the analysis", (p. 33). Thus, the researcher is sensitive to the concepts in the data and the connections between the concepts. This is accomplished through a combination of immersion in the data, the researcher's background, and personal experience (Corbin & Strauss, 2008). For this study, theoretical sensitivity was enhanced through this researcher's professional background as a neonatal intensive care nurse, working in urban hospitals, training as a perinatal bereavement counselor, and personal experience with loss.

Constant comparative analysis.

Digital recordings of the interviews were sent via secure password protected computer using Olympus DSS software to a transcriptionist who had completed the mandatory IRB human subjects training. Validity was protected by reading the completed transcripts word for word while listening to the recorded interviews to assure accurate transcription (Morse & Field, 1995). Data were managed using a personal computer and Olympus DSS software. Olympus DSS software is a computer program used to store and listen to digital data files. Interview transcripts were cleaned of all identifiers prior to analysis and each participant's identity and transcript number were known only to the researcher.

Data were then analyzed using constant comparative analysis consistent with grounded theory methods. Symbolic interactionism informed the analysis to consider how the participants ascribed meaning to the situation through cultural influences and

social interaction. Each interview was analyzed prior to collecting additional data from participants, thus the constant comparative analysis informed future data collection.

Initial steps of analysis included reading the interview data line by line and using open coding to identify and label broad concepts. The initial code list contained 30 codes.

Once the broad codes were identified, the researcher looked for additional evidence of the codes in subsequent interviews. As a result, several initial codes were abandoned and many codes were eventually collapsed into broader concepts, or axial codes. The axial coding resulted in the initial 30 codes collapsing to form 12 codes as data analysis progressed. For example, initial codes such as “role of the baby’s father”, “maternal support”, and “feeling cared for” were collapsed under the code “support”. Each transcript was read numerous times in order for the researcher to be immersed in the data and to get an overarching theoretical understanding of the phenomenon across the data. The researcher looked for linkages between the concepts to relate the categories and subcategories at a conceptual level, as well as to identify the core concept that is central to the experience. From the axial coding, relational statements were formed about how the concepts relate. The central category, “enduring the loss” was identified. Codes were defined in depth and linked as data were collected and the theoretical categories (selective codes) began to emerge. Supportive data (quotations) were linked to the theoretical categories as further empirical verification of the category labels.

The resulting disclosive theory with seven theoretical categories emerged during selective coding as the categories were richly saturated. After the final theoretical categories were identified and defined, a theoretical schematic was developed to illustrate the relationship between categories. Field notes were reviewed during the analysis of

each interview to inform the interpretation of data. Memos of theoretical insights were kept as data were analyzed. An audit trail recorded decisions about revisions to interview questions, insights and reflections of the researcher, and emerging codes and categories.

Theoretical sampling.

As the study progressed and data were analyzed, theoretical sampling was used to further clarify and expand the conceptual findings according to the emerging categories in the data. Theoretical sampling involves sampling based upon concepts that are relevant to the emerging theory (Strauss & Corbin, 1990), thus theoretical sampling is in response to the data as opposed to being planned in advance of data collection (Corbin & Strauss, 2008). Concepts that have theoretical relevance are considered significant if they are deemed as categories or if they are repeatedly present in the data during the constant comparative analysis (Strauss & Corbin, 1990). In grounded theory, methodology, constant comparative data analysis and theoretical sampling go hand in hand (Patton, 2002). Theoretical sampling was used in this study to refocus interview questions to gain more insights regarding themes that emerged from the data (Draucker, Martsof, Ross, & Rusk, 2007) and to describe the properties and dimensions of concepts (Corbin & Strauss, 2008). Strauss and Corbin (1990) maintain that theoretical sampling must be flexible, yet well thought out and planned such that there is depth of focus and cumulative, consistent gathering of data for each category. Theoretical sampling was used to go deeper with certain concepts that emerged in the data, such as “maintaining relationships”, “searching for meaning”, and “gaining new perspective” by directing questions to future participants to clarify and further describe these concepts. According to Creswell (2007), researchers may seek a more heterogeneous sample to confirm or

disconfirm the contextual components of the model, or to see how the categories hold true. In this study, theoretical sampling was also accomplished by seeking out participants who had early losses to investigate if and how these concepts rang true for them.

Theoretical saturation.

Sampling continued until theoretical saturation of all categories was reached, that is no new or relevant data emerged and the categories were dense with well-established relationships between the categories (Strauss & Corbin, 1990). Theoretical saturation is important in order to arrive at a theory that is conceptually adequate. The process of selective coding was used to further integrate and refine the theoretical linkages as theoretical saturation was reached (Strauss & Corbin, 1998).

Validity, reliability, and generalizability.

Validity in qualitative research is defined as the truth value of the data, whereas reliability addresses consistency over time, across researchers, and settings (Hupcey, 2005). The issues of validity, reliability, and generalizability must be addressed when a qualitative study is designed in order for the findings to be valid (Corbin & Strauss, 2008; Hupcey, 2005). Verification strategies built into the study will help the investigator avoid serious threats to reliability and validity (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Therefore, several safeguards to protect validity and reliability were built into this research during the proposal phase.

There is a debate in the scientific literature about what to label the terms synonymous with validity and reliability in qualitative research stimulated by the epistemological differences between the quantitative and the qualitative paradigms (Whittemore, Chase,

& Mandle, 2001). Morse et al. (2002) call for a return to the traditional scientific terms of validity and reliability to evaluate qualitative research. Others disagree, and assert that the positivistic terms of validity and reliability are too quantitative (Corbin & Strauss, 2008) or that qualitative research deserves its own terms (Miles & Huberman, 1994). Numerous versions and labels for validity criteria have been suggested by scholars, however, the criteria explicated by Lincoln and Guba (1985) have been cited as the gold standard and the most enduring for use in qualitative inquiry (Whittemore et al., 2001).

Miles and Huberman (1994) propose standards for evaluating the quality of qualitative research and advocate using a set of terms specific to qualitative inquiry that align with traditional terms as well as those proposed by Lincoln and Guba (1985). This set of criteria assigns parallel terms from both paradigms to the tenets of validity and reliability and was chosen to address the issues of validity and reliability for this research study. The following standards were employed to answer the questions of validity, reliability, and generalizability and to inform the provision of rigor for this study (Miles & Huberman, 1994).

Objectivity and confirmability.

Objectivity and confirmability assures that methods and procedures are described and that conclusions are linked to data. The researcher maintains objectivity by being explicit about bias and values. For this study, the researcher described the procedures and methods for the research in advance of the study. Conclusions from the data analysis are linked to data (direct quotations from participants). Although trained as a perinatal bereavement counselor and as a nurse, the researcher was careful not to confuse roles between nurse researcher and counselor during the data collection.

Reliability, dependability, and auditability.

Reliability, dependability, and auditability address whether or not the research questions are clear and congruent with the study design. Data must be collected across appropriate settings, times, and participants. For this study, the research questions were congruent with grounded theory methods. Reliability was maintained through collection of data from non-Hispanic Black adolescents who had all experienced the phenomenon of perinatal loss. Participants were interviewed over several weeks after the loss in order to answer the research questions which aimed to describe the experience of perinatal loss and bereavement over time. Trustworthiness of data was enhanced using techniques such as an audit trail and expert checking (Whittemore et al., 2001). The audit trail recorded decisions made with regard to interview questions, memos to record thoughts and insights, and any other procedural information.

Internal validity, credibility, authenticity.

Internal validity, credibility, and authenticity speak to the richness and meaningfulness of the descriptions. Likewise, these criteria ask “Do the results ring true and seem convincing?” and “Did original participants consider the findings to be accurate?” Participant interview data provided rich descriptions of the experience of perinatal loss and bereavement which led to theoretical insights and a disclosive theory of perinatal bereavement for Black adolescents. The researcher reviewed the theoretical conclusions with two participants in order to “member check” the results. Both participants affirmed the theoretical conclusions and results as “right on target” and “getting it exactly right”. Internal validity and theoretical sensitivity were enhanced through an expert panel review of theoretical findings with three doctorally prepared

nurse researchers who are experts in grounded theory methodology and neonatal intensive care nursing. It is helpful to have someone who is knowledgeable about pregnancy and loss to assist in verification of the findings in relation to the cultural milieu (Sutton et al., 2003).

External validity, transferability, fittingness.

External validity, transferability, and fittingness assure that the sample characteristics are described in detail to permit comparisons with other samples and that the findings “fit” the phenomenon. In other words, the findings must resonate with the participants and professionals alike. The findings from this study were confirmed for fittingness with two participants from the study via member checking. Likewise, the findings were placed back into the existing bereavement literature and although the data revealed new knowledge, the findings were found to fit the existing bereavement theory in many ways. Discussion of how the theoretical findings are placed into what is already known is presented in Chapter Five. The researcher believes that the findings from this study could be generalizable to other Black adolescents experiencing perinatal loss and bereavement as the findings are grounded in empirical data (Morse, 1997).

Utilization, application, action orientation.

The final category for assuring rigor in qualitative research addresses whether or not the findings are accessible to potential users and if so, what is the level of useable knowledge. Findings from this research study have great pragmatic utility to inform nurses about the experience of perinatal bereavement in non-Hispanic Black adolescents. Given the paucity of information about perinatal bereavement in this population, the knowledge generated in this study will be useful for practice. The researcher plans to

publish and disseminate findings via peer-reviewed scientific journals and professional meetings so that the information is available for clinicians and nurse scientists alike.

Ethical Considerations

IRB approval

Participants were recruited through hospital perinatal bereavement nurse coordinators to protect the confidentiality of participants. IRB approval was obtained initially at Penn State Milton S. Hershey Medical Center and then at five additional urban hospitals over a 12 month time span. IRB modifications were obtained to change the inclusion criteria to increase the age range of the participants and the type of perinatal loss.

Incentive for participation

Participation in the study was strictly voluntary and participants were advised that they could stop the interview at any time if they became distressed. A choice of \$10 cash or a \$10 gift card to a department store was offered to each participant in appreciation for her time and participation in the research study at the completion of each interview. Each participant had potential to receive a total of \$30 in gift cards or cash for completing all three interviews. The incentive was provided at the conclusion of every interview or mailed to the participant's home if the interview was completed by phone. Every participant in this research study chose the cash stipend as opposed to the gift card option. Participants returned signed verification forms to indicate that they had received the incentive money by using a postage paid envelope provided by the researcher.

Confidentiality

Strict confidentiality was maintained at all times. Interviews were conducted in the privacy of the participant's home or via phone from a private office area. Qualitative

data was protected by assigning each participant an identifying number known only to the researcher, such as 1.1, 2.1, 3.1, etc. A transcriptionist who has passed the mandatory IRB human subjects training transcribed every interview. All identifiers, such as hospital name, city, and doctor's name, were removed from all written interview transcripts prior to data analysis. All data were stored in computer files that are password protected accessible only to the PI and located in a locked office. All files were backed up on a jump drive to prevent loss of data due to computer failure over the course of the study. The jump drive was stored in a locked office. Digital recordings of the interviews were destroyed and computer files were erased after the data was completely and thoroughly analyzed.

Human Subjects Protection

Risk to the Subjects

The human subjects included in the research design include non-Hispanic Black adolescent females who had experienced involuntary perinatal loss. Only those participants without significant pregnancy complications and who were considered healthy enough to be discharged from the hospital were recruited. The PI contacted only those potential participants who gave their permission to be contacted by the researcher.

The rationale for including all non-Hispanic Black adolescents in the sampling is that the principal aim of the study was to describe the experience of perinatal bereavement from the perspective of the Black adolescent females in order to identify bereavement support needs. Very little is known about the bereavement support needs of adolescents who experience perinatal loss, in particular among non-Hispanic Black adolescents. Additionally, perinatal mortality rates are the highest among non-Hispanic Blacks.

Sources of materials.

There were no specimens collected on human subjects and at no time did the PI have access to hospital records. Data collection was via interviews which were digitally recorded. Field notes were kept to describe participant reactions to the interview and any other applicable notes about the setting. Demographic data was collected by way of the interview questions about ethnicity, race, marital status, education, length of pregnancy, and age.

Potential risks.

The risks to participants in this qualitative study about the experience of perinatal bereavement were anticipated to be minor. In fact, literature suggests that many women find it therapeutic to talk about their loss with someone who will actively listen to their story. (Kavanaugh et al., 2006). This bore out to be true over the course of this research study. The most significant potential risk in conducting this research was the possible psychological distress that talking about or thinking about the loss of an infant may cause the participants. The likelihood of this happening was unknown; however, the PI was prepared by way of more than 20 years experience as a Neonatal Intensive Care nurse and through experience in communicating with bereaved mothers. In addition, the PI has a Master's degree as a Neonatal Nurse Practitioner. As part of the curriculum for the Neonatal Nurse Practitioner degree, communication techniques were learned and modeled to assist nurse practitioner students to acquire the skills to deliver "bad news" to parents. In the course of earning the Master's degree, and over the many years of clinical experience, there were rich opportunities for developing skill to hold sensitive conversations with parents about the serious illness or death of their infants. As a

Neonatal Intensive Care nurse, the PI has had many years of experience working in hospitals with a high proportion of Black teenage mothers from the inner city.

At the beginning of every interview, participants were assured that they could selectively answer questions or elect to stop the interview at any time. This process consent helped to protect participants who may have been vulnerable to psychological harm and avoided coercion (Kavanaugh et al., 2006). Strategies to minimize the distress of the participants were employed, such as offering appropriate support, arranging for referrals, and de-briefing participants (Kavanaugh & Ayres, 1998).

The PI completed a “Resolve Through Sharing” perinatal bereavement seminar in June 2008 to enhance knowledge and skill to communicate with bereaved mothers. The purpose of this seminar was to relate bereavement and loss theory to caring for bereaved parents, learn communication techniques for dealing with bereaved parents, and understand appropriate interventions for responding to someone who has experienced perinatal loss with sensitivity to individual needs. The curriculum included communication techniques for talking with mothers who have experienced perinatal loss. This two day intensive workshop further enhanced the PI’s knowledge, skill, and competency to interact with young women who have experienced perinatal loss. This workshop also provided the researcher with additional training to recognize the normal course of grieving versus anxiety and despair, and to assess for signs of post-partum depression. During 2009, the PI volunteered two days a month as a perinatal bereavement counselor at a local urban hospital. In this capacity, the PI had multiple opportunities to interact with women from various ethnic and racial backgrounds who have experienced perinatal loss via miscarriage, stillbirth, or neonatal loss.

Each of the hospitals from which IRB approval was received employs social workers available for consultation and referral if depression, domestic violence, drug abuse, psychosocial distress or other issues of concern would arise. In order to minimize the distress of a participant that may be caused by the interview, de-briefing occurred at the conclusion of each interview and the opportunity for referral for additional counseling was available if needed.

Each participant was approached with respect and compassion for her loss to minimize potential distress. At any time during the interview process, participants would have the option to stop the interview or drop out of the study. The PI was prepared to make an immediate referral to the appropriate provider if needed, although this event never materialized.

The other potential risks for participants were the invasion of privacy and the loss of confidentiality. In order to minimize this risk, the PI only contacted those participants, who after being approached by the perinatal bereavement nurse coordinator, gave their permission to be contacted. All personal identifiers were removed from the written transcripts of the interviews prior to analysis to ensure anonymity.

Adequacy of Protection Against Risks

Recruitment and informed consent.

Participants were recruited through the perinatal bereavement nurse coordinators at six urban hospitals. To prevent a violation of patient privacy, potential participants who met the inclusion criteria were contacted and informed about the study by the perinatal bereavement nurse coordinator who used a script to explain the study. Interested potential participants gave permission to the perinatal bereavement coordinator

to pass on their contact information to the researcher.

The PI contacted interested potential participants by telephone to further explain the study and the need for verbal consent. Throughout this process, the researcher used strategies to promote respect, such as speaking to them in private to protect confidentiality and being genuine and sincere (Adderley-Kelly & Green, 2005). Because of the potential for an adolescent to be limited in her literacy, the PI offered to read the Summary Explanation of Research aloud to the participant. The Summary Explanation of Research was written at a sixth grade reading level as recommended by Erlen (2005). As a means of ascertaining the understanding of the participants, the researcher asked, "Tell me in your own words what this research is about." (K. Kavanaugh, personal communication, November 12, 2008). Each participant was given a copy of the Summary Explanation of research to keep.

Protection against risk.

The most significant risk for participants in this study was the potential for psychological distress triggered by talking about their loss. The PI approached participants in a respectful, caring, and compassionate manner in all communication to minimize the threat of psychological distress. Participants were assured that they could freely withdraw from the study or reconvene an interview at another time if so desired. Each interview concluded with a debriefing session as previously described.

The researcher understood the importance of establishing trust through the provision of appropriate information about the study, in language that is understandable to the participants, and to remain open, honest, and trustworthy at all times (Erlen, 2003). Patient advocacy was also important in this study. The researcher recognized the

importance of being sensitive to the needs of participants, both spoken and unspoken, and to provide the participants with a sense of control and respect (Erlen, 2006).

Potential benefits of the proposed research to the subjects and others.

One of the potential benefits to the participants is that the opportunity to discuss their loss with a health care professional may prove to be very therapeutic and helpful. There may be some adolescents for whom the knowledge that they are helping others by participating in a research study will be meaningful. This has been validated in the literature on perinatal loss and bereavement. Low-income African American parents who have experienced perinatal loss report feelings of emotional relief, the value of being listened to, and a unique opportunity to help others as outcomes of their participation in research (Kavanaugh & Hershberger, 2005). The benefits of this research to both nurses and adolescents who have experienced perinatal bereavement are highly significant. The results of this study inform health care professionals about the experience of perinatal bereavement in non-Hispanic Black adolescents so that culturally and age-appropriate bereavement support can be designed and implemented.

Importance of the knowledge to be gained.

Because of the paucity of research about the experience of perinatal bereavement in non-Hispanic Black females, the results of this study fill a gap in the literature to inform nursing practice and impact perinatal bereavement support. The importance of this research topic is echoed by the National Institute for Nursing Research and many other health policy related organizations in an effort to improve end of life care and close the gap on health disparities in this country. The risks to participants were minimal and the richness of the data will help nurses to develop a better understanding of perinatal

bereavement in this vulnerable adolescent population.

This study included only non-Hispanic Black females because this group represents the highest perinatal mortality risk, yet very little empirical evidence exists to inform nursing practice about their perinatal bereavement needs. A single racial/ethnic group was proposed to fill a significant gap in current research.

Chapter Summary

In summary, this study aimed to build an understanding of the experience of perinatal bereavement in non-Hispanic Black adolescent females who have experienced perinatal loss. The data yielded rich descriptions of the experience that follows perinatal loss in order to build a disclosive theory of perinatal bereavement in non-Hispanic Black adolescent females. In addition, the researcher sought to identify critical transitions in the experience which may be important times to offer culturally sensitive bereavement support interventions. A qualitative approach using grounded theory methods was the most appropriate way to study this phenomenon given the paucity of information in the scientific literature and the high rates of perinatal loss in the African American community. Findings from this research study will inform nursing practice and potentially improve the care and bereavement support that is offered to non-Hispanic Black adolescents when they experience a perinatal loss.

Chapter 4

Results

This chapter presents the results of this qualitative, grounded theory study which employed constant comparative analysis to derive a disclosive theory of perinatal bereavement in non-Hispanic Black adolescents. Demographic information is presented in chart format in order to describe the characteristics of the population represented in these data. The theoretical concepts that emerged from the data are presented and described beginning with the pre-bereavement context. A disclosive theory of the experience of perinatal loss and bereavement in non-Hispanic Black adolescents is presented, along with supportive data for each theoretical concept. The specific aims of the research are addressed and the research questions are answered. Additional findings related to the participants' feedback about research participation are offered.

Participant Demographics

Eight non-Hispanic Black females who had experienced a recent perinatal loss agreed to participate in this research study. One participant dropped out after the first interview for health reasons. The mean age of participants at the time of the first interview was 18.9 years with an age range of 18-21. The mean time interval between the time of the loss event and the first interview was five weeks with a range of three days to eight weeks. Participants were followed for up to twelve weeks. The mean gestation of the baby lost was 19.8 weeks with a range of 9 weeks to 32 weeks. Six of the participants had graduated from high school and were either in college classes or planning to attend college in the near future. Four of the participants reported prior pregnancies, but none of the participants had any living children. Of the eight

participants, three reported having had one elective abortion in the past and two of the participants disclosed a prior second trimester pregnancy loss.

Table 2. Participant Demographics

Code	Age	Gestation and Type of loss	Pregnancy History	Education	Partnered at time of loss?	Residence
P1	18	26 weeks; Stillborn	1 st pregnancy	1 year Community College	No	Lives with mother and grandmother
P2	19	22 weeks; Stillborn	1 st pregnancy	1 semester Community College	Yes	Lives with mother
P3	18	32 weeks; Placenta Abruption	2 nd pregnancy Abortion at age 16	Quit HS in 12 th grade; plans to finish	Yes	Lives with mother
P4	18	22 weeks; Preterm labor	2 nd pregnancy Prior preterm loss at 20 weeks 10 months prior to this loss	Graduated HS; Accepted to college	Yes	Lives with grandmother
P5	21	18 weeks; Stillborn	1 st pregnancy	Graduated HS and Trade school; working	Yes	Lives with mother
P6	20	9 weeks; Miscarriage	3 rd pregnancy Abortion; Prior loss at 19 weeks 8 months prior to this loss	1 year college	No	Lives with mother
P7	18	18 weeks; twins; Preterm labor	2 nd pregnancy Abortion	High School Senior	Yes	Lives with father
P8	19	12 weeks; Blighted ovum	1 st pregnancy	Community College	Yes	Lives with a girlfriend

The Grounded Theory: Enduring to Gain New Perspective

The final product of a grounded theory study is a disclosive theory. According to Morse (1997), disclosive theory is a product of a grounded theory study that exposes the linkages between concepts and delimits the stages and phases of a process. This grounded theory study produced a theory of perinatal loss and bereavement in Black adolescents: “Enduring to gain new perspective”. The theory is conceptualized over time, beginning in the pre-bereavement context. The core concept “enduring the loss” represents the basic psychosocial process that is occurring during the experience of perinatal loss and bereavement in this population.

Emergence of Theoretical Categories

As data were analyzed, the initial codes that emerged from the open coding were compared against new data and thus several of the original codes were collapsed into axial codes. As the study progressed, theoretical sampling was used to delve more deeply into key conceptual patterns by redirecting questions toward specific aspects of the experience. Corbin and Strauss (2008) describe theoretical sampling as sampling in response to the concepts that are emerging to discover their relevant properties and dimensions. Theoretical sampling drives the researcher to investigate persons and situations that will yield more information about the concepts that are important to the emerging theory. Thus, “theoretical sampling is concept driven” (Corbin & Strauss, 2008, p. 145). Concepts were defined through the rich descriptions of the experiences of the informants. For instance, as the category of “support” was fleshed out through in-depth questioning, it became clear that support was both “sought” and “received”; that is, it was both passive and active. Therefore, the final concept was labeled “seeking and

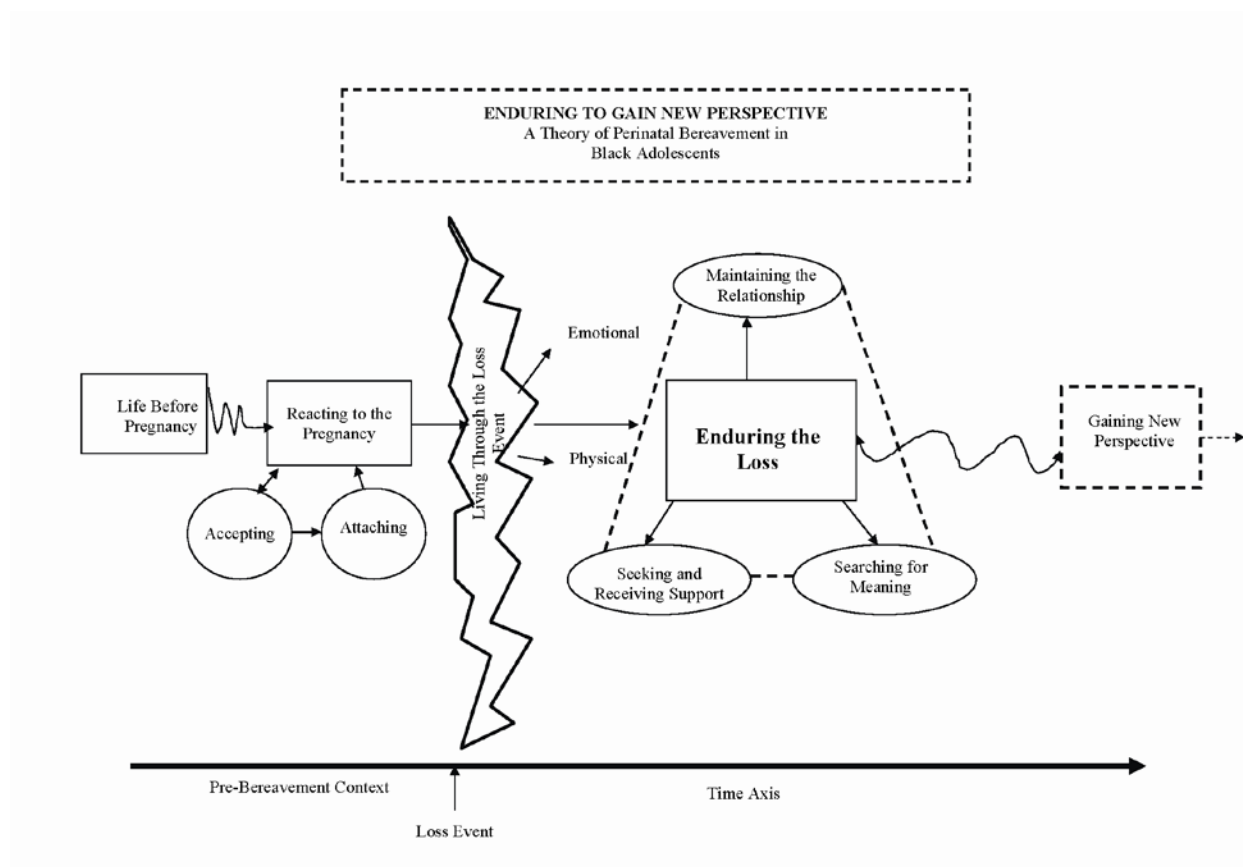
receiving support”. Likewise, the original category of “remembering the baby” expanded to become a more abstract concept of “maintaining relationship” in the final theory.

The conceptual components of the theory begin in the pre-bereavement context and progress through the loss event and into the bereavement period. The theoretical categories are: “life before pregnancy”; “reacting to the pregnancy” (subcategories “accepting” and “attaching”); “living through the loss event” (subcategories “emotional” and “physical” response); “seeking and receiving support”; “maintaining relationship”; “searching for meaning”; and “gaining new perspective”. The core concept of the theory is “enduring the loss”.

The temporality or the role of time in this experience and the notion of bereavement as a process is evident throughout the data as participants richly describe the experience of enduring the loss to gain new perspective. The concepts represent the dynamic nature of the bereavement experience and are not purported to be crisp, mutually exclusive phases with beginning and ending points, but rather fluid and responsive to each other in the context and social interactions of the participant. Likewise, the theory is not totally linear, but represents the conceptual rendering of the bereavement experience that is grounded in the data. Thus enduring the loss is an interpretive process of living through the loss, emotional and physical responses, seeking and receiving support after perinatal loss, searching for meaning in the experience of perinatal loss, and maintaining relationship with the lost baby, all working together to contribute and lead toward the last concept: “gaining new perspective”. This relationship is illustrated in Figure 1 which provides the schematic representation of the theory “Enduring to Gain

New Perspective”. A full description of the conceptual categories along with supporting data follows the explanation of the schematic diagram of the theory.

Figure 1. Diagram of Theoretical Model



Explanation of Theoretical Diagram.

The shapes and lines used to depict the theory in a diagram were purposeful and are explained as follows. The pre-bereavement context of life before pregnancy is depicted in a simple box to indicate “life as normal”. The jagged line leading to the next category implies the disruption and shock that accompanied the news of the pregnancy. The category of reacting to the pregnancy contains two sub-categories: accepting and attaching. The bi-directional arrow between reacting to the pregnancy and accepting

implies the iterative process of social interaction that occurred as the young women shared the news of their pregnancy with friends and family and came to an acceptance of the pregnancy. The one way arrow from accepting to attaching depicts the process of moving from acceptance to attaching to the baby.

The next part of the diagram represents the bereavement experience, beginning with the loss event itself. This category, called living through the loss event, is symbolized on the schematic diagram as a bold, sharp jagged shape to portray the pain and the abruptness of the event and the renting of dreams. The concept of living through the loss event contains two sub-categories: emotional response and physical response, both of which are depicted as manifestations of the concept of living through the loss. A straight arrow connects this concept to the larger box signifying the core concept of enduring the loss. The arrow implies the passing of time which brings to bear the notion of continuing on, or enduring. Surrounding the core concept and coming out of the process of enduring the loss, are the three concepts of seeking and receiving support, maintaining relationship, and searching for meaning; all connected by a dotted line. The dotted line indicates the fluid nature of these concepts and the dynamic relationship between them.

The conceptual theme of gaining new perspective is portrayed on the schematic diagram coming from the core concept of enduring the loss as a bi-directional wavy line, indicating that it is a fluid and dynamic process experienced in the “ups and downs” of the bereavement experience. The dotted line around the box of the concept of gaining new perspective indicates the “unfinished” nature of the concept. The future is indicated by a dotted line extending from the concept of gaining new perspective to illustrate that

the process of enduring the loss to gain new perspective continues as time goes on. The theoretical scheme is placed over an arrow that indicates that the process happens over time, but it is not intended to be prescriptive or limiting with respect to time.

The following table is included to provide an overview of the theoretical categories, the definition of each category, and the manifestations of the concepts from the data.

Table 3. Theoretical Categories

Theoretical Categories and Sub-categories	Definition	Manifestations
Life Before Pregnancy	Referring to the time before becoming aware of pregnancy	Going to school, hanging out with friends; making plans for college
Reacting to Pregnancy <ul style="list-style-type: none"> • Accepting • Attaching 	Reacting= Acting in response to the news of pregnancy ----- Accepting = acknowledging the reality of pregnancy as positive ----- Attaching = maternal process of establishing a bond to the unborn child	Shock, disbelief, ambivalence ----- Telling boyfriend Telling family and friends ----- Getting closer to the baby through: <ul style="list-style-type: none"> • hearing heartbeat • seeing ultrasound • naming baby
Living Through the Loss Event <ul style="list-style-type: none"> • Emotional Response • Physical Response 	Living through the loss event= The actual event of labor and delivery and immediate time period afterwards ----- Emotional response = outward expression and inward feelings felt in reaction to the loss ----- Physical response = natural post-partum bodily changes	Viewed as sudden and disrupting Feeling frightened and uncertain about what is happening Physical and emotional pain ----- Crying Sadness, depression Jealousy and anger ----- Unexpected painful lactation Hard to deal with
Seeking and Receiving Support	Seeking = actively looking for support either through other people or written material	Telling friends about the loss Attending a support group Journaling Finding other “like” women with similar experience

	Receiving = passively accepting support from others	Having emotional and physical need being taken care of by nurses, mothers, boyfriends, grandmothers Accepting the memory box of mementos
Maintaining Relationship	Preserving the memory of the baby and fostering continuing bonds with baby	Looking through the memory box Visiting gravesite Displaying baby's photo Writing letters to baby Saving baby's ashes
Searching for Meaning	Actively looking for a reason and a way to make sense of the loss; a process that happened over time and in interaction with others	Asking why? Reflecting on the purpose Finding out the medical reason for loss Coming to terms that God had a reason
Gaining New Perspective	The outcome of personal reflection about the experience of loss and seeing themselves as different and changed as a result of the loss experience	Stronger More humble Greater appreciation for family and for life Resolve to do better Starting over
Enduring the Loss (core category)	Enduring= A process of bearing up and carrying on over time in spite of difficulty Loss= the absence of a valued object/person	Being strong for others Staying the course through the ups and downs of the experience

Descriptions of Theoretical Categories

Pre-bereavement context.

According to Corbin and Strauss (2008), context refers to the “structural conditions that shape the nature of situations, circumstances, or problems to which individuals respond by means of actions/interaction/emotions” (p. 87). Process then flows from the actions and emotions that transpire in response to an event or problem (Corbin & Strauss, 2008). In order to fully understand the bereavement process, the

context in which the loss occurs must be considered (Bonanno & Kaltman, 1999). Findings from this study are considered through the theoretical lens of symbolic interactionism which posits that people respond to the problems they face and make meaning out of situations they encounter based upon their perception of the event which flows out of their interactions with others. Thus, the experience of perinatal loss and bereavement is best understood in light of the pre-bereavement context, which begins with what life was like before pregnancy, followed by the reaction to the situation of pregnancy and the time leading up to the loss.

Life before pregnancy.

Early in the course of the first interview, each of the participants was asked to describe her life before the pregnancy. Their responses were fairly consistent as follows:

“Just hanging out, going to the mall, movies, stuff like that. Normal things.”

“Hanging out with my friends...going to school.”

“Everything was pretty normal. Basically, I was just trying to save money to get out of my mom’s house and be with my boyfriend. It was just a pretty normal lifestyle.”

Two of the participants reported having difficulties in relationships or in school.

“Basically it was okay, but then at the same time it wasn’t because I was having problems with my mom; me and her argued a lot and we never were on good terms so I was always leaving.”

“Before I got pregnant I was kind of messing up in school a lot and playing around all the time. That’s pretty much it.”

Participants described a normal daily pattern for adolescents that involved school, work, family and friends. This “normal” changed with the news of their pregnancies and is described under the category of “reacting to the pregnancy”.

Reacting to the pregnancy: “unexpected but not unwanted.”

None of the participants in this study were planning to become pregnant and each one reported being surprised and shocked by the news of the pregnancy. In each case, the pregnancy represented a disruption to the norm for the participants in varying degrees. Many of them had plans to graduate high school, go to college, or even to finish a semester of college. The concept of reacting implies acting in response to a situation. This category represents the participants’ reaction to the news of an unplanned pregnancy and details the phases within the category as the subcategories of “accepting” and “attaching”. The in vivo code of “*it was unexpected but it wasn’t unwanted*” sums up the overall category of reacting to the pregnancy as the participants appraised the situation and weighed the options of what to do next. In the immediate reacting to the pregnancy, many of the participants went through a period of time where they were shocked and unsure about what to do and therefore did not seek prenatal care until several weeks into their pregnancies.

“I actually took a pregnancy test at my job. Something was telling me you know my period was late and I was like you know something just didn’t feel right. So I took a pregnancy test at my job and it turned out that it was positive. And I really didn’t believe it at first. I was by myself. I was in the bathroom and I was like oh my God. It was a complete shocker.”

“I actually didn’t find out that I was having twins until I went to the hospital because I was kind of confused as to what I was going to do about the situation. So I waited a couple of months and then when I finally decided that I wanted to keep it, keep the baby or whatever, it was (winter month) and I called the hospital for an appointment and they were giving me like far away dates. So I didn’t I didn’t have a doctor’s appointment until (spring month) but I had them before that.”

“Well, I kind of figured I was pregnant. I just hesitated. I was in denial for like the first month and a half. Like my breasts were sore and stuff like that and I wasn’t getting my period. So I was like wow...I thought about it and I finally called the doctor.”

“I thought I was having like a bladder infection, yeah, only it wasn’t a bladder infection. I went in to the hospital and like I was having bad cramps. And they told me I was five weeks pregnant.”

Participants who had experienced prior losses were asked about their feelings when they found out they were pregnant again. Their responses indicate their ambivalence at the news of another pregnancy so close to a prior perinatal loss.

“I don’t know why I didn’t get on birth control. That should have been like the first thing I should have did. Cause I think in like (fall month) I got pregnant again which is like the worst. It was like the biggest mistake. I was sad because I thought, I don’t want this same thing to happen again; it was kind of happiness but it was still sad because I’m like if this happens again I don’t know what I’m going to do. That’s what I kept thinking.”

“I was a little surprised, but at the same time I wasn’t. I wasn’t excited, but I wasn’t sad.”

As each participant moved through the process of reacting to the news of her pregnancy, there was an interaction of first accepting the pregnancy and for most, concrete descriptions of attaching to the baby. Thus, the overarching category of “reacting to the pregnancy” includes the subcategories of “accepting” and “attaching”.

Sub-category: Accepting.

Accepting often came by way of making the pregnancy known to a boyfriend, friends and family members. Accepting the pregnancy involved the decision to keep the pregnancy and tell friends and family. Participants described moments in time when they began to accept the fact of pregnancy. It was in the social interactions with family and friends, that the pregnancy took on meaning and they came to accept the pregnancy. Participants shared their stories of telling their family members who initially responded to the news in shock, disappointment, and anger, but over time became supportive.

“Well my mom and my grandmother were very upset and I cried too, but after a while you start to get used to it and you start to plan for the baby that’s coming. I think after a while everyone was excited and stuff like that; but at first everyone was just like me, because it was very unexpected.”

“And I knew from the get go my mom was going to be upset and my dad was going to be more of the supportive, calmer type. And that’s exactly what it was. You know I just said I have something to tell you, ‘I’m pregnant’. And my mom went off the deep end. She was very upset because she’s more of the conservative type like get married and then have babies. She expected more from me even though she supports my relationship with (boyfriend), you know, she just set more values for us. It took her a while, but she

overcame that and she was getting prepared and getting excited for it. And my dad, the first thing he told me was I'll be here for you regardless."

"With this pregnancy, I was afraid to tell people. I was scared to tell my sister because I didn't want her to look at me in an ugly way. But my grandma knew. She said 'there's something different'...see, I knew my grandmother all my life and she said she knew cause I looked different....like she told me she wasn't mad, she was just worried cause she didn't want the same thing (another loss) to happen again."

"At first I hid it from my dad. He didn't find out until I was like a month before I had them. I didn't really have time to tell him. But then I kind of got big kind of fast. At first he didn't talk to me for a couple of days, and then he finally did say something to me. He kind of cursed me out a little bit. He was like yelling at me and stuff, but I ignored it. He was angry a little, but he's helped me."

Likewise, in the social interaction of telling friends about their pregnancies and in receiving positive responses, participants came to an acceptance. The following quotes describe sharing the news with their friends.

"Two of my friends were crying. They were happy because all of my friends have kids. I was the only person out of all of them that didn't have kids."

"Everybody was excited. They were shocked too, cause nobody expected me to be pregnant because I was going to school and working a lot."

"My friends were even more excited than I was. They wanted to buy clothes. The people I met in college, they were excited too, but they were kind of not expecting that from me because they knew I was in college and they knew that I had dreams and goals."

Sub-category: Attaching.

While accepting the pregnancy happened in social interaction with others and was more of an internal process, attaching to the baby was related more to the meaning of the pregnancy and not specifically to the amount of time before the loss and was often demonstrated by outward actions. Maternal attachment has been described as the process that establishes a bond between the unborn child and the mother through a complex series of actions that includes conceptualizing the baby and preparing for the ways in which the child will impact life (Robinson et al., 1999). In these data, attaching was expressed through feeling a closer connection to the baby. One participant with an early loss describes her happiness to be pregnant as follows:

“I knew I was pregnant for 21 days...I had 21 days of heaven knowing that I was pregnant and it was one of the best times in my life. You know, for 21 days it was just exciting to know I was carrying something that was mine and that I had made.”

Things that impacted the attachment behaviors were seeing the baby on ultrasound, hearing the baby’s heartbeat, seeing their growing abdomen, and feeling the baby move. Outward expressions of attachment included choosing the baby’s name, writing letters to the baby, journaling, dreaming about motherhood, and making plans for the future. All of the participants in this study named their babies regardless of the length of the pregnancy. The following quotes illustrate the sub-category of “attaching”.

“That’s when they told me how far I was and that’s when I had my ultrasound and all that, and I actually got to see the baby move. Because my first initial reaction was I don’t know if I’m going to be able to keep the baby. Once I seen the baby move and stuff, I changed my whole idea of thinking. It’s really when I first seen the first heart beat.

I was like I don't know how I'm going to be able to do this but that's someone growing inside of you, further more it's my child."

"I wrote something about, because I had an appointment one time and that's when I first heard my baby kicking and I wrote about that. It was just – I was so happy that day. Like that was like one of the happiest moments in my pregnancy. I was so happy. The doctor said well this one is a kicker. It was so nice."

"Once you know you created something, what makes you want to throw it away you know, or want to lose it or anything. I just wrote a letter to the baby saying I can't wait to meet you, I love you, I'm so glad I found out about you. I was alright. You know I was in denial for a couple of months, but you're here..."

"Yeah, you connect, you bond you know. Like you're getting ready for this whole new life... We talked about it every day what our plans were and you know if it was a boy or if was a girl what we would name it, we were thinking of names and everything. You know that's exactly how it went."

Likewise, several participants showed attachment behavior by trying to take good care of themselves, making healthy nutrition choices and learning what they could about pregnancy.

"You know how when you first go to the doctor and find out you're pregnant and they give you little handouts and books to read on like 'What to do when you're expecting' and I had been reading it."

"When I first went to my first prenatal visit I got the delivery books when you look at your first visit, how you set up your delivery and stuff. I have that and then I got a Similac pregnancy planner. And it lets you know when you go through it, it goes over if

you're this many weeks this is what your fetus looks like, this is what your baby looks like, this is what you will look like. I got a book like that and I kept all of that stuff."

In summary, the category of reacting to the pregnancy included accepting and attaching as the young women began to dream about their future as mothers and to dream about what would be. Their dreams changed almost in an instant when they experienced the loss event.

Living Through the Loss Event: "All that Pain for Nothing".

The next broad category of this theory is "living through the loss event" with the sub-categories of "emotional response" and "physical response". The in vivo code of "*all that pain for nothing*" was evident in several participants' accounts of living through the loss. Living through the loss event begins with the time period that the actual events of the perinatal loss began; that is, symptoms of bleeding, cramping, and absence of fetal movement or heartbeat. Many of them misread the cues of preterm labor as "*not feeling well*" or as a "*stomach ache from something I ate*" and therefore did not seek medical attention immediately. Several participants reported very frightening and painful experiences of being in early labor and getting to the hospital for help, sometimes all on their own. This period was characterized as a time of uncertainty, fear, and "*pain for nothing*".

"After the doctor came and I pushed the baby out, like that was the worst pain ever in my life. Like a thousand hurts put together. I thought the worst part about pushing babies out is like the baby is not going to survive or like just going through all that pain for nothing. That's why I feel like I was going through a whole bunch of pain for no reason. Cause the baby wasn't going to live anyways."

“I was on my way to school and I was having back pains. I really didn’t pay any attention. As I was walking to school, my water just broke. I was by myself. After my water broke, I was panicking a little bit and I called the ambulance but they were asking me a lot of questions so I got frustrated and just hung up....The crossing guard had seen me and she stopped a cop car and they took me to the hospital. By the time I got to the hospital, my water broke again and I had blood everywhere.”

“So then I was just sitting in a chair and I just felt like all this stuff run out, and I thought my water broke. I didn’t know what it was. So I had put my hand in my pants and when I pulled it out there was all this blood on my hand. It was like there was all this blood going down my legs. I thought no way. I started crying. I said to my boyfriend something is not right. I said you’re not supposed to bleed this much when you’re pregnant. He said just stay positive babe and when we get to the hospital you’ll be alright. I mean when we got there, I was sitting in the ambulance for like 10 minutes. I’m telling them I’m bleeding. Then I felt this blood clot come out. I was bleeding real bad. Then when I got to the hospital they were checking for his heart beat. The first time they didn’t tell me nothing, they just took me upstairs. But you know when you see doctors and stuff whispering you know there’s something wrong.”

Many gave accounts of not understanding what was happening to their bodies and what that meant to the outcome for their babies. In many cases fear of the unknown and physical pain usurped the reality of the loss of the baby as participants asked “what is happening?” and it was often only after the delivery that the reality of the death of their baby really sank in. In fact, some participants describe their inability to cry even though they knew it was expected by other people that they should cry.

“I just wanted to cry like so bad; when it came out I was just shocked. I was nervous and I just wanted to cry so bad and I just could not cry. It seemed like it wouldn’t come out. The only time I cried was when the lady was trying to get me to hold the baby but I didn’t want to hold the baby. Oh I cried like afterwards, but at the time I couldn’t cry. The time that I thought I would really cry cause I didn’t know what was happening, but I cried afterwards.”

“Um, I wasn’t really emotional I was just in pain. Like it hurted. I was a little depressed after I had them. I wasn’t really thinking about like oh, my baby is dying or anything. I wasn’t thinking about that at the time. At the time I was thinking about having the pain.”

“Oh it was the worst pain I ever felt in my life. Oh my goodness it was so much pain. They gave me the pump, I’m not sure what kind of medicine it was but I know there was a button I had to press.”

Participants describe an underlying fear knowing things are not okay, but still hoping and praying for a miracle. Some described their disbelief at what had actually happened.

“He (doctor) gave me some medicine for me to start contracting and he said you know it could take all day or you could deliver in a couple of hours. It depends on your body. I thought she was still going to make it. I thought some miracle was going to happen. He never really said. He had it on his face, but he never really came out and said she wouldn’t make it.”

“I was emotional because I didn’t know what was going on. So they cleaned me up and everything. The whole time I was there I still didn’t like believe it. I’m sitting

there like okay. Till like the next morning it hit me like when I went to go take a shower like my front of me was like flat.”

Importantly, participants re-told their story of the loss event in graphic sequence with great attention to detail. This symbolizes how much the actual loss event is seared into their memory. Especially poignant is the following account of a young woman who experienced two second trimester losses as she watched her second child take her last breath in the delivery room.

“So when they took her out they cut the umbilical cord and I asked my boyfriend what the sex of the baby was. He said it was a girl. Then they laid her down and you could see her chest moving up and down and her gasping for air and I saw her chest moving up and down. And like the only hard part was to watch her chest move up and down fast and like watch her slowly die and her chest just kept going slower and slower.”

In addition to these moving accounts of the actual loss event, participants shared details of the experience that reflect the emotional and physical responses that came out of the immediate aftermath of living through the loss. Thus the sub-categories of “emotional response” and “physical response” richly describe the feelings and deep emotions experienced by the participants as well as the physical changes in their bodies during the post-partum recovery as outcomes of living through the loss event.

Sub-category: Emotional response.

The emotional response was demonstrated both outwardly and internally by crying, anger, depression, jealousy, and disappointment. In living through the loss, participants endured as they became strong for others, not wanting their friends or family to be uncomfortable with the situation. They put on a strong face with family and friends

and most often only let their tears flow in the presence of their boyfriend or when alone. Interestingly, but not surprisingly, they informed friends and family members of the loss through texting or social media (Facebook) to avoid having conversations with people. Participants described it as follows.

“Well I just let everybody know. I did it through text messages because I didn’t want everybody questioning me and asking me if I was okay because I would probably cry. So I think everybody that I told I sent them a text message and I was like I lost the baby, I’ll be okay, I’ll talk to you guys in a couple of days.”

“I told them through text messages, cause at the time I didn’t feel up to talking so I just text them.”

“I’m more of the one to stay strong and tough you know and don’t cry in front of people you know, well except for my boyfriend, I can sob in front of him but with my friends of more of the—like I was always the stronger person you know. Everybody tells me how strong I am you know dealing with all of this, but really when I go home I’m not that person that they see. So it’s easier when they ask me how I’m doing I’ll be like oh I’m fine.”

In the immediate aftermath of the loss they had to learn how to deal with the emotional pain and turmoil that they felt as described below.

“The pain felt so bad I was crying so much I couldn’t breathe. The pain is like I don’t know. I would never wish that pain on my worst enemy. It’s just like I can’t even explain. I’m talking like about the pain of losing the baby...the emotional pain.”

“Well when it first happened, maybe a couple weeks after that, it was just pain. It was just a pain that I couldn’t understand, a confusion on why it happened. A lot of crying, mixed emotions going everywhere.”

“I think going through all the pain and at the end of the day felt like it was for nothing. Like all of my happiness is turned upside down like because I lost the baby. It’s like we did something wrong to lose the baby. Like prior to and before, like it was always moving and I would be like smiling when the baby was like kicking and stuff and I was so happy and then like the next day my stomach was so flat.”

The emotional response was often triggered by seeing other pregnant women or women with babies either in real life, or in TV and movies. It prompted a “Why can’t that be me?” feeling and a sadness for lost dreams of motherhood.

“To be honest, ever since then I’ve seen pregnant women and women with babies and to be honest I would look at them, well why do you get to have a baby and I don’t. So I was just slightly jealous because you know what happened to me and I see them with a baby, but I had to realize that everything happens for a reason and that God knows best. But yes I was jealous. You know looking at another woman and seeing that they had a baby and everything—it went right for them but why didn’t it happen for me?”

“It’s frustrating seeing pregnant women that are about to deliver and you know just as far along as I was. It gets irritating to see that because it seems like it follows me everywhere...the pregnancy clan. And it kills me...seeing pregnant women that I know. Like a lot of girls in (name of town) like they’re loose and they just make babies to make babies and it makes me mad because it’s like—it’s just one topic that frustrates me cause I know girls that are my age that are on their third child you know. You know I’m not

stomping on them or looking down on them but it's like, you know that person and how they were in high school and now they have all these babies, it's like—it's frustrating to me.”

“A lot of times I just wanted to be by myself. I didn't really want to be with people...I just wanted to be by myself. I went through like not even like sad, it was like I didn't want to look at pregnant people. I used to watch the baby channel, like the baby stories and stuff. I didn't want to watch nothing, I didn't want to look at pregnant people. I was like really depressed. I just felt like I was depressed.”

“Cause like one of my other friends got pregnant, you know pregnant around the same time I was and like she's starting to show now and I'm always rubbing her belly it makes me sad because I don't get to rub my own belly or you know I don't have a belly to rub. So it gets kind of sad then... I just, deep down inside, I cry like on my insides cause I'm like, I wish it was me.”

Sub-category: Physical response.

The physical response to living through the loss was characterized by a sometimes unexpected physiological post-partum response such as lactation and fatigue that the participants dealt with by seeking information and counsel from older women with children. Some had received anticipatory guidance about lactation, but it was always worse than they expected and very painful to deal with on top of the emotional pain.

“It was like a couple of days after I was at the hospital my breasts got really swollen and lumpy. Yeah and like I had to call my mom and ask her what to do and she told me to put some warm water and try to squeeze the milk out.”

“I think that was the worst part. It was like the worst part. Because the first I remember like the first time it happened, I never really knew. I think it started like the second day it got real, real, real sore. My whole neck was hurting and everything was hurting and everybody was telling me like just put cabbage on your breast and stuff that would make it go away. That was like the worst pain. My whole body felt like it was shutting down and everything, like I couldn’t even move.”

“I went through a lot of changes. One of them was heat flashes. Through the night I would just feel like I’m burnt, like literally on fire; someone had set me on fire. I had to actually lay underneath the air, right directly underneath the fan. Of course, I was with my mom through it all. Another thing was my breasts were very engorged and very, very, very tender and very sore. I can’t express how painful it really was, but it was to like the tenth degree. It was so painful because they were so engorged. I was literally in tears. The pain was just horrific I couldn’t take it. I even called my doctor and they said the best that they could do or the best that they could tell me to do was to just use cabbage leaves and drink sage tea. Yeah I don’t wish that even on my worst enemy because you know that’s really how painful it was.”

Seeking and Receiving Support.

The next major theoretical concept of this theory is seeking and receiving support. Support for bereaved mothers occurred in two distinct ways: seeking and receiving. It is important to note here that a critical finding from this analysis is not just whether the support was sought out or whether it was received, but whether it was effective and perceived as helpful by the participants. Details about what helped or hindered the bereavement process are provided later in this chapter in the section related to answering

the research questions. This section will address only the theoretical concepts of seeking and receiving support. During the second and third interviews, participants reflected on the support they had received during their bereavement experience. Seeking support was an active process of looking for support as participants actively reached out to others in a quest for help, whereas in receiving support, the support was accepted and came by way of others reaching out to the mother.

One way in which participants sought support was to call or text girlfriends to talk. In some cases, despite the behavior of seeking support from friends, participants found that their friends were not available or they felt awkward around them.

“Like after I lost the baby, like after I was calling people and sending them pictures of him, they were just, my friends weren’t there for me at the time I needed them. You know how they say they’ll be here when you call them and you’re crying about your baby and stuff. Then they don’t answer your phone calls or come to your house, they said they would, but they didn’t come.”

“Like I have one close friend. I have like three of them and when it happened they were sad. Everybody was sad, but I think most people were sad about the first one like every time I talked to somebody that I haven’t talked to in a while they’re like oh you probably all big and stuff I’m like no I lost a baby and such and such. Then they’re like real sad. It would be real awkward.”

Only one participant reported seeking out and attending a support group offered by the hospital along with her boyfriend.

“You know the married couple in the group, she was pregnant, she announced that she was pregnant and I think the support group nurses even, they lost children, but

they were all married and they had a life experience and they were all out there and I just felt kind of different. You know us not being married and it was our first child and I was like not that far along. Like it was good to get it out and it was good to talk, but I felt like I needed like a younger person.”

Other examples of seeking support include journaling and reading on-line blogs about perinatal loss.

“I cried. I cried a lot. And I’ve wrote a lot. Well, writing during that period was a big deal cause I really didn’t have no one to talk to and when I went out and talked to people they would kind of like listen and they’re like okay well I gotta go. Like they didn’t want to talk about it with me. So I just started writing. Writing made me feel better. Like I wrote to myself and just reading online blogs and stuff helped me to know that things happen and stuff like that. Like miscarriage support pages and stuff like that and blogs. Blogs that other females have wrote and talked about their miscarriages and stuff about their losses. So just reading and writing to myself every day helped me out a lot.”

“I was going to write something today. I usually write things down sometimes. That’s what I usually do. When I keep things to myself I write it out.”

Another way that participants either sought out or received support came by way of hearing from other Black women who had experienced perinatal loss. In some cases, the participants received the support via a visit or call; and in other instances, they sought out and reached out to other Black women who had also experienced a loss, whether that woman was a peer or an older woman in the family or church.

“Someone from the church actually came to visit me. I didn’t expect anyone to; but they’re very good about helping people through their hard time. She came to the

hospital because she found out that I was in the hospital and everything that happened and actually the same thing happened to her twice. It was very helpful because they know exactly what you're going through. They know how hard it is and at times you're just speechless. There were times I was very speechless, I didn't know what to say and she noticed and felt everything that I went through she went through the same thing."

"Yeah, my one best friend she experienced a loss. She was 22 weeks. So whenever I went through it you know I was like wow she went through something like this. So I like texted her like how did you deal with this? Did you feel this, did you feel that? She was really positive about it. She has been there. She was a really good support."

Most participants sought out support from their boyfriends (if they were still together) although these young men demonstrated a wide range of responses to the loss themselves according to the participants' accounts. Each participant was asked to describe how her boyfriend reacted to the loss and what kind of support he offered. Many of the boyfriends withdrew and became distant, which led to further distress for the participants. Some however, were extremely supportive and caring.

"...Well like my boyfriend, he like blocks everybody out and he like blocked me out and it was like kind of sad—like where's everybody. He blocked me out like he walked away and I'm like you should be helping me."

"Yeah he helped me do everything. He was there through thick and thin. You know some people's boyfriends they don't be there or they just don't want to deal with the baby, but it felt good to know I wasn't by myself."

"My boyfriend has been my most support. He's been so good throughout this whole thing. He has never left my side. He's always been there and as you know that's

hard to come across especially in our society, our age.... He's very much a part, I don't know what I would do or where I would be without him."

Support was also received by the women of the family, most often the mother or grandmother.

"My mother and my grandmother. They're the biggest support that I've had throughout the whole thing."

"When I came home she wouldn't let me go anywhere, she wouldn't let me even stay in my own room for a couple days, probably for like a week until I got myself together. Cause I couldn't really sleep by myself."

"My grandmother is very supportive. She called—and she's always like, if I'm not here – well even if I am here, she will want to talk to me and ask me if I'm alright."

"When they found out, we just had like a family meeting about everything and everybody was telling me like do this, do that...and my grandmother was in charge and they were supportive."

"My mom has been there since I told her I was pregnant. You know it took her a while to come around to it, but she has been there since day one. She went to my first doctor's appointment. You know when I told her I was in the hospital she was right there, then she has been wonderful... Like when she was 18, she was like 8 months when she had her miscarriage. So she knows like the experience of it, she knows the grieving process. So I think she knows the words to say to me. Like I said we do have our moments where you know I'll be in a whole other element, a whole other world and sometimes I feel like she doesn't understand but I know she does. You know it's just at that moment I feel like she doesn't understand. But she's been really great."

In spite of seeking support from family, sadly, not every participant received family support.

“I mean I looked for support from my family. I didn’t get it, but ultimately I could do it myself without them helping me move on because I can do this by myself and no one has to help me or give me praise or let me know how I’m doing...”

Receiving support also came more passively by way of bereavement support care given by the hospital bereavement nurse in the form of standardized bereavement care. Each of the participants delivered in a hospital with a perinatal bereavement support program and thus all participants in this study were offered some level of standardized bereavement support. This support varied according to the gestational age of the baby and the particular resources and creativity of the individual hospital programs, but most typically included tangible items such as a memory box, footprints, hat, blanket, photographs, bereavement pamphlets and follow-up phone calls after discharge. The contents of the memory boxes are offered as a means of bereavement support, but these data revealed that the significant meaning of the memory boxes is more important in helping the mothers maintain relationship with their babies. Thus, this theoretical concept, maintaining relationship, is discussed more fully in the next section.

Maintaining Relationship.

During the initial open coding of the data, there were multiple codes about things such as photos, memory boxes, and visiting the baby’s gravesite. As data collection progressed and axial coding ensued, the more abstract concept of maintaining relationship emerged as it became clearer that the participants were continuing the bond with their baby. Maintaining relationship involves preserving the memory of the baby

through tangibles such as the memory box and photographs, and intangibles such as dreaming about what the baby would have been like. Every participant did something to maintain a relationship with the baby, such as keeping and regularly looking at the memory box or keeping the baby's ashes in a prominent place; getting a necklace to wear the ashes; framing and displaying the photographs; journaling letters to the baby; visiting the gravesite; holding a memorial; keeping the hospital band from the ER visit; keeping the pregnancy planner book. The memory box and the photographs were mentioned repeatedly by many of the participants as being an important gift that they will always treasure.

"I thought that the memory box was really nice. That helped a lot cause it's in my room and sometimes I just open it and I smell the hat and it smell like, and I smell the hat and the comb and stuff and the ultrasound. I look at the birth certificate. I just look through it."

"It has pictures and everything and they gave me this box. It's got everything...it has the pictures of his feet, his little feet, a little blanket and the outfit he had on and like three extra pictures of him and the little hat. His footprints and everything. I thought it was one of the best gifts because I'm so glad I have it. It's something I can always remember him by."

"We actually had that keepsake box right there. (She pointed to lavender memory box on a side table). It has like a little hat that she had on and a little, like it looks like a sleeping bag that she got to wear and her hand prints, her feet prints. I printed out a bunch of the pictures. I have them in a frame in my room."

“I put the memory box on my dresser. I got like a little dresser for it. It’s like a small dresser and I put a wreath right there and the baby picture and the teddy bear.”

One participant who had experienced an early loss did not receive a memory box, but she had received several bereavement pamphlets. She describes how she collected her prenatal and bereavement educational materials and hospital identification bracelet as a memorial.

“I kept like from when I first had my first ultrasound, the doctor at the emergency room did it, so I kept my wristband from that and then I kept my wristband from the surgery. And I think that’s all I had to keep. It’s all in the binding that they gave me for the delivery. So I have all that stuff in that binder. And all my letters to the baby are in there too.”

This participant even got a tattoo as a more permanent reminder of her early loss.

“I still think about it sometimes. It’s on my mind a lot. So what I did was the day after I had the surgery I went in and got a tattoo. Because I thought about it. I knew I was pregnant for 21 days. So, after that 21 this was my lucky number. Yeah I got a 21 with angel wings around it.”

The action of holding the baby after the baby died or just keeping the baby in the hospital room for as long as possible indicated a desire to maintain a relationship with the baby.

“My sister asked me like how could you stay in the room with her. I’m like I don’t know. When they ask you it’s a different story, when it really happens to you; it’s now when they ask you it’s like I want to spend as much time as I can cause I thought I’ll

probably never see her again. I couldn't even go to sleep that night. I was just up the whole night."

"They let us hold him and stuff. I got to hold him like the whole day cause I had him like in the morning so I had him like the whole day. I held him the first day, then I held him the day I was leaving."

"We actually stayed there until the evening and she was in the room the whole time. So a lot of his family members came down and got to see her and got to hold her."

If there was a gravesite where the body or ashes were interred, several participants reported getting up the courage to visit the gravesite. A few of the participants were able to keep the baby's ashes after cremation.

"Actually last week I was able to go visit her grave site. She's not too far away from my grandfather that passed away earlier this year. Then she got a spot where if I or my mom happen to pass away we'd be right next to her."

"I keep the ashes in my room. And I got a necklace made with his ashes."

Maintaining relationship was also manifested in continuing thoughts and dreams about the baby as demonstrated in the following data.

"Sometimes like, I have my days. It's not how it was when I first lost him, but it's like I have my days when I think about him a lot, almost every day, wishing he was here and what he would be like."

"I think about her at night. Probably because I'm laying down and then being the fact that (name of month and date) was the day I was due so that was kind of hard too. You know that night laying down I'm thinking well maybe I would be in the hospital right now giving birth. That night was kind of hard for me. I didn't get any sleep."

In maintaining relationship with their babies, these young mothers were beginning to put the experience of perinatal loss into the context of their life and revisit the experience as thus, remembering their baby through the tangibles (memory boxes, photographs) and the intangibles (dreams of what could have been).

Searching for Meaning: “Everything Happens for a Reason”.

In searching for meaning, the participants asked “why?” and “why me?” As time passed, participants sought out a medical reason for the loss and at times blamed themselves for the loss. They had to wrestle with their inner feelings about the experience and weigh them with what others were telling them. It was through this search for meaning that participants could begin to make sense of the situation. As they considered the reactions of others around them (family, friends) and their own personal inner reflection they were able to endure the loss, and find meaning in the experience of their loss. Symbolic interactionism rings true here, as participants made sense of the loss in light of their interactions with others. The element of time is particularly salient to this category and it is notable that these reflections and insights from the participants occurred in later interviews and after some time had passed from the loss event itself. Also of particular note are the many references to God; even though many participants did not attend church regularly, they all referenced God as the power behind the reason for the loss. The in vivo code, “*everything happens for a reason*” captures the essence of this category as evidenced in the quotes from each participant.

“Like I say, I believe in God. And that was part of what, like not just my mom but God got me through it. Like I said if it wasn’t for my mom and God I wouldn’t have

gotten through it. I pray and I know that everything happens for a reason and that he knows best.”

“God took him for a reason. The other thing maybe he didn’t think I was ready yet and he wanted me to probably finish school.”

“At first I was like really mad like I didn’t want to believe in God no more. That’s how mad I was. I used to always think like why does this happen to me. Like I’m not a bad person. Like I don’t have no criminal record, like I don’t do bad things. Like I’m about to graduate. Like I really felt in some way these people that do all sorts of things like drugs and do all this stuff like do weird, bad stuff and nothing happens to them, like I was always asking like why did this happen to me. Like I never did anything wrong. He’s (boyfriend) like ‘you know that’s how things work. That’s how God do things’.”

“Yeah there was a reason why I wasn’t meant to be a mother at this point in time. God would not give me anything I can’t handle and I truly believe that. I was raised to believe that and maybe there was something later in life that I couldn’t handle with her you know that something might have happened to her or something between me and him might have happened you know. So there was a reason why this happened and I’m searching for it, but maybe it’s like I just have to come at peace with it you know. You’re kind of forced to come at peace with it because you know life goes on and maybe they have to roll with the punches or it’s gonna test you, it could kill you, you know. So it is what it is and you know you just have to pray about it and you know keep it moving.”

“I definitely am one of those people that think everything happens for a reason. And just the way that everything is going now, I see that what happened was not my

problem. Like when I'm in school and everything and working after that and I should wait to get pregnant."

"I don't know I just was thinking about a lot of things whenever, I just took it in and everything kind of happens for a reason and I just felt like that was supposed to be my wake up call for me to do everything that I am supposed to do."

"A lot of people would say 'get over it' or at first when people would tell me it happened for a reason it bothered me because what reason would anybody you know what reason would it happen, like why. There should be no reason for it. So for people at first would tell me you know there's a reason for everything I didn't want to listen to it, but I had to come to my own conclusion that things do happen for a reason."

Gaining New Perspective.

As participants endured the loss through the emotional and physical responses, the process of seeking and receiving, maintaining relationship, and searching for meaning, they gained new perspective on the situation of the loss, the bereavement experience, and their future life. Perspective implies a point of view, a way of seeing things. Gaining new perspective involved seeing themselves in a different light, changed by the experience and moving ahead with a fresh outlook on life. Once more, the relationship to time and process can be seen in this concept as participants themselves reflect on how the experience of perinatal loss and bereavement has changed them. Thus gaining new perspective may be conceptualized as an outcome, yet not a finite outcome of the bereavement experience. Participants talked about their goals in life and how they felt stronger and somehow changed by the experience of losing their baby. For some of them, the fact that the loss happened at a prime point in their life was a signal to them to

get back on track. As they endured through their experience of loss, they were able to reflect on what the experience meant to how they were defining their future and their personal character.

“Everything I went through, I swear, it makes me a stronger person than I’ve ever been. This whole experience has humbled me in so many ways. I don’t even know where to begin by saying that. No I’m not the same. I would probably go on for hours talking about how it humbled me honestly. Yeah it’s not the same.”

“Well I feel I got stronger from it. Even though I’ve never been through a situation like that I dealt with it.”

In gaining new perspective, participants demonstrated resolve to do better, to do more, and to stay focused on their goals as illustrated by the following quote from a young woman with plans for college.

“He (boyfriend) wants to work and he wants us to move together but I’m like ‘I really want to go to school. I don’t want to move with you’. Sometimes he thinks everything I say is like in a mean way, but I’m telling him it’s not in a mean way. I’m just—I want to go to school. I’m breaking it to him that like I want to go to school. He’s like ‘well you got enough money saved up we’ll just move in together’. I’m like alright, but I want more than a high school diploma. I want to graduate and do something more with my life.

For other participants, the change was more existential.

“You know my outlook on life has changed you know. Just to be more cautious and you know act like every day is your last one you know and just cherish what you have with your friends and what you have with your family because you never know. So just try

to go on with life and you know be there for people and not like I was a mean person before, but it's just taught me to be more positive and cherish everybody that's around you, you know because you just never, ever know what might happen."

"I do believe it made me a lot stronger and you know I can deal with things easier now. You know if something were to come my way you know I'd be like well you know what, I have God on my side. He's brought me through it before; I know he can bring me through this."

This participant describes how she turned her grades around from failing to passing after losing her twins. She describes it as a "wake up call" to do better for her babies.

"I just felt like that was supposed to be my wake up call for me to do everything that I am supposed to do. Because I actually wasn't passing this year at all you know. But my last marking period after I lost the babies I've gotten my grades up and I got honor roll. All I wanted to do is hang out with my friends and I didn't really care too much about school. I'm not gonna lie. But I came every day, I did come every day and I felt like school was just social for me. I didn't really care you know about my grades or nothing. I didn't have nobody caring about my grades, not really. I felt like I want more for myself. I always felt like I wanted more for myself but I was just too lazy to act on it. Now I just feel like—now I don't feel like I have to do it for myself, I feel like I have to do it for my babies too."

The following quote describes the process of gaining new perspective as a continuum of starting over.

“It just made me want to just start over completely. Just redo everything over. Just redo anything that I could do and that’s what I did. I just moved and started completely over, well I’m starting over. I’m not done. I have more—I’m in progress to start over.”

The Role of Time

This study was conducted by following participants over twelve weeks in order to describe the experience of perinatal bereavement. Several quotes from participants give evidence to the meaning of time in relation to the theoretical conceptions of the process of perinatal bereavement.

“I think it kind of changed for the fact that I would say up until like a month and a half I would cry every night, now I cry every once in a while. Not that I don’t think about it every day it’s just it has made me stronger so I think every day that goes by I realize that you know God has blessed me to still be here because you know they say that giving birth is the closest thing to death and sometimes I even thank God that I’m still here.”

“...like at this point now like I can talk about it, I can talk about it with other people and not cry about it you know. So you know I’m doing a lot better with it.”

“It’s a little easier for me to talk about it than in the beginning.”

“I used to cry every day but it’s less now.”

“As time went past that’s when I was able to finally do other things as time moved along. Yeah, as the weeks and months go by I feel a lot better.”

The next section of this chapter discusses the findings in relationship to the specific aims and the research questions.

Findings Related to Specific Aims

In review, the specific aims of this research were:

- 1) To generate a disclosive theory of perinatal bereavement in non-Hispanic Black adolescent females.
- 2) To identify critical transitions in the perinatal bereavement process that may signal a need for well-targeted, culturally sensitive bereavement support services.

The first aim was achieved in the development of a disclosive theory of perinatal bereavement “Enduring to gain new perspective” as previously described. The second aim was to identify critical transitions in the process as a trigger for bereavement support services. This aim was also achieved, however the transitions in the process were not as crisp and delineated as the researcher originally expected. Nonetheless, potential points of contact within the experience that would be amenable to nursing intervention did emerge. These transitions are discussed under research question three to follow.

Findings Related to Research Questions

Research Question One.

What is the process of perinatal bereavement in non-Hispanic Black adolescents who have experienced perinatal loss?

The process of perinatal bereavement in Black adolescents is richly explained through the conceptual themes of the theory of enduring to gain new perspective. Limited scientific literature was found to describe the experience of perinatal loss and bereavement in non-Hispanic Black adolescents, thus there was inadequate supporting evidence to suggest that the perinatal bereavement process as it is experienced by young Black women is at all similar to the experience of women of other ages or from other

racial and ethnic groups. Thus, the depth and breadth of the experience of loss as it has been described from the perspective of young Black mothers is a unique contribution to the science.

The following response was received in reply to the researcher's request to a participant to sum up her experience of bereavement in one or two words. After a few moments of thought, she gave the following response which supports the conception of bereavement as a process.

"I'm still in the middle of it, you know. I've accepted it and I'm trying to move forward with it, but it's still so fresh. Yeah it can be a transforming experience. I'm still in the process. That's the word, it's a process."

Research Question Two.

How do non-Hispanic Black adolescents describe the meaning of the experience of perinatal bereavement after perinatal loss?

This question was answered in the conceptual category that emerged from the data, searching for meaning. Participants described the meaning of the experience as "everything happens for a reason" and over a few weeks time, they were able to see the experience of loss within the context of their lives and give meaning to the experience. At the start of this research study, it was unknown how articulate and verbose the participants would be during the interview process and if they would be willing to open up about their feelings to the researcher. Participants did, in fact, share their experiences thoughtfully and freely. These adolescents viewed the loss and bereavement as an impetus for change and they placed the loss into the context of their future and how they will live life as a result of the experience. Their reflective responses about what losing a

baby means and the subsequent bereavement experience that followed gives even more insight into the meaning of the experience of perinatal loss. Indeed, the experience of perinatal loss and bereavement is a pivotal life event for a Black adolescent with meaning and significance.

“It taught me life. It’s taught me how to deal with certain things, but it’s meaningful because it helped me grow as a person.”

“You know just to get an understanding of how it could change your life. Like for example it (the loss) really has changed me.”

“I imagine when I’m older and I have kids I would want them to understand what happened to me. Especially if I have a girl, a daughter I would tell her about my pregnancy and that everything doesn’t always turn out the way you expect it would turn out to be. I would use it to show her and guide her that everything happens for a reason in life.”

“The next time I do get pregnant, not that I’m planning on it now, but I want to be married. I want to have all the things cause I don’t really have space here with my mom because I share it all with my little sister.”

Research Question Three.

What are the critical transition points during the process of perinatal bereavement for which interventions may be helpful?

As noted above, there were transitions within the experience of perinatal loss and bereavement for which nursing interventions may be helpful; however the transitions were not always clear and crisp transitions that acquiesce to prediction and anticipation.

Specific recommendations for nursing interventions for these transitions are discussed in Chapter 5 under the heading of “Implications for Practice.”

One of the key transition points of the bereavement experience and perhaps the first opportunity for nursing intervention is in the experience of living through the loss event. This part of the experience was characterized by uncertainty, chaos, and fear. When participants received the devastating news that the baby had died or would not survive when born, they felt very alone and scared.

Another important moment after a baby has died is the decision point about whether or not to see and hold the baby. Many of the participants in this study needed gentle encouragement and reassurance before deciding to hold or see their babies. Some reported being too scared to hold the baby, but all were grateful for the opportunity when they took it. Many did not initially understand that their extremely pre-term infant would still look like a baby, just much smaller.

In the immediate time frame after the loss, key decisions about autopsy and disposition of the baby’s body often must be made. Participants relied on the input of their mother, grandmother, and boyfriend to help them make these decisions, thus accurate and easily understood information that informs the decision is very important. Financial resources may play a role in how a patient chooses. With regard to the cost of cremation, one participant explained how a doctor gave her wrong information about the price for cremation.

“At the hospital one of the doctors told us that it was going to be a \$50 fee for us to keep the ashes, but it turned out to be more. It was \$300. She finally did a discount and

it came out to \$240 basically cause I bought the urn and it was \$40 more. I'm glad my grandmom is paying for it."

Another participant opted for hospital cremation based upon cost.

"No they said we can't keep the ashes. The ashes went to the hospital and like at a burial site for the baby. And I thought it was okay because the funeral costs like a whole lot of money. So that was the best decision to do."

As young women go through seeking and receiving support, they have various levels of support available to them depending on their family structure, resources, and interpersonal relationships. This is an important aspect of the loss experience and young women will need guidance on how to seek support that will be helpful. Hospital discharge is a critical time of transition as the adolescents prepare to leave the hospital and their baby for the last time. Most are anxious to go home and put the hospital experience behind them. The discharge transition affords a time for teaching and anticipatory guidance. Only one of the participants reported having to go back to high school after her loss and inform others about what had happened. The awkwardness of having to explain her loss to teachers was difficult but something she thought was important for them to know. In this situation, contact with a school nurse may help the adolescent to make the transition back into school with less stress.

Lastly, a critical transition may take place as young women find meaning in the experience and gain new perspective. This is a time when adolescents seem ripe for encouragement from nurses, parents, teachers, or mentors to follow their dreams and recognize how they have changed in a positive way through the process of enduring to gain new perspective.

Research Question Four.

What factors influenced, helped, or hindered the process of perinatal bereavement?

Every participant was asked to reflect on what helped and what didn't help them through their bereavement experience. The participants characterized effective, helpful support as feeling cared for by the person offering the support, being able to talk with someone who had lost a baby who knew what it was like, and getting affirmation that "what I'm feeling is normal". The support that participants received from the follow up phone calls from the perinatal bereavement counselor was perceived as helpful as noted by the following quotes.

"It's just that they care. I don't know, like why are they calling and asking me how I am doing, you know? At first I thought it was weird and then I thought oh, they actually care and they are trying to understand what's going on and they want to know how I'm doing."

Likewise, the compassionate care from hospital staff, particularly the nurses, was valued as helpful.

"The people in the hospital were all very generous and helpful. They were very sympathetic. They expressed their condolences and everything. So that's another part that helped. The nurses were very helpful and generous...very sympathetic."

"The nurses, they talked to me and was there when I needed them like. There was a nurse that came in here and talked. Some of the nurses said they didn't know how I was doing it, but it was going to be okay."

"I don't know, some people might have looked down at them and made it seem like it was their fault. They (the nurses) just treated me real nice."

In terms of hospital staff, one participant shared the importance of consistent care providers in the clinic setting so that patients receive consistent information. .

“I would just want the same person to check me every time and to know that you know she knows my body and like I don’t have different doctors telling me different things.”

Participants shared that support coming from someone who had experienced a perinatal loss, especially someone from their peer group, was extremely helpful. This was evident in the data supporting the category of seeking and receiving support. It was helpful for them to get affirmation that what they were feeling was normal and to talk to someone who knew the right things to say.

“To hear other peoples’ stories and understand that I’m not the only one and relating to other people and that people went through the same thing. It’s hard to see that and it would make me feel better to hear other people say well this is what I did to make me get through it.”

Participants were asked if they had attended or would consider attending a perinatal bereavement support group. Their responses were mixed. This speaks to the influence of a person’s personality and her interpretation of the experience as to what would be helpful to her. Thus, bereavement support is not a “one size fits all” type of intervention. One participant attended a hospital-based support group but found it only slightly helpful as she felt out of place among the older married couples.

“Yeah we went to a support group and they were really good about everything, but like I said they were all married and, you know they had kids already. So I kind of felt left out.”

Other participants thought it might be good for some, but not for them.

“I don’t know. I just sometimes I don’t like to re-live and go through some of the things that have already happened. I try to move on and get past it...It’s a great idea and I’m not putting or degrading down but I just don’t think I could re-live that again or just keep talking about it over and over and over again.”

“Yeah a support group. Yeah for our age, yeah that would be helpful for some people but I don’t think that most because you’re like sad and depressed and stuff like that and I don’t think that most people would come. Some people, well some people are more open about it so maybe they would come. You know it would be helpful for some people...but I tend to keep everything inside.”

Another participant thought that the support group was a good idea, even if there were varied ages and situations represented there.

“I would go. I don’t know about no one else. I’m kind of like an open book. I don’t mind talking about things that have happened to me or things that have happened to me in the past and in the present. You know my life is an open book and I tell everyone that. I don’t mind talking about anything. I don’t care who’s around. That’s just the kind of person I am.”

One noted factor that influenced the bereavement experience is the occurrence of multiple losses. Remarkably, several participants had experienced recent losses of a parent, grandparent, or friend either just before their pregnancy or during their pregnancy.

“Because like I said before losing my dad and then losing her like I never really lost anybody really close to me until I lost my dad. I lost my grandma years ago but I was really young so I really didn’t understand it then, but losing my dad and then two months

later losing my daughter that was like a deep hole that I couldn't escape. I would cry every single day. And then I would go around people and then I would smile and I was like stronger. So yeah it was definitely grief."

"It was hard. I would say for my mom she had two losses, first of all her grandchild and her father...but I think everyone took it hard because I remember the day I came home we were all sitting in the living room and we were crying you know because of what I went through but after a while they were there to encourage me and lift me up. But yeah we all took it hard. The simple fact it was just like 4 months ago we all lost someone we loved and close to our hearts too."

One participant lost a friend to a shooting and then shortly afterwards lost another friend to a car accident. These events resulted in raising her stress throughout her pregnancy and made her question the cause of her loss.

"Yeah my whole pregnancy I was stressed and I don't know if that was the cause of what happened but I mean my whole pregnancy I was stressed but they say he was a healthy baby. So they don't know what caused it."

Two of the participants had experienced prior second trimester losses. These prior losses influenced their bereavement experience as noted below.

"I had just found out and when I found out I was a little upset that it happened again. Yes, all over again. And I was scared that I was going to go through the same thing."

"I got pregnant again which is like the worst. It was like the biggest mistake. I was sad because I thought, I don't want this same thing to happen again; it was kind of

happiness but it was still sad because I'm like if this happens again I don't know what I'm going to do. That's what I kept thinking."

The main things that participants reported as not helpful were the lack of support from their circle of friends, particularly their boyfriends, and the unkind things they heard from those who were trying to offer support. For example,

"'Get over it'. A lot of people would say 'get over it'...I didn't really tell anyone I wasn't really close to. So I got a few get over it you'll be alright, it's alright, just don't worry about it, but I mean I didn't really get it too often, but when I did hear it, it hurt."

"And the hospital gave us a box with all of the baby's things and my boyfriend, he said he never wanted to look at it, he never wanted to talk about it. It was like—to me I felt like he didn't care. I was like I felt he didn't care like cause he never said nothing, he never showed no emotion, never cried. Well he cried one time but like he never cried as much as I did. I just felt like he didn't care."

Research Participation

One important finding from this research study is not related to theory development or to answering the aims or research questions, but rather it is the positive participant response that the researcher received to the question, "what was it like for you to participate in this research study?" Feedback from participants was overwhelmingly affirmative and confirms the researcher's suspicions that young Black adolescents who have experienced perinatal loss have a powerful story to tell and they want to tell it. It was not the intent of the researcher for participation in the study to be therapeutic, however, participants clearly voiced that they had an appreciation for a caring, non-biased listener to whom they could express themselves.

“It gave me another opportunity to explain to someone else what I went through. Not that they’ve been through it or anything, but you know just to get an understanding of how it could change your life. I obviously can say for me it has helped me. You know just expressing my feelings to someone else outside of the family. Cause with your family it’s like you know they know you and if it’s someone outside your family, they don’t know you, they don’t know what you’re going to say, they don’t know what to expect.”

“It was nice talking to you.”

“I feel like I got to speak my mind openly without judging and somebody that listens and cares and understands you know with how I’m talking to you I feel like you’re very open and you’re very understanding and you want to know what’s going on in all these women’s lives. And that matters to us. You know that matters, like that somebody is listening and somebody understands and somebody cares.”

“I think your questions were helpful for me to talk more about it. Yeah. It was a good experience because I didn’t get to talk much about it to anyone else. So it was good for me.”

“Like the questions you ask make me think harder about what I was already thinking about and what I was already going through. You know it helped me—it helped me along because I had somebody to talk to that really wanted to know and understand what’s happening. So it helped me a lot.”

Chapter Summary

In summary, this chapter presents the findings from a qualitative study of perinatal loss and bereavement in non-Hispanic Black adolescents which aimed to derive disclosive theory in order to better understand the experience. The grounded theory,

“Enduring to gain new perspective” is the conceptual representation of the experience of perinatal loss and bereavement in Black adolescents with the major concepts of life before pregnancy, reacting to the pregnancy, living through the loss event, seeking and receiving support, maintaining relationship, searching for meaning and gaining new perspective. In Chapter Five, the findings of this study will be considered in the context of what is already known about perinatal loss and bereavement. No published studies were found in the literature to describe the experience of perinatal bereavement in Black adolescents, thus this study makes an important contribution to knowledge and practice.

Chapter 5

Discussion

The purpose of this chapter is to discuss the findings of this study by examining the results of the research in light of what is already known about the phenomenon of perinatal loss and bereavement. In review, the purpose of this study was to develop a disclosive theory of perinatal bereavement in Black adolescents using grounded theory methods of qualitative inquiry. A second aim was to identify critical points within the experience that may signal a need for well-targeted, culturally sensitive bereavement support services. Seven themes, or theoretical categories emerged from the data to produce the grounded theory, “Enduring to gain new perspective”. The core category that describes the basic psychosocial process through the theory is “enduring the loss”. This study represents a novel contribution to knowledge about perinatal loss and bereavement in Black adolescents. In this chapter, the disclosive theory is compared to the extant literature by themes in order to place the theory into the context of what is already known about adolescent development, perinatal loss and bereavement, and bereavement theory.

The application of symbolic interactionism as the theoretical underpinnings for this grounded theory study is presented. Strengths and limitations of the study are offered, along with the implications of the research. Lastly, recommendations for future research are suggested.

Application of Findings to the Scientific Literature

The purpose of this study was to build an understanding of the experience of perinatal loss and bereavement in non-Hispanic Black adolescents through qualitative

inquiry and grounded theory methods to develop a disclosive theory. What follows is a review of the significant findings according to the themes that were generated from the data analysis to produce the theory, “Enduring to gain new perspective”. Each theme is discussed in relation to the existing scientific literature.

Pre-Bereavement Themes: Life Before Pregnancy and Reacting to the Pregnancy

The pre-bereavement context of the theory includes the themes of “life before pregnancy” and “reacting to the pregnancy”. Life before pregnancy was described as “*normal*” as participants spoke of hanging out with friends, going to school, and working. Considering the pre-bereavement context findings of this study in light of developmental theory provides an added understanding of the contextual factors that impact attitudes towards pregnancy and the eventual experience of perinatal loss and bereavement in this group of adolescents. Erikson’s theory of psychosocial crisis posits that during adolescence there is a new sense of self-awareness and heightened cognitive ability which prompts an identity crisis requiring resolution in order to achieve a sense of self-worth and value (Green & Piel, 2002). Moreover, adolescence is a period of simultaneous transitions involving school, jobs, friends, and puberty which can bring about intrinsic challenges that require a great deal of emotional maturity and internal control from an adolescent (Green & Piel, 2002). Adolescence is also a time for achieving emotional separation from parents and for establishing an independent identity. Hence, in essence, adolescence is a vulnerable time period both intrinsically and extrinsically.

The young women in this study were all urban Black females between the ages of 18 and 21, an age span referred to in the literature as “late adolescence” (Balk, 1996).

They were in the midst of the developmental tasks connected with late adolescence and the transitions associated therewith: graduating from high school, planning to go to college, or working to save money to move out on their own. They had plans and dreams and were establishing an identity that by their account, did not include immediate motherhood. Thus, it not surprising that the participants in this study described receiving the news of the pregnancy as a disrupting event that initially created shock and disbelief. Conversely, half of the participants had experienced at least one previous second trimester pregnancy loss, yet none of the participants reported trying to prevent future pregnancies. Moreover, many participants shared that their friends already had at least one or more children. Thus it remains unclear if the pregnancies were truly unintended in each case, or if there may have been a subconscious denial of the possibility of pregnancy despite the lack of birth control. Alternatively, there is the possibility that the adolescents who had already experienced a perinatal loss were replacing the loss with another pregnancy, although that was not explored in this study.

As participants described a time of reacting to the pregnancy, the sub-categories of accepting and attaching emerged. Accepting the pregnancy included activities of first informing the boyfriend of the pregnancy and then telling the parents. In the act of telling others of their pregnancy, it became real. Attaching came by way of developing a close connection to the baby, often as a result of seeing the baby on ultrasound or hearing the heartbeat. This description of accepting and attaching is consistent with the classic theory of maternal tasks in pregnancy as espoused by Rubin (1976). According to Rubin, pregnancy is a time of identity reformation as women reorder their personal relationships and experience maturity while going through the psychosocial tasks of pregnancy which

include: “(1) seeking safe passage for herself and her child through pregnancy, labour and delivery; (2) ensuring the acceptance of the child she bears by significant persons in her family; (3) binding-in to her unknown child; and (4) learning to give of herself.” (p. 369). Rubin describes these tasks as concurrent and equal, weaving in and out throughout the pregnancy but yet vulnerable to disruption. Rubin asserts that finding acceptance for the pregnancy involves securing acceptance for the child by the persons in the mother’s intimate circle. This notion of acceptance was confirmed in this study as participants spoke of telling their parents, grandmothers, and friends in hopes of receiving acceptance of the pregnancy in return.

The task of binding-in as described by Rubin (1976) occurs first by accepting the idea of being pregnant, and then as the pregnancy continues, it becomes experiential as the mother feels the baby move and the child within her becomes more valued and loved. Rubin’s conception of “binding-in” has also been referred to in more recent literature as maternal fetal attachment. Maternal fetal attachment is a complex process that begins before birth and includes both tangibles, such as feeling fetal movement, as well as intangibles, such as making preparations for the baby and dreaming about the way the baby will contribute to the family (Robinson et al., 1999). Thus, according to maternal fetal attachment theory, there is a relationship between the fetus and the mother that develops before the baby is born (Brandon, Pitts, Denton, Stringer, & Evans, 2009).

The adolescents in this study had developed a relationship with their unborn baby on some level as evidenced by their attachment behaviors that were both tangible, experiential occurrences, such as seeing the baby on ultrasound and hearing the heartbeat; and intangible behaviors, such as dreaming about the baby and naming the baby. This

attachment becomes foundational in interpreting the experience of perinatal bereavement through the lens of symbolic interactionism. It is also a critical finding in terms of establishing what the baby meant to the mother and therefore, how she interprets the meaning of the loss. No prospective studies were found that queried adolescent women about the pre-bereavement context that preceded their loss.

Other researchers have suggested that in the bereavement follow up it may be important to ascertain the meaning of the pregnancy to the adolescent as a way of helping the mother acknowledge her feelings about the loss (Wheeler & Austin, 2001). Furthermore, Soto (2011) offers case study evidence to suggest that adolescents who experience perinatal loss may fall into one of three categories: an adolescent who accepted the pregnancy and is mourning deeply; an adolescent who is ambivalent and indifferent; and an adolescent who does not acknowledge the loss at all. Thus it is important to consider the adolescent's acceptance and attachment to the pregnancy in order to understand the bereavement experience. In the next theoretical category, living through the loss event, the maternal fetal attachment relationship is threatened.

Living Through the Loss Event

Living through the loss event is the next theoretical category which was described by the participants as sudden and unexpected and includes the sub-categories of emotional response and physical response. Living through the loss event was characterized as an emotionally and physically painful experience fraught with overwhelming uncertainty and confusion. The adolescents were often confused by the information they received about what was happening and the hushed tones of the doctors did not go unnoticed by the anxious mothers. McCreight (2008) reported similar findings

on the impact of the blunt delivery of bad news and insensitive, hurried physicians which was interpreted by the mothers as failing to acknowledge the emotional aspects of the loss.

The adolescents in this study reported feeling frightened, confused, and in shock or disbelief. The nature and type of emotional response reported by the participants in this study is consistent with what other qualitative perinatal loss research has reported (Dyson & While, 1998; McCreight, 2008; Murphy & Merrell, 2009; Sefton, 2007). In addition, many quantitative studies have measured the grief response after perinatal loss using tools that measure attributes that were noted in the emotional response of the participants in this study, such as sadness and crying (Toedter et al., 1988); sadness, guilt, and anger (Theut et al., 1990) and perceptions of reality (Hutti et al., 1998). Although the quantitative research does not describe the depth of the experience, results from these studies do support that there is a complex emotional response that follows perinatal loss. The finding that the adolescents reported an emotional response of sadness, jealousy, or anger when seeing other pregnant women whether in person or on television is also consistent with findings by other qualitative perinatal bereavement researchers (Kavanaugh & Hershberger, 2005; Sefton, 2007).

Participants in this study gave detailed accounts of the loss event, beginning with the moment they first sensed trouble. Many of them misread the cues of preterm labor as a stomach ache or as a normal part of pregnancy and as a result did not seek immediate medical attention. Kavanaugh and Hershberger (2005) also report that the African American women in their study misread the signs of early labor and reported the loss event with clarity of detail.

Many of the participants in this study reported difficulty dealing with the physical symptoms of lactation during the post-partum period. The participants described the lactation as a painful and annoying physical symptom to be dealt with and not as a reminder of the loss, whereas others have suggested that lactation is a painful cue to bereaved mothers that there is no baby to breastfeed (Bartellas & Van Aerde, 2003).

Seeking and Receiving Support

The next theoretical category of the theory is seeking and receiving support. Participants in this study most often sought support from their partners, their immediate family (particularly mothers and grandmothers), and their friends. Many of the participants sought the support of their girlfriends after the loss, often informing them of their loss via social media, such as Facebook or texting. Few participants reported a favorable response from reaching out to their friends for support, saying “*they just weren’t there for me*”. This finding did not appear in other perinatal bereavement studies, possibly because of the dearth of scientific literature about the phenomenon of perinatal loss and bereavement in adolescents. Nonetheless, authors have suggested that it may be possible that an adolescent’s peers may avoid her after perinatal loss because they don’t know what to do or say and because they do not know how to cope with the situation (Chesterton, 1996). Another possibility is that their peers do not understand the experience and thus, are uncomfortable facing it.

The partners or boyfriends of the young women in this study demonstrated various capacities for support according to the accounts revealed by the participants. Some of the young men were very attentive to the needs of the mother, even to the point of accompanying her to a support group meeting; while others were distant and silent.

Some expressed emotion and held the baby; others never showed emotion, saying they wanted to “*be strong*” for the mother. Other qualitative researchers have reported that fathers have varying responses to perinatal loss that include feeling the intensity of the loss but keeping busy to deal with their own personal grief (Armstrong, 2001) and feeling like they need be strong or stoic to support their partner (O’Leary & Thorwick, 2006). All agree that the father’s response to perinatal loss warrants further investigation (Armstrong, 2001; O’Leary & Thorwick, 2006).

Most of the participants in this study turned to the women in their family circle for support: mothers, sisters, grandmothers, aunts. These were the women they felt closest to and with whom they were comfortable sharing their experience, and whose presence gave them comfort; “*they were just there*”. Other researchers who have studied bereavement in African Americans confirm this finding that Blacks rely heavily on the support of kinship during a loss experience (Laurie & Neimeyer, 2008; Van & Meleis, 2003). Notably, Laurie and Neimeyer (2008) report that little distinction is made between immediate and extended family within the African American family and thus they posit that when kinship is strong, bereaved individuals are less likely to seek professional services for support.

In addition to family support, the importance of seeking support from someone with similar experience and culture was noted in these results. For example, one of the participants sought out a hospital-based bereavement support group, but found that she felt out of place as the only unmarried and Black woman in attendance. Participants in this study also demonstrated seeking and receiving support by hearing from other Black women, such as women from their churches, or other Black girlfriends who had

experienced a perinatal loss. It was helpful to talk to someone who “*knew what it was like*”. One participant used the internet to connect with other women who had experienced perinatal loss by seeking out support sites and reading the blogs. This theme of trying to find other women with similar stories was reported in a qualitative study that examined the culture of an online support group (Capitulo, 2004). Similarly, Van and Meleis (2003) found that African American women who had experienced perinatal loss wanted to talk with women of their culture as they felt constrained in support groups with White women.

Maintaining Relationship

Although the outward expressions differed among the participants, all of the young mothers in this study gave evidence of maintaining a relationship with the baby. Many of the ways in which participants remembered their babies and maintained relationship were evident in other research studies, such as visiting the gravesite (Uren & Wastell, 2002), keeping the baby’s photograph in a prominent place their home (Dyson & While, 1998), looking through the memory box for comfort (Van & Meleis, 2003) and getting a tattoo to remember the baby (Kavanaugh & Hershberger, 2005).

Maintaining relationship most often began with holding the baby. A few of the participants admitted they were too afraid to hold the baby but still kept the baby in the room for several hours. The literature is inconclusive about the therapeutic benefit in encouraging mothers to hold their deceased infants. No definitive empirical evidence was found to support the practice as a way of decreasing grief after perinatal loss. In a review paper discussing the psychological aspects of perinatal loss on mothers, Badenhorst and Hughes (2007) adamantly stress that health care professionals should use

caution in assessing whether holding the dead baby will be therapeutic for the mother, citing evidence that such practice has been correlated with post-traumatic stress disorder that may surface in subsequent pregnancies (Hughes, Turton, Hopper & Evans, 2002). Nonetheless, many suggest that this practice be considered in routine perinatal bereavement care and in fact, that parents be encouraged to hold their baby even if they are initially resistant (Capitulo, 2005) or if sedation during the delivery postpones the ability to hold the baby until later (Bartellas & Van Aerde, 2003).

Photographs were an important way for the mothers in this study to remember their babies and to maintain relationship. Having a photograph of the baby validates the existence of the baby especially when there are few other things by which to remember the baby (Alexander, 2001). In addition to the hospital photographs, Johnson and Langford (2010) suggest giving the parents a disposable camera to use for photographs.

Only one participant in this study chose private burial for her baby although she chose not to have a funeral service. All of the other participants chose cremation, and of these, only one of the participants in this study held a memorial service for her baby after cremation. The service was held in her home and was attended by her extended family. They read poetry and scripture and prayed. Her mother prepared a large meal to feed the twenty people in attendance. This type of in-home service is customary for African American families and is an example of the cultural expression during bereavement (Clements et al., 2003).

Other researchers have reported that bereaved mothers maintain a sense of attachment and relationship to the baby even months and years after the loss, refuting the notion that bereavement has a specific end point. Behaviors such lighting a candle on the

baby's birthday and talking to the baby are examples of actions that indicate maintaining relationship through attachment (Uren & Wastell, 2002). The notion of continuing the ties to the deceased person has been scientifically supported by other contemporary bereavement theorists and reflects the current direction of bereavement theory (Davies, 2004; Florczak, 2008; Lindstrom, 2002).

Searching for Meaning

Searching for meaning has been described as the process of cognitively appraising a negative event and finding significance in the event within the purpose of life that changes how the person thinks about the event (Skaggs & Barron, 2006). Park (2010) asserts that meaning making is a dynamic process that occurs over time and thus cannot be confirmed in one interview, but must be followed over time. Even though data collection occurred within the 12 week window after the loss, the adolescents in this study showed an amazing capacity for expressing themselves and relating their inner feelings about the meaning of the experience of recent perinatal loss. These reflections and insights were most often shared in later interviews several weeks after the loss event. All of the participants referenced God in some manner as the reason behind the loss, such as "*God took him for a reason*".

Other qualitative researchers have suggested the connection to spirituality within the African American community with regard to searching for meaning in a loss experience. For example, in a qualitative study of African American parents followed within four months of a perinatal loss, Kavanaugh and Hershberger (2005) report that parents tried making sense of the loss by finding a reason for the loss and by questioning the loss from a spiritual context. Van and Meleis (2003) reported that African American

women used the strategy that God does everything for a reason as a means of coping with perinatal loss.

Searching for meaning has been categorized as healing by Sefton (2007) who reported that the Latina adolescents in her study expressed searching for meaning in a way that strengthened hope and lessened despair. Making sense of the loss and finding meaning in the experience was also confirmed by Uren and Wastell (2002) who suggested that the death of a baby prompts a search for meaning by shattering a person's expectations about life. Other qualitative researchers have found that even when interviewed years after the loss, women were able to describe searching for meaning (McCreight, 2008) and reflecting on the loss (Dyson & While, 1998).

Gaining New Perspective

As participants in this study endured through the loss experience, they gained a new perspective on life, on their loss, and on the future. Many of them resolved to reach their goals and to "*do better*". They reflected on how they had changed and how the experience had made them stronger, more humble and more appreciative of life. They credited the experience of perinatal loss as the impetus for change.

Interestingly, several of the adolescents in this study have a history of prior perinatal loss, thus raising the question as to why they had a repeat pregnancy. Was it because they failed to gain new perspective? The literature provides a possible explanation. Adolescents with a history of miscarriage are more likely to have a repeat pregnancy within the second post-partum year, thus researchers suggest that the accompanying sense of loss and grief after miscarriage may create a heightened desire to become pregnant again (Coard, Nitz, & Felice, 2000). In this study, two of the

participants had experienced rapid repeat pregnancy after perinatal loss, two had repeat pregnancy after elective abortions, and one participant reported that she and her boyfriend were planning to “try again”. Another possible explanation is that over time the adolescent has matured and is able to add to her life experience and knowledge in order to arrive at a new perspective after the most recent loss.

Several of the participants verbalized a desire to help other young women through the experience of perinatal loss and bereavement as a result of their own experience. They viewed their participation in this research study as one way in which they could reach out to help others, a finding also confirmed in the study by Sefton (2007).

The notion that there are outcomes of bereavement is supported by the work of noted bereavement theorists Stroebe, Folkman, Hansson, and Schut (2006) as proposed by the Integrative Risk Factor Framework. This framework posits that the experience of bereavement includes an appraisal and coping that is considered in light of personal and non-personal factors to lead to an outcome or measurable change in grief intensity, physiological changes, cognitive changes, or social changes. Furthermore, they suggest that the outcomes may be manifest either in the short-term or long-term.

Bereavement researchers have studied the phenomenon of bereavement in adolescents who have lost a sibling or a parent and have had similar theoretical conclusions. In a grounded theory study of adolescent bereavement after the loss of a sibling, Batten and Oltjenbruns (1999) reported six themes to describe spiritual growth during bereavement: new perspective of self, new perspective of others, new perspective of higher power, new perspective of death, new perspective of life, and new perspective of sibling relationship. The core variable in their theoretical conclusions was “a quest to

understand life's meaning". The researchers viewed their findings through a spirituality framework and determined that in bereaved adolescents, spirituality is manifest in the effort to make meaning in life.

As the crisis of bereavement challenges the adolescent's assumptions about life and the meaning of human existence, spiritual change may be triggered. Furthermore, giving rise to the assertion that adolescents may go on to develop new perspectives on the experience over time is the suggestion by Leighton (2008) that as adolescents mature, they continually reflect on the crisis of loss and reconstruct their views about the loss in a way that results in spiritual change and new perspective.

Grounded Theory: Enduring to Gain New Perspective

The adolescents in this study shared poignant and detailed accounts of their stories of perinatal loss and their bereavement experience over a 12 week time frame. Although 12 weeks is not a long time, Balk (1996) asserts that bereaved adolescents do not delay developmental tasks while grieving a loss; thus, it is impossible to tease out what effects normal development may have had on the emotional progress that these young women made in their bereavement journey. Nonetheless, there is supporting evidence in the conclusions from previous perinatal loss and bereavement research that demonstrate consistency and agreement in many of the findings of this study in relation to the interpretations that guided the development of the grounded theory model of enduring to gain new perspective. The concepts of living through the loss event, seeking and receiving support, searching for meaning, and maintaining relationship are fluid and responsive to one another, and together they encompass an enduring that leads to gaining new perspective. In addition, the view that the bereavement experience should be

considered in light of the pre-loss context is supported by Bennett and colleagues (2005) who cite that the context of loss and the perceived strength of attachment to the baby are key variables that deserve future investigation.

Support for the interaction and dynamic nature of the theory of enduring to gain new perspective is noted in Paletti's (2008) assertion that grief is a catalyst for change and as such, it has potential to be transformational. Likewise, support is found in Balk's (1999) assertions that the ongoing attachment or relationship to the deceased may be a mechanism for spirituality in bereaved adolescents that leads to a search for meaning and the outcome of gaining new perspective. For example, adolescents who have experienced bereavement are emotionally more mature than their non-bereaved adolescent peers and thus are able to offer empathy and endure another person's sorrow and emotional distress (Balk, 1996). This scenario was noted in the data from this study when a participant discovered that her friend's cousin, someone she had never met, had lost a baby and she immediately felt as though she had to reach out to the cousin to offer her words of comfort.

“Like his cousin just lost a baby and like that really, really bothered me...and my heart hurt. I'm not sure how far along she was. So whenever he told me that I just wanted to call her on the phone and I don't even talk to her and ask her like how she's doing right now. You know my heart just dropped.”

Findings in Relation to Symbolic Interactionism

In brief, symbolic interactionism posits that 1) people act toward things and people according to the meaning that things and people hold for them, 2) meaning is

derived from social interaction, and 3) people modify the meanings of things through an interpretative process as they respond to things that are encountered in the human experience (Benzies & Allen, 2001).

Through the lens of symbolic interactionism, the meaning of the pregnancy for participants in this study was determined in interaction between the participants and those with whom they shared the news of their pregnancy: their partner, their friends, and their family. As the young women told others about their pregnancy, the interaction and reception of the news gave meaning as to how the pregnancy was viewed. Participants wanted the approval of family and friends and for most, their initial fear in telling the news resolved as they came to accept the pregnancy through the process of interaction. Likewise, the process of attachment can be understood through the tenets of symbolic interactionism as participants again modified the meaning of the pregnancy through things they encountered, such as ultrasound and feeling the baby move.

Within the framework of symbolic interactionism, meaning is also ascribed in accordance with societal norms, thus the cultural norms of Black adolescents also serve to inform the experience. For example, most of the participants reported that their girlfriends already had children, therefore, there was no stigma attached to the pregnancy from their friends. This acceptance of childbirth outside of marriage is confirmed in the literature. According to Smith and Zabin (1993), non-marital birth is more normative among Black adolescents than Whites, thus there are fewer negative consequences attached to childbirth out of wedlock. In lower socioeconomic backgrounds, adolescents are often immersed in a community where childbearing and single parenthood is the expected cultural norm (Gordon, 1996). In a study comparing the marital and birth

expectations between White and Black high school students, researchers concluded that adolescents gauge their perceptions of premarital conception on the experiences and perceptions of their own community of significant others such as mothers, sisters, aunts and friends (Smith & Zabin, 1993). Researchers discovered a Black-White discrepancy between the expected age for birth and marriage, where the expected age for childbirth in Blacks was lower than the expected age for marriage.

After the loss, the participants sought the support of their friends but reported that their girlfriends were “not there” for them. The reason for this lack of support from their peer group may be assumed to be that the girlfriends did not know how to interact with someone of their own age who had experienced the death of a baby. Moreover, it may have been that the notion of losing a child was painful because they were all young mothers themselves. These assumptions were not explored in this research study.

The meaning of prior loss experience is also understood through the lens of symbolic interactionism. Several of the participants in this study experienced prior losses of friends, family members or even a prior perinatal loss. Having prior loss experiences informed their experience of loss across the continuum of the perinatal bereavement experience as they drew on former experience, conversations, and interpretations to make decisions about their own rituals. For example, prior loss of a family member impacted decisions about cremation versus burial based upon the meaning that these choices represented for the participants. The decision of disposition of the baby’s body had to be made prior to the mother’s discharge. The following quotes illustrate the purposeful reflection and thought that went into this very emotionally charged decision.

“I mean it’s hard to know that you lost, but it’s different from like losing a family member, cause you lost something that you created. You lost something that someone that you loved created. So it hurts a little more to me than losing anyone else.”

“Even though she’s not here she’s already passed, but I just didn’t want her to be burned at all. Most people will say well I’ll do cremation so I can keep her ashes in an urn, but I still didn’t want that. I didn’t have a service because honestly it was just too much for me. I just had a funeral for my grandfather and having another service for my child, I don’t know if anyone would think oh you shouldn’t feel that way, that’s your daughter, but I think it would have been too much for me. I don’t think I could have handled it.”

“Well I knew I didn’t want a burial because me just burying my dad a couple months ago. I don’t think I would have been able to see that or handle it. I didn’t want her cremated either you know. It’s hard enough to make that decision but me and (boyfriend) both come to terms like you know maybe it’s better to have her cremated and have her here with us.”

Symbolic interactionism also informs the interpretation of how the participants ascribed meaning to the loss of their babies based upon what the pregnancy and the dream of motherhood had become for them. For instance, one of the participants had an early loss that was diagnosed as a blighted ovum which had never progressed to development. Nonetheless, this participant reported that the pregnancy had been meaningful to her and when she miscarried, she felt as though she had lost her baby. Her actions to maintain relationship and to gain new perspective are in concert with her perception that the pregnancy, although brief, was real and meaningful. In interaction

with others and through personal reflection, participants were able to find meaning in the experience of loss and to put it into the context of their lives and their future.

Implications of the Research

The implications of this research are many. First of all, this study represents a unique approach to the study of perinatal bereavement in non-Hispanic Black adolescents. No published studies were found in the scientific literature to describe the experience of perinatal loss and bereavement from the perspective of Black adolescents. Thus, the findings of this study will inform practice for nurses and other disciplines concerned with providing evidence-based care for bereaved mothers. Moreover, the study findings will add to the extant literature on bereavement theory and the perinatal loss and bereavement literature. Importantly, this study gives voice to young Black women who have previously not been adequately represented in the perinatal bereavement science.

The contribution of the grounded theory “Enduring to gain new perspective” provides insight and rich description about the experience of perinatal loss and bereavement in Black adolescents. It also confirms that the perinatal loss and bereavement experience of Black adolescents has many theoretical parallels to the bereavement experience for others and yet the manifestations of the theoretical concepts are in many ways different. Thus, the major implication for this study is not so much *what* was found, but *that* is was there to find.

The findings from this research also provide salient advice for practice disciplines such as nursing, social work, and medicine, and are discussed here along with

recommendations for practice. The theoretical categories provide a framework from which to consider the interventions, beginning with living through the loss event.

Suggested Interventions: Living Through the Loss Event

Careful and compassionate disclosure of bad news and a thorough explanation of what is happening in terms that the adolescent can understand are very important as the loss event unfolds. Women remember the details of the loss event; therefore, what is said to them and how it is presented will linger in their memory of the experience. The presence of a nurse, social worker, or perinatal bereavement counselor during the delivery of bad news to assure that young women get clear and thorough information about what is happening is essential to help them through this frightening time. Attention to pain control and allowing them to have family members and the father of the baby present as desired are also important considerations.

Likewise, nurses can give anticipatory guidance about the emotional and physical responses that can be expected after a loss and offer assurance that emotional responses, such as crying, sadness, jealousy, and anger are normal. Education about how to deal with lactation, fatigue, and the roller coaster of emotions in the post-partum period is critical. Providing written information with details about physical care and bereavement literature will also help the adolescents after discharge. Follow up appointments for post partum care and contraceptive counseling should also be provided.

Suggested Interventions: Seeking and Receiving Support

The decision about disposition of the baby's body is an important and irrevocable decision that must be made in the immediate aftermath of the loss. Nurses can view this decision-making as an opportunity for intervention and help the patient make a wise

choice for autopsy and burial or cremation in light of the knowledge that maintaining relationship is part of the bereavement experience. Within the African American family, older women, especially grandmothers have great influence in these types of decisions and thus adolescents may wish to consult with a mother or grandmother before making the decision (Chichester, 2007). Cultural considerations about such rituals as baptism should also be addressed and facilitated (Kobler, Limbo, & Kavanaugh, 2007).

Prior to discharge from the hospital, nurses can assess the mother's support systems in advance to determine the type of support desired, quality of family relationships, and availability of support. If possible, nurses can guide the family on how to support the bereaved mother with compassion and care. Additionally, suggesting that the mother reach out to a friend or relative who has also experienced a perinatal loss may prove helpful and offer encouragement during her bereavement. Adolescents should be given anticipatory guidance about the gender differences in grieving a loss in order to better understand their partners' responses.

Some participants reported that blogging and journaling were helpful to them, thus mothers can be encouraged to try these as additional support strategies. Follow up phone calls made by the perinatal bereavement counselor are a way to show care and compassion and were valued by the participants in this study as well as supported in the bereavement literature as a sound intervention (Johnson & Langford, 2010). Most importantly, a nonjudgmental attitude and receptive posture should be conveyed in all interactions with all adolescents who have experienced perinatal loss.

Suggested Interventions: Maintaining Relationship

Memory boxes were an important part of maintaining relationship with the baby and preserving the baby's memory, thus this intervention is well-timed to also coincide with the transition of hospital discharge. Memory boxes are a widely used and welcomed bereavement support tool which typically contain the baby's footprints when available, a hat or other clothing items, a name band or crib card, a lock of hair if available, a birth certificate, and a blanket (Bartellas & Van Aerde, 2003; Capitolo, 2005; Kavanaugh & Moro, 2006).

Offering photographs of the baby is another way to preserve the memory and help the mother maintain relationship. Two of the hospitals in this study provided professional photography for parents of deceased infants at no charge to the family. The photographs were staged in such a way as to preserve the dignity of the baby and the mother, and often included photos of grandmothers as well. One of the photographers transferred the photos onto a DVD set to music, which was greatly appreciated by the mothers. Perinatal bereavement literature supports the use of photographs as means to facilitate meaning and preserve the memory of the baby (Alexander, 2001; Capitolo, 2005; Kavanaugh & Moro, 2006). Even when parents choose not to accept the photographs, hospitals are advised to keep the photos in the event they eventually change their minds.

Suggested Interventions: Searching for Meaning

During their search for meaning in the loss and bereavement experience, adolescents often asked "why?" Some of them were searching for a medical reason to relieve the guilt they felt about the loss being their fault, while others were simply

questioning the fairness of their fate. However, only two of the participants in this study requested an autopsy in search of a medical reason for their loss. The literature does suggest that results of an autopsy may be helpful in determining the cause of perinatal loss, as well as to plan a future course of treatment for subsequent pregnancies (Chichester, 2007). Autopsy results should be offered by the physician in terms the mother can understand (Badenhorst & Hughes, 2007).

Assessing bereaved adolescents for prior losses of any type, perinatal loss or loss of family members and friends, provides insight into their experience in dealing with loss and may provide an opening to begin a conversation about what the baby's death means to them in light of their other losses. Swanson (1999) suggested that a woman's feelings about perinatal loss can only be understood in the context of what the pregnancy meant to her. Importantly, this research confirms that it is vital to assess what being pregnant and experiencing the loss meant to the mother in order to understand the loss in context.

Suggested Interventions: Gaining New Perspective

Checking in with the mothers over the course of the experience through follow up phone calls allows nurses to provide encouragement and support for the adolescents to pursue their dreams and goals. Shortened hospital stays do not allow for an adequate window of time to address the changes in perspective over time and thus these discussions are most likely to be helpful several weeks after the loss. Asking adolescents to describe what the experience of perinatal loss has meant to them may spark personal reflection that will move them forward toward gaining new perspective. Older adolescents possess the cognitive ability to consider the events of their experience and

place them into the context of their life in order to appreciate how the experience has changed them.

Strengths of the Research Study

One of the major strengths of this study is that it reveals an interpretation of the phenomenon of perinatal loss and bereavement in non-Hispanic Black adolescents which has not yet been described in the scientific literature. The prospective design to follow participants from a point close to the time of loss through the first 12 weeks of their bereavement experience is also a noted strength. The intentional pursuit to capture the experience of bereavement over time and as it progresses strengthens the researcher's conclusions that conceptualize the theory of enduring to gain new perspective over an axis of time. As noted previously, prior perinatal loss and bereavement research has been fraught with inconsistencies in the time period between the loss event and the data collection, making the ability to draw conclusions about the experience somewhat challenging (Flenady & Wilson, 2008).

The rigor of the study design, much of which was set and planned in advance of the study, also contributes to the strength. For example, the audit trail, memos, cleaned and verified transcripts, member checking and expert panel review of findings are all considered strengths. The participants for this study were somewhat homogeneous in that they were all in the period of late adolescence and all but one had experienced a second trimester loss.

Limitations of the Research Study

Each of the hospitals approached for recruitment for this study offer a perinatal bereavement support program whereby the bereaved mother receives a standard of

bereavement care that includes a memory box, photographs of the baby, and follow-up phone calls by a trained perinatal bereavement counselor. Although the details and mechanisms of the bereavement programs differed across sites, each contained similar elements consistent with the current standard of bereavement support. Thus, all of the participants in this study received a certain level of perinatal bereavement support in the hospital and after discharge. This may have been a limitation because it did not allow for comparison of the experience of young women who did not receive hospital-based perinatal bereavement support. Moreover, each participant shared that her pregnancy was unplanned, thus the sample did not include any perinatal losses of planned pregnancies. Although each participant accepted the pregnancy and attached with her unborn baby, it is unknown how the notion of the unplanned pregnancy may have impacted the findings and the experience of loss and perinatal bereavement.

Another limitation to this study is the possibility that the participants may not have been truthful about their experience with the researcher; however, it is the researcher's judgment that each participant was very open and candid about their experiences. Attempts to build trust between the participant and the researcher were built into the study.

Thirdly, the researcher relied on referrals from the perinatal bereavement nurse coordinators to identify potential participants. The work schedules of the perinatal bereavement nurse coordinators and the referral process in each hospital may have hindered a more immediate recognition of those patients who fit the study criteria causing a delay in the desired timing of the first interview. All of the perinatal bereavement coordinators had other job responsibilities and spent a limited number of hours each week

on bereavement follow-up. The PI sent email queries to each of the perinatal bereavement nurse coordinators every two weeks to canvas for potential participants in an attempt to stay in close contact and keep the study moving forward.

Some practical challenges of this research centered on the reliability of the participants' cell phones. Calls were dropped, and re-dialed, cell phones were often not charged so there were delays in reaching participants, and at times, participants either changed their number or ran out of available paid minutes. One participant called the researcher to say she had a new phone number, and one participant was lost to follow-up after two interviews because of a changed number.

External threats to validity include that the results will not be generalizable to the entire population of women experiencing perinatal bereavement, however, the intent of the study was to focus on the unique perspectives of non-Hispanic Black adolescents. The disclosive theory that is generated from the data is however, generalizable to other non-Hispanic Black adolescents experiencing similar phenomenon (Morse, 1997).

Recommendations for Future Research

This study represents a beginning understanding of the experience of perinatal loss in Black adolescents and raises several recommendations for future research. The theory, "Enduring to gain new perspective" can be used to generate future research questions such as "How is the degree of attachment related to bereavement?" The concept of attachment and its relationship to the perinatal bereavement experience deserves further exploration in terms of how the degree of attachment and the timing of the loss relate to and impact the bereavement experience. Likewise, exploration of the concept of planned versus unplanned pregnancy and how this variable impacts the

perinatal bereavement experience would inform the theoretical conceptions of bereavement after perinatal loss.

A longer study following the mothers for at least a year would also be helpful to illuminate the outcomes of gaining new perspective through the process of continued bereavement. Additionally, a greater understanding of the father's experiences with perinatal loss is needed in light of the wide range of expressions of emotion and support seen in this study. A qualitative study focusing on the experience of young Black fathers would add great insight to the experience of perinatal bereavement. Many of the young women in this study had very close relationships with either a mother or grandmother as their major support person. According to Roose and Blanford (2011), grandparents are grieving two-fold; first for their grandchild and then for their daughter's loss. Thus, a study with a family focus to include grandparents and their reactions to losing a grandchild through perinatal loss may be helpful in identifying support strategies for both the mothers and the grandmothers.

Much more work can be done to study the cultural impact of bereavement both in adolescents and adult Black women. Comparisons of the perinatal loss and bereavement experience across racial and ethnic groups would be helpful to better understand the cultural nuances of the bereavement experience, in particular for nurses working in urban settings with diverse patient populations. As diagnostic technology continues to provide earlier detection of lethal fetal anomalies, the emerging science of perinatal palliative care is a growing area for nursing research. Much still needs to be discovered about the bereavement experience and how it is impacted by the delivery of perinatal palliative care.

Bereavement science continues to grow and is ripe for research across disciplines. Interdisciplinary research with colleagues from psychology, social work, and medicine has great potential for strengthening the level of collaborative care to bereaved families. Finally, much work is needed to develop and test the effectiveness of bereavement support interventions across a variety of types of losses, age ranges, socioeconomic groups, and cultures. Thus, the theory can also be used to develop hypotheses to test the effectiveness of interventions for bereavement support in adolescents who experience perinatal loss.

Conclusions

Perinatal loss and the bereavement experience that follows are important and often transforming life events in the lives of Black adolescents, thus the phenomenon is worthy of attention both in practice and in research. Noted thanatologist David Balk (1996) asserts that when bereavement is anticipated, outcomes from the crisis of loss are better than when bereavement is unexpected. Pregnancy loss is most often a sudden loss and as in the case of the young women in this study, it was an unexpected crisis. The purpose of this study was to gain a better understanding of the experience of perinatal loss and bereavement in Black adolescents through qualitative inquiry using grounded theory methods and to produce a disclosive theory of perinatal bereavement. The outcome of this research is a grounded theory, “Enduring to gain new perspective” which discloses the main theoretical concepts of the experience, grounded in the data from the thick, rich descriptions of the participants in this study. The theoretical concepts of the theory correspond in many ways to what other perinatal bereavement researchers have found, yet the manifestations of the experience within the non-Hispanic Black

adolescents in this study were different, mostly attributed to age and culture. This study offers new knowledge and suggestions for interventions that add to the perinatal bereavement science to address a gap in the literature.

Prior studies of perinatal loss and bereavement have largely focused on the experience of loss in married White women to the exclusion of the racial and ethnic group that experiences the highest rates of perinatal loss: non-Hispanic Black women. Moreover, most of the perinatal research has been conducted from a quantitative paradigmatic perspective, asserting that the experience of perinatal bereavement is something that can be measured. As qualitative research has gained more credibility within the scientific community, a more interpretive paradigmatic stance has been used to approach the study of perinatal bereavement. This study has been an attempt to contribute to the need for qualitative research that will help to close the knowledge gap. In order to continue to build knowledge, researchers must attend to the tasks that build trust between them and adolescent research participants such as assessing developmental level, acceptance, attentive listening, and letting them know they are valued (Mack, Giarelli, & Bernhardt, 2009). Likewise, conveying mutuality and a sincere desire to improve the well-being of African Americans is essential for successful recruitment and retention of Black research participants (Earl & Penney, 2001). This research study was successful in part because of trust building strategies, attentive listening, and sincerity of the researcher which in turn fostered trust and openness between the participants and the researcher.

In summary, perinatal bereavement is an interpretive process that is lived out in relation to the meaning that the adolescents ascribe to their pregnancy and their dreams of

motherhood. Young Black women in late adolescence attribute meaning to the experience of perinatal loss and bereavement in interaction with partners, family and friends, taking cues from their cultural norms and inherent value systems. Over time, as they endured the loss, through seeking and receiving support, maintaining relationship with their baby, and searching for meaning, these adolescents gained new perspective on what matters in life, how they have changed from the experience and how the experience will shape their future. In the poignant and profound words of one participant, *“It taught me life.”*

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APPENDIX A

Standard Script for Perinatal Bereavement Counselor to use with Potential Subjects

I am asking your permission for Kim Fenstermacher, RN to call you or stop by your room to see if you are interested in a research study she is doing. Kim Fenstermacher does not work at this hospital. She is a nurse from the Penn State University. Kim has worked in a neonatal intensive care unit for many years and cared for many parents. She has learned that the loss of a baby is very difficult and young women need special care to feel better after this kind of a loss. Kim would like to talk to you in an interview at three different times over the next three months. She wants to find out from you how nurses and doctors can be more helpful to young women like yourself when you are dealing with the loss of a baby.

It will be up to you to decide if you want to participate and how much you want to tell her. You do not have to participate. Your care with this hospital will not be affected.

She would like to call you or stop by your room to tell you more about this research study and see if this is something you would like to do. This letter (*hand the patient a copy of the recruitment letter*) tells a little more about the study. We can read over it together and if you are interested in being a part of the research, Kim will contact you. She will only contact you if you say it is ok.

Thank you for letting me tell you about this research study.

APPENDIX B

Sample recruitment letter

Hello,

I am writing to you to let you know about a research study I am doing. First I want to tell you that I am so sorry for the loss of your baby. I am sure that this must be a hard time for you.

The most important thing right now is for you to receive the best care possible.

The reason for this letter is to ask you if you would be willing to talk with me about the loss of your baby as part of a research study. I am a student at Penn State School of Nursing and I am interested in how nurses can help teenagers like you to feel better after the loss of a baby. I would like to talk with you about being a part of this research study. The research will involve talking with me three times over the next three months. We can talk either in person or by phone. I will ask you questions about how you are feeling and what kinds of things helped you deal with your loss in a better way. What you have to tell me will help nurses to better understand what you are going through and how other young women can be helped. Everything you say to me will be kept private. The doctors and nurses will never know what you have said. You will decide how much you want to tell me. I expect each interview will last about 45 minutes to an hour.

If you think you might be interested in being a part of this research study, please tell the Perinatal Bereavement Counselor and she will contact me to let me know that it is ok to stop by to see you or to call you. You or your parents can also call me at (717-531-3695). This is my private office number. Or, you may call the School of Nursing to reach me at 717-531-4211. Please leave a message and I will call you back promptly. Again, I thank you for giving me some of your time. I hope for the best for you and your family.

Sincerely,

Kim Fenstermacher, RN

Penn State School of Nursing, 717-531-3695

APPENDIX C**Adult Summary Explanation of Research*****IRB Protocol No.: 33221EP******Date: 04-05-10******ADULT SUMMARY EXPLANATION OF RESEARCH***

Penn State College of Medicine
The Milton S. Hershey Medical Center

Title of Project: Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents

Principal Investigator: Kimberly Fenstermacher, MS, PhD(c) Penn State School of Nursing

Other Investigators: Dr. Judith Hupcey, Advisor; Penn State School of Nursing

You are being invited to volunteer to participate in a research study. Research studies include only people who voluntarily choose to take part. This summary explains information about this research. You may ask questions about anything that is unclear to you.

- The purpose of this research is to learn more about how non-Hispanic Black teenage girls feel after the loss of a baby. A second purpose is to find out what kind of support and help teenagers need after they have lost a baby.
- You are being asked to participate in this research study because your baby died by stillbirth (before the baby was born) or your baby died in the hospital. You will be asked to take part in three interviews with the researcher over a 12-week time frame. The interviews will be done in person or by telephone, whichever is better for you. The researcher will ask you questions about your experience of losing a baby and the kinds of things that either helped you, or did not help you after the baby died. The questions will all be related to your experience and how you are dealing with the loss. Each interview will be recorded on a digital recorder and then typed out for the researcher to read.
- There are no risks in taking part in this research other than those you may have in everyday life. Some of the questions will be about your personal feelings and might cause you to feel sad as you talk about your experience. Everything you tell the researcher will be kept private. Every effort will be made to protect the privacy of your information.
- By taking part in this research study, you might have a better understanding of the meaning of your experience of loss. By sharing your experience with a researcher, you may be helping other teenagers who have the same experience of

losing a baby. This research might provide a better understanding of how to support teenagers after they lose a baby.

- Three interviews are planned at different times over the next 12 weeks. Each interview is expected to last about 45 minutes to an hour. The researcher will try to do the first interview while you are still in the hospital. If this is not possible, the researcher will call you to set up a time for the first interview. The researcher will call you to set up a good time for the second and third interviews. The researcher can do the interviews over the telephone, or meet with you in person at a time and place that works for you.
- Your participation in this research is confidential. The information from your interview will be stored in a locked office at the School of Nursing, on a password protected computer file. The Pennsylvania State University's Office for Research Protections, the Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. When the researcher writes a publication about the results of this research study, there will be no way to link anything that is written to your identity.
- Your interview will have a code assigned to it so that only the researcher knows your name and phone number. This will help to protect your privacy.
- You have the right to ask any questions you may have about this research. If you have questions, complaints or concerns or believe you may have been harmed from participating in this research, you should contact Kimberly Fenstermacher, RN at 717-531-3695. If you have questions regarding your rights as a research participant or concerns regarding your privacy, you may contact the research protection advocate in the Hershey Medical Center Human Subjects Protection Office at 717-531-5687.
- You will receive a ten-dollar gift card or ten dollars cash (your choice) for each interview you complete. There are three interviews planned.
- This research study has received funding from the National Institute of Nursing Research through a grant.

You do not have to participate in this research. Taking part in the research study is voluntary. Your decision to participate or to refuse to participate will not change the quality of care you receive. You may change the decision to participate at any time.

Tell the researcher your decision regarding whether or not you give consent to participate in the research.

APPENDIX D

Parental Summary Explanation of Research

IRB Protocol No.: 33221EP

Date: 04-05-10

SUMMARY EXPLANATION OF RESEARCH

Penn State College of Medicine
The Milton S. Hershey Medical Center

Title of Project: Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents

Principal Investigator: Kimberly Fenstermacher, MS, PhD(c) Penn State School of Nursing

Other Investigators: Dr. Judith Hupcey, Advisor; Penn State School of Nursing

Your daughter is being invited to volunteer to participate in a research study. Research studies include only people who voluntarily choose to take part. This summary explains information about this research. You may ask questions about anything that is unclear to you.

- The purpose of this research is to learn more about how non-Hispanic Black teenage girls feel after the loss of a baby. A second purpose is to find out what kind of support and help teenagers need after they have lost a baby.
- Your daughter is being asked to participate in this research study because her baby died by stillbirth (before the baby was born) or her baby died in the hospital. Your daughter will be asked to take part in three interviews with the researcher over a 12-week time frame. The interviews will be done in person or by telephone, whichever is better for your daughter. The researcher will ask your daughter questions about her experience of losing a baby and the kinds of things that either helped her, or did not help her after the baby died. The questions will all be related to your daughter's experience and how she is dealing with the loss. Each interview will be recorded on a digital recorder and then typed out for the researcher to read.
- There are no risks in taking part in this research other than those she may have in everyday life. Some of the questions will be about her personal feelings and might cause your daughter to feel sad as she talks about her experience. Everything your daughter tells the researcher will be kept private. Every effort will be made to protect the privacy of her information.
- By taking part in this research study, your daughter might have a better understanding of the meaning of her experience of loss. By sharing her experience with a researcher, your daughter may be helping other teenagers who have the same experience of losing a baby. This research might provide a better understanding of how to support teenagers after they lose a baby.
- Three interviews are planned at different times over the next 12 weeks. Each interview is expected to last about 45 minutes to an hour. The researcher will try to do the first interview while your daughter is still in the hospital. If this is not possible, the researcher will call your daughter to set up a time for the first interview. The researcher will call


your daughter to set up a good time for the second and third interviews. The researcher can do the interviews over the telephone, or meet with your daughter in person at a time and place that works for her.

- Your daughter's participation in this research is confidential. The information from your daughter's interview will be stored in a locked office at the School of Nursing, on a password protected computer file. The Pennsylvania State University's Office for Research Protections, the Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. When the researcher writes a publication about the results of this research study, there will be no way to link anything that is written to your daughter's identity.
- Your daughter's interview will have a code assigned to it so that only the researcher knows the name and phone number of your daughter. This will help to protect her privacy.
- You have the right to ask any questions you may have about this research. If you have questions, complaints or concerns or believe your daughter may have been harmed from participating in this research, you should contact Kimberly Fenstermacher, RN at 717-531-3695. If you have questions regarding your rights as a research participant or concerns regarding your daughter's privacy, you may contact the research protection advocate in the Hershey Medical Center Human Subjects Protection Office at 717-531-5687.
- Your daughter will receive a ten-dollar gift card or ten dollars cash (her choice) for each interview she completes. There are three interviews planned.
- This research study has received funding from the National Institute of Nursing Research through a grant.

You do not have to allow your daughter to participate in this research. Taking part in the research study is voluntary. Your decision to allow your daughter to participate or to refuse to allow her to participate will not change the quality of care she receives. You or your daughter may change the decision to participate at any time.

Tell the researcher your decision regarding whether or not to give consent for your daughter to participate in the research.

APPENDIX E
IRB APPROVAL LETTERS

Date: April 23, 2010
To: Kimberly H. Fenstermacher, M.S., Ph.D. (c), Nursing
From: Kevin Gleeson, M.D., Executive Chair 
Institutional Review Board
Subject: IRB Protocol No. 33221EP - Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents

Thank you for your application to the Institutional Review Board (IRB). The above IRB protocol number was assigned for the research and should be included on all future correspondence and documentation. In accordance with Federal guidelines and institutional policy, the proposed research was determined to qualify for expedited review and was reviewed accordingly.

Official approval: Official approval was granted for this research effective April 23, 2010 through March 31, 2011, at which time IRB reconsideration will be required. This approval includes the following:

- Research Protocol - (dated 04/05/2010)
- Total entry - 15 subjects. This research may enroll children. This research may not involve prisoners. If an individual becomes incarcerated after enrollment contact the IRB to address specific regulatory requirements in order to continue participation.
- Waiver of Consent - Waiver of informed consent is granted, in accord with federal regulation 45 CFR Part 46.116(d).; Summary Explanation of Research for Parents (04/05/2010); Summary Explanation of Research for Adults (04/05/2010)
- Authorization to use protected health information (PHI) - Inapplicable, as PHI is not accessed for this research.
- Advertisement – Recruitment Script (received 03/08/2010); Recruitment Letter (received 03/08/2010); Reminder Letter (dated 04/05/2010); • Questionnaires – Interview Guide (received 03/08/2010); Demographic Information (received 03/08/2010)
- IRB member exclusions from this review: No investigators for this research serve on the IRB.

Clinical Trials Registration: Not required

Required Reports and Modification Requests: See instructions on the IRB web site, <http://pennstatehershey.org/web/irb>, under Investigator Resources, to submit reports for this research or requests for modifications.

- **Problem Reporting:** Investigators are required to promptly report any events that may represent unanticipated problems involving risks to subjects or others. See the web for the



IRB policy "Reporting of Unanticipated Problems Involving Risk to Participants or Others" and the applicable report form and tracking log.

- Proposing Changes: Federal regulations require prompt reporting to the IRB of any proposed changes in a research activity and prior approval before changes are initiated, except where necessary to eliminate apparent immediate hazards to the subject. Submit a request for a 'Modification' if changes are needed in the existing investigation.
- Continuing Review: A progress report will be required for reapproval of this research. You will receive an e-mail notice and instructions 8 weeks before the current approval expires.

The Institutional Review Board appreciates your efforts to conduct research in compliance with the institutional policies and federal regulations that have been established to ensure the protection of human subjects. Please feel free to communicate any future questions or concerns regarding this research to the IRB via its administrative arm, the Human Subjects Protection Office.

KG\kl

Date: January 05, 2011
To: Kimberly H. Fenstermacher, M.S., Ph.D. (c)
From: Catherine P. Wickey, R.N., B.S.N. CPW
IRB Coordinator
Human Subjects Protection Office
Subject: IRB Protocol No. 33221EP - Perinatal Loss and Bereavement in Non-Hispanic
Black Adolescents

The Human Subjects Protection Office (HSPO) received your December 14, 2010 correspondence with the accompanying documentation regarding the above investigation.

In accordance with Federal guidelines and institutional policy, this issue qualified for review by a designated Institutional Review Board member.

The revised protocol (dated 12/14/10) received expedited review and approval was granted on January 05, 2011.

The revised protocol summary abstract (dated 01/03/11) was noted and filed.

Thank you very much.

CPW



April 30, 2010

Kimberly Fenstermacher, MS, CRNP, PhD(c)
Principal Investigator



Re: Expedited Review of a New Study

PHH# 10-014 -- Perinatal Bereavement in Non-Hispanic Black Adolescents

Dear Ms. Fenstermacher:

We received your request for an Expedited Review of a New Study.

Reviewed was the protocol, a script for bereavement counselors (Appendix A), a sample recruitment letter (Appendix B), a summary explanation of research for verbal consent (one parental; one for subjects > 18 years of age) and the Penn State Hershey IRB approval dated 04/23/2010. The purpose of the research is to generate a disclosive theory of perinatal bereavement in non-Hispanic black adolescent females and to identify critical transitions in the perinatal bereavement process that may signal the need for well-targeted culturally sensitive bereavement support services. Girls ages 16-18 who have lost babies to stillbirth or in the NICU will be referred to the study by a recruitment letter given to them by their bereavement counselor. Verbal consent will be sought from the subject/subject's parents (for those subjects under age 18) and directly from subjects who are 18 years of age. Subjects may verbally withdraw consent at any time. The study consists of 3 interviews either by phone or in person lasting 45 to 60 minutes each. 15 subjects will be accrued. A \$10.00 gift card or \$10.00 cash will be offered at the completion of each of the three interviews. Personally identifiable information will be removed from the data when used for analysis. The study will be conducted at Harrisburg Hospital (Pinnacle Health Systems), Penn State Hershey Medical Center and Lancaster General Women's and Babies Hospital.

This request was reviewed by the Chairman, David Scher, MD.

This qualifies for expedited review as per 45 CFR 46.110, 21 CFR 56.110 and Policy IRB# 07. Approval has been granted. This action will be reported to the Institutional Review Board at the next scheduled meeting.

Thank you for your continued cooperation. If we can be of any assistance to you, please call our Board at (717) 782-6444. Any requested follow-up should be addressed to our Board and forwarded to Nancy Cribari, IRB Coordinator, PinnacleHealth at Polyclinic Hospital, 709 Landis Building, 2501 North Third Street, Harrisburg PA 17110.

Sincerely yours,



David L. Scher, MD
Chairman, Institutional Review Board

DLS:nlc



PINNACLEHEALTH

December 23, 2010

Kimberly Fenstermacher, MS, CRNP, PhD(c)
Principal Investigator

Re: Expedited Review of an Approved Study – Revised Protocol/Consent

PHH# 10-014 -- Perinatal Bereavement in Non-Hispanic Black Adolescents

Dear Ms. Fenstermacher:

We received your request for an Expedited Review of an Approved Study – Revised Protocol/Consent.

Reviewed was a request to change the inclusion criteria from "experienced a perinatal loss via stillbirth at 20 weeks or greater" to "16 weeks or greater". The rationale for this is that for losses at 16 weeks or greater, the state of PA requires a birth or death certificate to be filed and a decision to be made by the parents regarding the disposition of the baby. The change is necessary to increase potential recruitment.

This request was reviewed by the Chairman, David Scher, MD.

This qualifies for expedited review as per 45 CFR 46.110, 21 CFR 56.110 and Policy IRB# 07. Approval has been granted. This action will be reported to the Institutional Review Board at the next scheduled meeting.

Thank you for your continued cooperation. If we can be of any assistance to you, please call our Board at (717) 782-6444. Any requested follow-up should be addressed to our Board and forwarded to Nancy Fisher, IRB Coordinator, PinnacleHealth at Polyclinic Hospital, 709 Landis Building, 2501 North Third Street, Harrisburg PA 17110.

Sincerely yours,

David L. Scher, MD
Chairman, Institutional Review Board

DLS:nf



PINNACLEHEALTH

March 22, 2011

Kimberly Fenstermacher, RN
Principal Investigator

Re: Expedited Review of an Approved Study – Revised Protocol/Consent

PHH# 10-014 -- Perinatal Bereavement In Non-Hispanic Black Adolescents

Dear Ms. Fenstermacher:

We received your request for an Expedited Review of an Approved Study – Revised Protocol/Consent.

Reviewed was the Summary of Changes, Adult Summary Explanation of Research, Summary Explanation of Research, Protocol Summary and the Pinnacle Health Research Proposal. The inclusion criteria has been broadened to 16 to 25 years of age; inclusion is now all perinatal losses. Three additional recruitment sites have been added: York Hospital, University of Maryland Medical Center/Baltimore and Mercy Medical Center/Baltimore. Title will be changed to reflect "And Young Women". Reference to funding in the assent document is clarified.

This qualifies for expedited review as per 45 CFR 46.110, 21 CFR 56.110 and Policy IRB# 07. Approval has been granted. This action will be reported to the Institutional Review Board at the next scheduled meeting.

Thank you for your continued cooperation. If we can be of any assistance to you, please call our Board at (717) 782-6444. Any requested follow-up should be addressed to our Board and forwarded to Nancy Fisher, IRB Coordinator, PinnacleHealth at Polyclinic Hospital, 709 Landis Building, 2501 North Third Street, Harrisburg PA 17110.

Sincerely yours,

David L. Scher, MD
Chairman, Institutional Review Board

DLS:nf

University of Pennsylvania
Office of Regulatory Affairs
Yvonne Higgins, Executive Director Human Research Protections
Emma Meagher, MD, IRB Executive Chair
3624 Market St., Suite 301 S
Philadelphia, PA 19104-6006
Ph: 215-573-2540/ Fax: 215-573-9438
INSTITUTIONAL REVIEW BOARD
(Federalwide Assurance # 00004028)

14-Jul-2010

Cathyann Schantz
Hospital of the Univ of Penn
Nursing Administration
Email: cathy.schantz@uphs.upenn.edu
kxf131@psu.edu

PRINCIPAL INVESTIGATOR : CATHYANN SCHANTZ
TITLE : Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents
[Kimberly Fenstermacher, PhD Candidate - Penn State Univ.]
SPONSORING AGENCY : NATIONAL INSTITUTES OF HEALTH
PROTOCOL # : 812037
REVIEW BOARD : IRB #4

Dear Cathyann Schantz:

The above referenced protocol was reviewed and approved by the Executive Chair (or her authorized designee) using the expedited procedure set forth in 45 CFR 46.110, category 6,7, on 14-Jul-2010. This study will be due for continuing review on or before 13-Jul-2011.

Approval by the IRB does not necessarily constitute authorization to initiate the conduct of a human subject research study. Principal investigators are responsible for assuring final approval from other applicable school, department, center or institute review committee(s) or boards has been obtained. This includes, but is not limited to, the University of Pennsylvania Cancer Center Clinical Trials Scientific Review and Monitoring Committee (CTSRMC), Clinical and Translational Research Center (CTRC) review committee, CAMRIS committee, Institutional Bio-safety Committee (IBC), Environmental Health and Radiation Safety Committee (EHRS), and Standing Conflict of Interest (COI) Committee. Principal investigators are also responsible for assuring final approval has been obtained from the FDA as applicable, and a valid contract has been signed between the sponsor and the Trustees of the University of Pennsylvania. If any of these committees require changes to the IRB-approved protocol and informed consent/assent document(s), the changes must be submitted to and approved by the IRB prior to beginning the research study.

If this protocol involves cancer research with human subjects, biospecimens, or data, you may not begin the research until you have obtained approval or proof of exemption from the Cancer Center's Clinical Trials Review and Monitoring Committee.

An expedited review procedure was used for the HIPAA authorization waiver because the research involves no more than minimal risk to the privacy of the individuals who are the subject of the protected health information for which use or disclosure is being sought.

Documents submitted for review:

- Informed Consent and HIPAA Authorization Form (Parental Consent), Submitted 7/6/10
- Informed Consent and HIPAA Authorization Form (Adult Summary of Explanation of Research), Submitted 7/6/10
- Cover Letter, Dated 7/6/10
- Social and Behavioral Sciences Application for Review of Human Research, Signed 7/1/10
- IRB Protocol Summary Social/Behavioral, Submitted 7/6/10
- IRB Required Documents List, Submitted 7/14/10
- CITI Training (Kimberly Fenstermacher), Dated 12/1/09
- CITI Training (Judith Hupcey), Dated 2/10/09
- CITI Training (Lori Lobb), Dated 4/16/10

- Vulnerable Populations: Children, Submitted 7/6/10
- IRB Request for Waiver of HIPAA Authorization, Submitted 7/6/10
- Demographic Information Sheet, Submitted 7/6/10
- Interview Guide, Submitted 7/6/10
- Appendix A Script, Submitted 7/6/10
- Appendix B Sample Recruitment Letter, Submitted 7/6/10
- Penn State IRB Approval Letter (Protocol #33221EP), Dated 4/23/10
- Penn State IRB Approval Letter (Revised Protocol #33221EP), Dated 6/30/10
- Grant Application, Submitted 7/6/10
- Email Correspondence (Concerns to Protocol), Dated 7/9/10 to 7/13/10

The IRB reviewed and approved a waiver of written documentation of consent as per HHS 45 CFR 46.117(c)(1): That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern.

The IRB reviewed and approved the Subpart D review as per Federal Regulations 45 CFR 46.404 (FDA 50.51), as the research was determined to be no greater than minimal risk. The IRB determined that permission of one parent is sufficient and that adequate provisions are made for soliciting permission. The IRB has determined that assent must be obtained from subjects, but documentation of assent is not required.

The review of the research has determined the following:

- An adequate plan has been presented to protect the identifiers from improper use and disclosure;
- An adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research exists, unless there is a health or research justification for retaining the identifiers, or such retention is otherwise required by law; and,
- An adequate written assurance has been provided that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of protected health information would be permitted under the law.
- That the research cannot practicably be conducted without the waiver to access and use of the protected health information.

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website: <http://www.upenn.edu/regulatoryaffairs>.

Thank you for your cooperation.

Sincerely,

**Kyle
Stephens**

IRB Administrator

Digitally signed by Kyle Stephens
DN: cn=Kyle Stephens, o, ou=IRB,
email=kstep@upenn.edu, c=US
Reason: I attest to the accuracy
and integrity of this document
Date: 2010.07.16 11:26:23 -04'00'

University of Pennsylvania
Office of Regulatory Affairs
Yvonne Higgins, Executive Director Human Research Protections
Emma Meagher, MD, IRB Executive Chair
3624 Market St., Suite 301 S
Philadelphia, PA 19104-6006
Ph: 215-573-2540/ Fax: 215-573-9438
INSTITUTIONAL REVIEW BOARD
(Federalwide Assurance # 00004028)

27-Sep-2010

Cathyann Schantz
Hospital Of The Univ Of Penn
Nursing Administration
Email: Cathy.Schantz@Uphs.Upenn.Edu
Kxf131@Psu.Edu

PRINCIPAL INVESTIGATOR : CATHYANN SCHANTZ
TITLE : Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents [Kimberly Fenstermacher, PhD Candidate - Penn State Univ.]
SPONSORING AGENCY : NATIONAL INSTITUTES OF HEALTH
PROTOCOL # : 812037
REVIEW BOARD : IRB #4

Dear Cathyann Schantz:

The documents noted below, for the above-referenced protocol, were reviewed by Dr. Emma Meagher, Executive Chair of the IRB (or her authorized designee) using the expedited procedure set forth in 45 CFR 46.110 and approved on 27-Sep-2010.

- IRB Modification Form, Signed 9/16/10
- Summary of Modifications, Submitted 9/27/10
- IRB Protocol Summary Social/Behavioral, Submitted 9/27/10

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website: <http://www.upenn.edu/regulatoryaffairs>.

Thank you for your cooperation.

Sincerely,

IRB Administrator

University of Pennsylvania
Office of Regulatory Affairs
Yvonne Higgins, Executive Director Human Research Protections
Emma Meagher, MD, IRB Executive Chair
3624 Market St., Suite 301 S
Philadelphia, PA 19104-6006
Ph: 215-573-2540/ Fax: 215-573-9438
INSTITUTIONAL REVIEW BOARD
(Federalwide Assurance # 00004028)

03-Jan-2011

Cathyann Schantz
Attn: Kimberly Fenstermacher
Email: kxf131@psu.edu
Cathy.schantz@uphs.upenn.edu

PRINCIPAL INVESTIGATOR : Cathyann Schantz
TITLE : Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents
[Kimberly Fenstermacher, PhD Candidate - Penn State Univ.]
SPONSORING AGENCY : NATIONAL INSTITUTES OF HEALTH
PROTOCOL # : 812037
REVIEW BOARD : IRB #4

Dear Cathyann Schantz:

The documents noted below, for the above-referenced protocol, were reviewed by Dr. Emma Meagher, Executive Chair of the IRB (or her authorized designee) using the expedited procedure set forth in 45 CFR 46.110 and approved on 23-Dec-2010.

-IRB Modification Form, signed by PI 12.14.10
-Summary of Modification, received 12.20.10
-IRB Protocol Summary, received 12.20.10

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website: <http://www.upenn.edu/regulatoryaffairs>.

Thank you for your cooperation.

Sincerely,

IRB Administrator

April 20, 2011

Kim Fenstermacher, MS, CRNP, PhD(c)
Penn State School of Nursing
1300 ASB/A110
600 Centerview Drive
Hershey, PA 17033

Re: MMC 2011-55 Perinatal Bereavement in Non-Hispanic Black
Adolescents

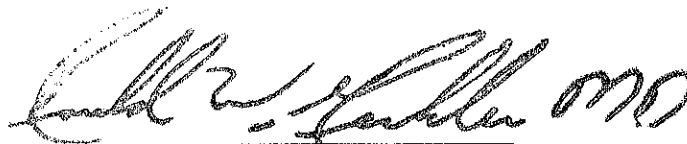
Dear Ms. Fenstermacher:

At the April 5, 2011 Mercy Medical Center IRB meeting the committee reviewed and approved the above captioned study with a few minor changes to the script to be used with potential participants. The revised script was given final approval on April 20, 2011. You are free to move forward with your project.

Please bear in mind that federal regulations require the IRB to conduct substantive and meaningful continuing review of this study. The IRB has determined that this study will be subject to continuing review every 12 months and the first review must occur on or before **April 20, 2012**. **Please adhere to the Investigator Responsibilities outlined below.**

Thank you for your interest in research at Mercy Medical Center and please use the MMC IRB number 2011-55 on any and all future correspondence.

Sincerely,

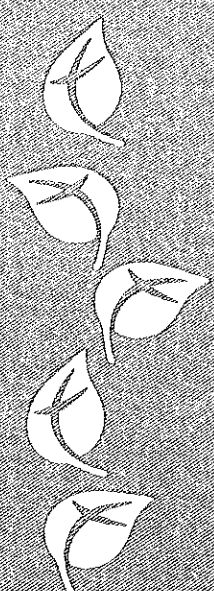


Ronald W. Geckler, M.D.
Chairman
Mercy Medical Center IRB

RWG/elw

INVESTIGATOR RESPONSIBILITIES

- Conducting the research according to the IRB approved protocol
- Ensuring that each potential subjects understands the nature of the research and of the subject's participation



- Providing a copy of the IRB –approved informed consent document to each subject at the time of consent unless the IRB has specifically granted a waiver or alteration of the informed consent requirements.
- Providing only stamped IRB-approved documents to the research subjects, e.g., questionnaires, survey instruments, etc.
- Promptly reporting proposed changes in previously approved human subject research activities prior to initiation of the changes of the changes, except where necessary to eliminate apparently immediate hazards to the subjects.
- Submitting continuing reviews in the manner prescribed by the IRB
- Promptly reporting to the IRB any unanticipated problems involving risks to the subject or others.
- Promptly reporting to the IRB any new information that changes the risk benefit ratio or that could affect the subject's willingness to continue participation.



University of Maryland, Baltimore
Institutional Review Board (IRB)
Phone: (410) 706-5037
Fax: (410) 706-4189
Email: hrpo@som.umaryland.edu

New Study Approval Notification

Date: March 1, 2011

To: Debra Wiegand
From: Stephen Seliger
RE: HP-00048646
Risk designation: Minimal Risk
Submission Date: 2/9/2011
Original Version #: N/A

Approval for this project is valid from 3/1/2011 to 2/29/2012

This is to certify that the University of Maryland, Baltimore (UMB) Institutional Review Board (IRB) has fully approved the above referenced protocol entitled, "*Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents*".

The IRB has determined that this protocol qualifies for expedited review pursuant to Federal regulations 45 CFR 46.110, 21 CFR 56.110, & 38 CFR 16.110 category(ies).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

Please be aware that only valid IRB-approved informed consent forms may be used when written informed consent is required.

Below is a list of the documents attached to your application that also have been approved:

Eligibility Checklist for HP-00048646 v2-1-2011-1296588803962

Award

Table

Training goals

Sponsor bio

Applicant

Training

Co-sponsor

Sponsor

Research

Inclusion

Enrollment
Reference List
Interview Guide
IRB approval Pinnacle Health System
Appendix B Recruitment letter
Appendix A Script
Researcher CV K Fenstermacher
Parent Summary Explanation of Research
IRB approval WellSpan York Hospital
IRB approval Hospital of the University of Pennsylvania
Protocol Perinatal Bereavement
Adult Summary Explanation of Research
IRB approval Hershey Medical Center

Investigators are reminded that the IRB must be notified of any changes in the study. In addition, the PI is responsible for ensuring prompt reporting to the IRB of proposed changes in a research activity, and for ensuring that such changes in approved research, during the period for which IRB approval has already been given, may not be initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject (45 CFR 46.103(4)(iii)).

DHHS regulations at 45 CFR 46.109 (e) require that **continuing review** of research be conducted by the IRB at intervals appropriate to the degree of risk and **not less than once per year**. The regulations make **no provision for any grace period extending the conduct of the research beyond the expiration date of IRB approval**. You will receive continuing review email reminder notices prior to study expiration; however, it is your responsibility to submit your continuing review report in a timely manner to allow adequate time for substantive and meaningful IRB review and assure that this study is not conducted beyond the expiration date. Investigators should submit continuing review reports in the electronic system at least six weeks prior to the IRB expiration date.

In addition, you must inform the IRB of any new and significant information that may impact a research participants' safety or willingness to continue in your study and any unanticipated problems involving risks to participants or others.

Research activity involving veterans or the Baltimore VA Maryland Healthcare System (BVAMHCS) as a site, must also be approved by the BVAMHCS Research and Development Committee prior to initiation. Contact the VA Research Office at 410-605-7131 for assistance.

The UMB IRB is organized and operated according to guidelines of the International Council on Harmonization, the United States Office for Human Research Protections and the United States Code of Federal Regulations and operates under Federal Wide Assurance No. FWA00007145.

Institutional Review Board
1001 South George Street
P.O. Box 15198
York, PA 17405-7198
717.851.2223 Tel
717.851.3470 Fax
e-mail: irb@wellspan.org
www.wellspan.org



DATE: December 17, 2010

TO: Barbara Buchko, MS

FROM: WellSpan Health Medical/Surgical IRB

STUDY TITLE: [204884-1] Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents

IRB REFERENCE #:

SUBMISSION TYPE: New Project

ACTION: APPROVED

APPROVAL DATE: December 17, 2010

EXPIRATION DATE: December 17, 2011

REVIEW TYPE: EXPEDITED

REVIEW CATEGORY: Expedited review category 21 CFR 56.110(6)(7) and 45 CFR 46.110(6)(7)

Thank you for your submission of New Project materials for this research study. WellSpan Health Medical/Surgical IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Documents Approved:

- Protocol labeled, "Fenstermacher Research Proposal IRB Hershey #33221 December 9, 2010"
- Adult Summary Explanation of Research IRB Protocol No. 33221EP Date: 04-05-10
- Summary Explanation of Research IRB Protocol No. 33221EP Date: 04-05-10
- Recruitment Script - Appendix A
- Recruitment Letter - Appendix B

Waivers Granted:

- Informed Consent
- HIPAA

This submission has been reviewed based on the applicable federal regulation.

Investigators must notify the IRB of all Unanticipated Problems, Adverse Events, Deviations, and Violations that occur and when a Modification, Amendment, or Exception to the IRB-approved study is necessary. Deaths related to study procedures must be reported to the IRB within 48 hours of the investigator being notified. The investigator is responsible for following all FDA and sponsor reporting requirements.

Please report all Non-Compliance issues or Complaints regarding this study to the IRB office.

Please note that all research records must be retained for a minimum of three (3) years.

Based on the risks, this project requires annual Continuing Review by the IRB. Please use the appropriate renewal forms for this procedure.

As a courtesy, please inform the participant's primary care physician and attending physician of their patient's enrollment in this study.

If you have any questions, contact the IRB Staff at (717) 851-2223 or irb@wellspan.org. Please include your study title and reference number in all correspondence with this office.

This document has been electronically signed in accordance with all applicable regulations, and a copy is retained within our records.

VITA
Kimberly H. Fenstermacher, PhD, CRNP
kfenster@vcp.edu

EDUCATION:

Boston University; School of Nursing:

1982 Bachelor of Science in Nursing

The Pennsylvania State University; School of Nursing:

2004 Master of Science, Nursing; Neonatal Nurse Practitioner Option

2011 PhD, Nursing

PROFESSIONAL LICENSURE AND CERTIFICATION:

Registered Nurse, Pennsylvania RN255381L; July 1982 to present

Certified Registered Nurse Practitioner, Neonatal SP008656; January 2005 to present

PROFESSIONAL NURSING EXPERIENCE:

York College of Pennsylvania; York, PA

Assistant Professor of Nursing; August, 2011 to present

Pinnacle Health System; Harrisburg, PA

Magnet Project Director, Department of Nursing, 2004-2009

Staff Nurse, Neonatal Intensive Care Unit, 1996-2004

Nurse Manager, Neonatal Intensive Care Unit and Pediatric Unit, 1991-1996

Sinai Hospital of Baltimore; Baltimore, MD

Assistant Head Nurse and Staff Nurse, Neonatal Intensive Care Unit, 1983-1991

AWARDS and HONORS

National Research Service Award Pre-doctoral Fellowship

NIH/NINR **1 F31 NR010816-01A2** "Perinatal Loss and Bereavement in Non-Hispanic Black Adolescents", Funded August 2009 through December 31, 2010

PUBLICATIONS

Hupcey, J. E., Penrod, J., & **Fenstermacher, K.** (2009). A model for palliative care for heart failure. *American Journal of Hospice and Palliative Care Medicine*, 26(5), 399-404, doi: 10.1177/1049909109333935.

Hupcey, J., **Fenstermacher, K.**, Kitko, L. & Penrod, J. (2010). Achieving medical stability: Wives' experiences with heart failure. *Clinical Nursing Research*, 19(3), 211-229. doi: 10.1177/1054773810371119.

Hupcey, J. E., **Fenstermacher, K.**, Kitko, L., & Fogg, J. (2011). Palliative needs of spousal caregivers of patients with heart failure followed at specialized heart failure centers. *Journal of Hospice and Palliative Nursing* 13(3), 142-150.