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A Narrative Analysis of Perinatal Hospice Stories

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A NARRATIVE ANALYSIS
OF
PERINATAL HOSPICE STORIES

by

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ABSTRACT
A NARRATIVE ANALYSIS OF PERINATAL HOSPICE STORIES

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Technology has made it possible to detect abnormal fetal conditions, including lethal anomalies, prior to birth. Women who receive lethal fetal diagnoses during pregnancy face the decision whether to continue or terminate their affected pregnancies. The purpose of this study was to explore and describe women's experiences after the continuation of pregnancies affected by lethal fetal diagnoses and the subsequent loss of their infants.

A qualitative, descriptive methodology was chosen for this exploratory study. Fifteen women participants who learned during their pregnancies of lethal fetal diagnoses and chose to continue their pregnancies were recruited from perinatal hospice (PH) support organizations in three states of the Midwestern USA. Participants' stories of their PH experiences were recorded in individual face-to-face interviews. Narrative analysis techniques were used to identify themes and develop suggestions for care.

The participants identified themselves as mothers and their fetuses or newborns as babies. Mothers valued caring for and interacting with their babies. Health professionals who affirmed their status as mothers, the value of their babies, and the significance of their losses were perceived as supportive. Invalidating attitudes and behaviors caused significant distress.

The element of time was prevalent in mothers' stories. Some aspects of mothers' experiences continued, particularly feelings of love and connection to their babies. Mothers also reported evolving changes in their thoughts and feelings. Personal changes, such as increased compassion, faith, and strength, were frequently mentioned. Mothers described phases of highs and lows. Drawing personal meanings or life-lessons was the main way mothers connected their past experiences to their present lives.

Mothers' descriptions of their experiences enhance nurses' understanding of perinatal loss. Established care practices, such as birth planning and creating mementoes, were supported. Nurses can help mothers experiencing loss by elucidating and reflecting their personal meanings. Optimal care of PH mothers should support the development of maternal identity and contact between mothers and newborns when desired. Professionals who care for PH mothers can affirm their motherhood through their behaviors, statements, and attitudes.

ACKNOWLEDGEMENTS

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I. INTRODUCTION

Birth defects and pregnancy losses have always been part of the human childbearing experience. Ancient Mesopotamian texts, among the earliest known writings, contain references to stillbirth (Black et al., 2006). The earliest written record of birth defects is nearly 4,000 years old and contains a list of 62 congenital malformations along with their purported meanings and events they were thought to predict (The Teratology Society, 2007).

Developments within the past three decades have profoundly changed the kind of experiences women have when their pregnancies are affected by fetal abnormalities and losses. The emergence of technologies such as karyotype analysis, maternal serum screening, and fetal ultrasound have enabled health professionals to identify fetuses with life threatening conditions prior to loss of the pregnancy or birth of the infant. Diagnostic technology has also presented women with the previously unavailable option to terminate pregnancies when abnormal fetal conditions are detected.

During the same three decades, there has been increasing recognition of the psychological and emotional significance of women's experiences related to birth defects and pregnancy losses. Kennel, Slyter, and Klaus' (1970) classic work was the first to document grief responses among parents after perinatal losses. Since then, the health care literature on women's responses to abnormal fetal diagnoses (Howard, 2006; Hunfeld, Wladimiroff, & Passchier, 1997; McCoyd, 2007; Sandelowski & Jones, 1996) and pregnancy losses (Malacrida, 1999; Stirtzinger, Robinson, Stewart, & Ralevski, 1999;

Toedter, Lasker, & Janssen, 2001; Trulsson & Rådestad, 2004) and their experiences of terminating pregnancies with abnormal fetal conditions (White-Van Mourik, Connor, & Ferguson-Smith, 1992; Zeanah, Dailey, Rosenblatt, & Saller, 1993) has reflected an increasing body of professional knowledge. However, one area has remained relatively under-explored: the experiences of women who decide to continue their pregnancies after receiving diagnoses of lethal fetal anomalies. It is this under-explored area with which this dissertation is concerned.

<div style="text-align:center">Lethal Anomalies: Scope of the Problem</div>

Fetal anomalies are fairly common. Each year in the United States, approximately 120,000 infants are born with anomalies, about 8,000 of whom die within the first year of life (Centers for Disease Control and Prevention, 2009). Birth defects are the leading cause of infant mortality in the United States (Centers for Disease Control and Prevention, 2009).

Lethal anomalies are a classification of birth defects characterized by a radically shortened life span. The incidence of lethal anomalies is 0.2-0.3%; approximately 6-10,000 per year in the United States (Centers for Disease Control and Prevention, 1998). The most recent data on perinatal deaths from the Centers for Disease Control and Prevention (CDC) are accessible in an online database (CDC, 2007). At the time of this publication, the most recent data available were for the year 2005. These data reflected 6,925 fetal and infant deaths in the United States attributed to the lethal diagnoses

tracked by the CDC. Since the CDC only tracks a limited number of diagnoses, this figure probably underestimates the true incidence of lethal anomalies.

Fetuses or infants affected by lethal anomalies vary in their duration of survival, both in utero and after birth. In one published series, the range of survival for infants with lethal anomalies was 20 minutes to 256 days after birth (D'Almeida, Hume, Lathrop, Njoku, & Calhoun, 2006). In that series of 20 affected pregnancies, 5 were lost to fetal demise and stillbirth, 12 to neonatal death, and 3 deaths occurred beyond the neonatal period (D'Almeida et al., 2006).

<center>Perinatal Hospice</center>

Technology has made it possible to diagnose birth defects, including lethal anomalies, prior to birth. Parents who receive a prenatal diagnosis of a lethal anomaly are faced with the decision whether to terminate or continue the pregnancy. Reasons to terminate may include a desire to avoid suffering or distressing experiences (Calhoun et al., 2003). Recent trends such as improved sensitivity to the bereaved and increased focus on client choice and involvement in decision-making have resulted in some parents choosing to continue pregnancies affected by lethal anomalies (D'Almeida et al., 2006).

Perinatal hospice (PH) is a care option for mothers and families who choose to continue pregnancies affected by lethal anomalies. In diagnostic centers where PH is offered, up to 75% of couples have chosen this option (D'Almeida et al., 2006). Reasons

for choosing PH may be personal, ethical, or religious, or may simply reflect a desire to make the most of whatever time they have with their children (D'Almeida et al., 2006).

The concept of PH developed from the hospice movement and the recognition that medical science and technology poorly addressed end-of-life issues (Hoeldtke & Calhoun, 2001). The PH model of care is non-interventive, neither hastening nor delaying death of the infant, while providing support for the family's physical, psychosocial, and spiritual needs (Calhoun et al., 2003). The emphasis of PH care is on optimizing the family's experiences during pregnancy, birth, and the newborn period according to the family's needs and preferences (Hoeldtke & Calhoun, 2001).

Need for Perinatal Hospice Research

There is a paucity of research on the experiences and needs of PH mothers and families. The experiences and needs of PH mothers are particularly relevant to the profession of nursing because nurses provide direct bedside care during critical events such as diagnostic procedures, labor and delivery, postpartum, and the newborn period. Nurses probably spend more time in direct contact with PH mothers than any other professional discipline, and have been identified as the central coordinators of PH care in one care program (Leuthner & Jones, 2007).

Effective care for PH mothers and families requires an educated, informed approach from all professionals who provide their care. There is a significant need for research to guide the care of PH mothers, due to the number of women affected, the

difficult nature of their experiences, and the impact of nursing and other health professions on their care.

Research Purpose and Aims

The purpose of the present research is to explore and describe PH mothers' experiences from their perspectives. The aims of the study are to gather knowledge that will be useful to nurses and other health professionals providing PH care, and to guide future research as necessary.

Researcher Personal Statement

I am a certified nurse-midwife with significant career experience in the areas of high-risk pregnancy, ultrasound, and fetal diagnosis. I have often been in the position of discovering and delivering bad news to women about their pregnancies and caring for them in the aftermath of bad news. One of the worst kinds of bad news for any pregnant woman is the diagnosis of a lethal fetal anomaly.

When I first encountered women who wished to continue their pregnancies after learning that their newborns would not survive, I was surprised. Although this was not the choice that I expected, my background as a midwife had prepared me to try to understand and accept women's values and priorities, and help them plan their childbirth care in ways that reflected those values and priorities.

When I began talking to these mothers and families, some of them told me that they did not feel supported in their values and choices by their health providers. One woman was dismissed from her obstetrician's practice because she did not agree to

terminate her pregnancy. She reported that the obstetrician told her, "If you won't let me do anything, I can't help you, and if I can't help you, you can't be my patient." Other providers seemed to want to be supportive, but were not sure what to do or how to handle these clients and their needs.

These women's frustrations and the seeming inability of health providers and systems to understand their needs reminded me of the hospice movement I had read about in nursing school. In the 1970s and 80s, there was increasing realization that our health care was not very well suited to the needs of dying people or their families. Systems were designed and providers were educated to cure diseases. When they encountered a disease they could not cure, they did not seem to know how to respond. The hospice movement came about because people recognized that even dying people who could not be cured still had needs that could be met. They also recognized that there were different ways to die, and that some ways were preferable to others. In particular, it was preferable to die in a way that reflected the values and preferences of the individual, and made it possible for the dying person and his or her loved ones to share and make the most of what time they had.

It seemed to me that the greatest obstacle to meeting my clients' needs was that they were poorly understood by people in health care systems. To advocate for them, I needed to find ways to talk about their needs and choices. I started using the term *perinatal hospice*. *Hospice*, because there was a client and family with a lethal diagnosis and needs to be met. *Perinatal*, because these events were occurring in the context of pregnancy, childbirth, and the newborn period.

It was about this time that I learned I was not the only one using the term *perinatal hospice*. Byron Calhoun, a maternal-fetal medicine specialist who was making perinatal hospice (PH) a focus of his career, joined the group I was working with in Rockford, Illinois. With Dr. Calhoun's support, we started a PH care program to address the needs of women and their families in the Northern Illinois area who chose to continue their pregnancies after the diagnosis of a lethal fetal condition.

In some cases, I provided direct midwifery care including prenatal, delivery, and postpartum care. In others, I acted as a care planner and coordinator, with the woman's personal physician or midwife continuing to participate in her care. In all cases, I drew upon the resources of many different professionals including outpatient hospice and bereavement support providers, neonatologists, obstetric nurses, and chaplains or pastoral care providers.

I found this to be very rewarding work. I know our efforts were very much appreciated by the women and families we served. Some of these clients are still in regular contact with me. I seem to hear from them particularly often when they are pregnant and on anniversaries of the birth or death of the babies I helped them deliver.

It is difficult to characterize the reasons that I find this sad, difficult work rewarding. I have seen many women's health providers struggling when caring for women experiencing pregnancy loss, and I know that some either consciously or unconsciously avoid this work and these clients. Perhaps that is one reason I feel drawn to work with this population: I have seen the distress women and families experience

when their providers have avoidant or distancing responses, and I believe they deserve

care from someone who is willing to be fully present for them.

I also have a conviction that the way we die and the way we treat death and care

for the dying and bereaved reflect the way we value each other and respect life. Simply

recognizing that end of life and bereavement care is important work, and not always

available or done well, is a strong motivator for me.

One source of personal and professional satisfaction I have experienced as a PH

care provider is the sense of having facilitated a 'good death.' To leave the world

peacefully and with dignity, surrounded by a loving family whose wishes are respected,

can be a beautiful and life-affirming experience for all involved. One definite bias I have

is the belief that midwives are the ideal providers to attend PH births. By professional

culture, training, predisposition, or all three, midwives know what it is to facilitate a

'good birth.' Who better to midwife a 'good death' in the childbirth setting?

One of the things every midwife knows about a 'good birth' is that 'good' is

defined differently by various women and families. Part of the challenge and the reward

of midwifery is learning to see things from the perspectives of our clients and trying to

shape events to suit their preferences, meanings, and personal styles. It is much the same

challenge facilitating a PH birth.

The challenge of understanding events from the perspective of another person or

family, informed by preferences, values, and meanings that are not my own, has led me

to the belief that human beings are infinitely complex and individual. No two people

experience the "same thing" the same way. Indeed, I have come to believe that people's

experiences and the meanings they attribute to them are so various and idiosyncratic, it can hardly be said that any two different people ever experience "the same thing." For this reason, I made an explicit recognition of women's values, perspectives, priorities, and needs integral to the purpose of this research. In order for this research to produce knowledge that can be useful to providers and clients, I considered it essential to avoid any reduction or over-simplification of the profound individuality and complexity of human responses to significant life experiences.

Because PH represents a choice not to terminate a pregnancy, I find that some people respond to my interest in PH in a way that is informed, usually misinformed, by their views on abortion. Beliefs and feelings on both sides of the abortion debate are so very highly charged that even issues peripheral to abortion may trigger people's need to defend and advocate for their own views. Although these beliefs and feelings often create conflict, I believe that perinatal hospice is an area where those who want to promote the best possible life for the fetus and those who want to support women's choices could find common ground.

My experiences with PH families have convinced me that there is something profound and valuable for these mothers and fathers about the limited time they have during pregnancy and after birth with their children. I am not sure what it is, and since I have never had the experience myself, I do not feel it is my place to try to define or characterize what that value or importance is. I do know that it is highly significant for them, and I do know that they are often misunderstood. My personal goal for this research was to give voice to women who continue pregnancies after lethal fetal

diagnoses and let their stories characterize the value and meaning of their choices and experiences. I believe that our efforts to understand them will make us better care providers for them, who are able to facilitate the kind of experiences they want to have.

Definition of Terms

Antenatal diagnosis: ascertainment of an abnormal fetal condition prior to birth (synonymous with *prenatal diagnosis*) (Jenkins & Wapner, 2004)

Attachment: bonds of affiliation between people, which may be based on psychologic, physiologic, and/or social factors (Bowlby, 1969; George & Solomon, 1999; Muller, 1992)

Bereavement: the state of having experienced a significant loss (Cowles & Rodgers, 2000)

Fetal anomaly: an abnormal condition present in the individual prior to birth (synonymous with *birth defect* and *congenital anomaly*) (Jenkins & Wapner, 2004)

Hospice: (a) an approach to end-of-life care focused on facilitating subjectively desirable experiences for the dying person and his or her loved ones when cure is not possible (b) a facility, institution, or organization that provides hospice care (Hospice Foundation of America, 2007)

Lethal Anomaly: Many authors have used the term *lethal anomaly* without explicitly defining it (Calhoun et al., 2003; Chitty, Barnes, & Berry, 1996; D'Almeida et al., 2006; Hoeldtke & Calhoun, 2001; Leuthner, 2004b). Some authors have referred to fetal conditions that are 'incompatible with life' (Jenkins & Wapner, 2004; Ramer-

Chrastek & Thygeson, 2005). I find this unsatisfactory, because it is contradicted by the observed range of survival for newborns with these conditions, 20 minutes to 256 days in one published series (D'Almeida et al., 2006). These newborns clearly experienced some duration of life, albeit radically shortened compared to a normal human life span. For these reasons, I have chosen to define *lethal anomaly* as any fetal condition that is characterized by a radically shortened life span. Table 1 includes examples of some of the most common lethal diagnoses.

Miscarriage: loss of a pregnancy or death of a fetus prior to 20 weeks gestational age (March of Dimes, 2005)

Neonatal death: death occurring within the first 28 days of life (March of Dimes, 2005)

Perinatal death: broader tem inclusive of miscarriage, previable birth, stillbirth, and neonatal death (March of Dimes, 2005)

Perinatal hospice (PH): a care option for women and families who choose to continue pregnancies after the diagnosis of a lethal fetal anomaly (Calhoun et al., 2003; Hoeldtke & Calhoun, 2001). For the purposes of this discussion, PH does not refer to a specific program, location, or institution, but rather a general approach to care.

Perinatal palliative care (PPC): (a) a term sometimes used interchangeably with PH (Limbo, Toce, & Peck, 2008) (b) a broader term than PH, encompassing previable premature newborns, and newborns with overwhelming illnesses not responsive to treatment, in addition to newborns with lethal anomalies (Leuthner, 2004a). For the

Table 1

Lethal Fetal Conditions

Type of Anomaly	Diagnoses
Genetic	Trisomy 13, 15, or 18
	Triploidy
	Thanatophoric dwarfism
	Lethal forms of osteogenesis imperfecta
	Some inborn errors of metabolism
Renal	Potter's Syndrome (Renal Agenesis)
	Multicystic dysplastic kidneys
	Polycystic kidney disease
Central Nervous System	Anencephaly
	Acrania
	Holoprosencephaly
	Severe/complicated meningomyelocele
	Large encephalocele
	Severe hydrocephalus with absent or minimal brain growth
Cardiac	Acardia
	Inoperable cardiac structural anomalies
	Severe hypoplastic left heart syndrome
	Pentalogy of Cantrell (ecotpia cordis)
Other Structural Anomalies	Severe diaphragmatic hernia with pulmonary hypoplasia
	Inoperable conjoined twins

Note: From Leuthner, S. R. (2004a). Fetal palliative care. *Clinics in Perinatology, 31*, 649-665. Copyright 2004 by Elsevier Inc. Adapted with permission.

purposes of this discussion, PH will be used unless there is a specific reason to distinguish the two terms.

Perspective: the context or situation from which a person understands his or her experiences, including his or her thoughts, feelings, and motivations (Batson, Early, & Salvarani, 1997; Selman, 1980)

PH mothers: women who have chosen to continue pregnancies after learning of lethal fetal anomalies (my definition)

Prenatal Attachment: the development of feelings for, knowledge of, or interactions with a fetus prior to birth (synonymous with *maternal-fetal attachment*) (Cranley, 1992; Muller, 1992)

Prenatal Screening: assessment by history, biochemical markers, or ultrasound for the risk or suspicion of fetal anomalies (Jenkins & Wapner, 2004). Abnormal results on screening tests may indicate further, more definitive, diagnostic testing.

Previable birth: live birth prior to viability; generally defined as 23-24 weeks gestational age (March of Dimes, 2005)

Stillbirth: fetal death occurring after 20 weeks gestation but prior to birth (March of Dimes, 2005)

II. REVIEW OF THE LITERATURE

The purpose of this chapter is to review and analyze the existing state of knowledge potentially relevant to understanding the experiences of PH mothers prior to the present study. Prior to this study, there was a paucity of PH-specific research and a lack of PH-specific theory to guide scholarship and approaches to care. However, significant knowledge was identified in areas that were potentially relevant to the experiences of PH mothers. I reviewed this body of knowledge before undertaking my study because I recognized that processes, dynamics, or relationships described in existing literature could inform my investigation of PH mothers' experiences.

Prior to undertaking the literature review, I recognized a potential danger: that focusing on certain philosophies, theories, or research findings of unproven relevance to PH could bias my inquiry by creating expectations of relationships or phenomena which do not exist among PH mothers. At the same time, one must proceed from somewhere. As a researcher, one must have some notion where to look, what to look for, and how to look for it, if one is to pursue new knowledge in any kind of systematic way. The challenge, then, was to explore areas of knowledge that could potentially be related to the experiences of PH mothers and could be useful in guiding the inquiry. Throughout this exploration, my goal was to equip myself on the conceptual, theoretical, and empirical levels of thought to recognize a wide variety of different kinds of phenomena, while simultaneously avoiding becoming intellectually committed to any particular concept, theory, or empirical finding. Therefore, I approached this exploration of

potentially relevant knowledge according to three general categories or bodies of

knowledge: epistemology, theory, and empirical research.

<div align="center">Epistemological Foundations of PH Research</div>

Epistemology is the branch of philosophy concerned with the development and

justification of knowledge (Schick, 2000). Epistemological assumptions concerning what

constitutes knowledge, how knowledge is generated, and the criteria by which

knowledge is judged are often unacknowledged, but these kinds of assumptions can

powerfully influence the course of an inquiry and the nature of its product. I believe it is

useful to consciously examine and deliberately adopt an epistemological approach that

is consistent with the goals and aims of the inquiry, much as a craftsperson selects the

tools most appropriate for the work he or she is trying to perform. I chose to approach

the study of PH from a constructivist philosophical framework because I believed such

an approach was most compatible with what is known about prenatal attachment,

perinatal loss, people's responses to bereavement, and the way people make sense and

meaning of their experiences. Constructivism also seemed most consistent with the aims

of this study because it emphasizes the individual's own perspectives, experiences, and

meanings.

Constructivism was formulated in response to critical problems with positivism

and realism. According to positivism, no statement has meaning unless it is objectively

verifiable (Schick, 2000). Realism holds that there is an objective reality independent of

the observer, and that the aim of science is to accurately represent this reality (Schick,

2000). Together, positivist and realist assumptions formed the basis of most scientific inquiry through the nineteenth and early twentieth centuries. By the mid twentieth century, positivism and realism were subject to increasing criticism. Hanson (1958) argued that there is no such thing as atheoretical observation, an argument that undermined realist notions of scientific objectivity. Kuhn's (1970) insights about scientific paradigms and the way paradigms structure the socialization of scientists and define the kinds of questions scientists investigate, and his observation that there is no way to choose rationally between alternative paradigms, also undermined the absolutism of positivist and realist epistemologies.

Constructivism is an alternative to positivism and realism. Constructivism is best explained in terms of its ontology (conceptions of existence and reality) and its epistemology (assumptions about the nature and justification of knowledge). Constructivist ontology is agnostic regarding objective reality: there may be an objective reality, but we have no direct access to it. Our only direct access is to our own perceptual and conceptual worlds: "The world we experience is the world we construct" (von Glaserfeld, 1991). The observer is simultaneously constructing his or her version of reality while at the same time transforming reality and his or her self (Fosnot & Perry, 2005). Constructivist epistemology has been described as 'pragmatic' (von Glaserfeld, 1991). Rather than seeking justification of knowledge by correspondence to an objective reality, a constructivist approach evaluates knowledge by its functionality and utility (von Glaserfeld, 2005).

Constructivism is based on key assertions about how knowledge and meaning are generated. *Constructions* are internal mental representations of knowledge and meaning that are actively created by the individual based on his or her experience. Thus, knowledge and meaning are constructed by individual persons as acts of interpretation (Steedman, 1991) and pre-existing constructions profoundly influence how new knowledge and meanings are constructed (von Glaserfeld, 1991). Identity is a special case of construction: one's identity consists of one's constructions of one's self. Adaptation is the process by which internal representations are re-constructed when experience conflicts with existing constructions (Fosnot & Perry, 2005; von Glaserfeld, 2005)

Social and cultural contexts are important in the construction of knowledge and meaning (Fosnot & Perry, 2005; Gilbert, 2002). One's concepts and meanings are solidified by their viability and adequate functioning in one's social environment (von Glaserfeld, 1991). Although true objectivity is not possible according to constructivism, the acceptance and functioning of one's constructions in the social surround provide a form of external validation for the individual's constructed knowledge and beliefs. Social contexts heavily influence self-constructions of identity, because one's self-constructions are typically defined in terms of one's roles in relation to others such as daughter, son, mother, father, teacher, student, and so on (Gilbert, 2002).

The social dimension of knowledge construction is problematic because direct transference of thoughts, meanings, and knowledge from one person to another is not possible, and interpretation occurs in each individual's own experiential and conceptual

world (von Glaserfeld, 1991). Representation constitutes the interface between individual and social processes of knowledge construction, bridging the gap between the individual and other people. Representation is the use of symbols to transform constructions and make them accessible to others. Each representational medium, such as language, art, music, and mathematics, has its own attributes and limits: thus representation transforms and reconstructs knowledge and meaning (Fosnot & Perry, 2005). Representing experience with symbols allows the social process of negotiating meaning by allowing individuals to listen to and probe each other's understandings (Fosnot & Perry, 2005).

I believe that a major advantage of constructivism as a basis for PH research is its philosophical commitment to the unique perspectives and contexts of each individual. An inquiry founded on this philosophy seemed more likely to preserve and represent what was most salient to the participants, and less likely to reflect my own preconceptions. The purpose of the proposed research is to understand PH mothers from their points of view, respecting their perspectives and priorities. A constructivist approach is highly compatible with this purpose.

Another reason I was drawn to this approach is that I frequently encountered constructivist themes, both explicit and implicit, in my review of the theoretical and empirical literature. Concepts such as meaning reconstruction (Niemeyer, 2001, 2002), internal working models (Bowlby, 1988), and social processes of meaning negotiation (Walter, 1996), include constructivist elements. The recurrence of constructivist themes in my background reading suggested to me that this approach was conceptually

compatible with the subject and aims of the inquiry. I believed that ensuring

compatibility between philosophy, theory, and methodology could contribute the

success of the inquiry and a coherent account of the results. Compatibility between

epistemology and theory was particularly evident when reviewing classic and emerging

theories of bereavement that are shaped and informed by constructivist assumptions.

These theories and their potential relevance to PH are reviewed and discussed in the

following section.

There are, however, limitations to a purely constructivist approach.

Constructivism deals primarily with psychological, especially cognitive, processes such

as how individuals process their experiences and create new understandings.

Constructivism does not directly address biophysical bases of cognition and behavior. It

is important to note, however, that a constructivist approach does not preclude

consideration of biophysical factors, particularly regarding how individuals may

experience and understand biophysically-based phenomena. Another way to deal with

this limitation is to consider multiple theoretical approaches, including approaches

which include both psychological and biophysical factors, such as attachment and

caregiving, which are included in the following review of theoretical literature.

Theoretical Framework: Theories of Grief and Bereavement

An inescapable consequence of a lethal fetal anomaly is the eventual death of the

fetus or infant. PH mothers will inevitably experience the anticipation, occurrence, and

aftermath of such a loss. It would appear to be relevant, then, to review the body of theoretical literature that attempts to explain people's responses to loss.

Cowles and Rodgers (2000) analyzed major concepts of grief, bereavement, and mourning. Their evolutionary approach to concept analysis took account of the changing usage of concepts over time. They identified shortcomings in the literature, including frequent confounding of the terms *grief*, *bereavement*, and *mourning* and a tendency to define grief in terms of its symptoms. Based on the literature, these authors were able to clarify bereavement as the state of having experienced a significant loss, and mourning as rituals and practices associated with the social display of grief. Grief was identified as a multidimensional concept representing the consequences of bereavement. The attributes of grief Cowles and Rodgers (2000) identified included *dynamic*, *pervasive*, *process*, and *normative.* Table 2 includes descriptions and explanations of these attributes.

Cowles' and Rodgers' concept analysis reflects the complexity of bereavement experiences, with multiple dimensions and attributes. This complexity is reflected in the proliferation of theories as scholars have attempted to explain people's responses to significant losses. The subsequent sections include review and discussion of some of these theories, including attachment, meaning reconstruction, continuing bonds, and post-traumatic growth. Caregiving, a theoretical approach that is complementary to attachment, is not explicitly a theory of bereavement but is included in this discussion because of its central role in mothers' experiences of attachment to their infants.

Table 2

Attributes of Grief

Attribute	Description/Explanation
Dynamic	Grief is a nonlinear, fluctuating complex of emotions, thoughts, and behaviors.
Pervasive	Grief may affect the individual in the psychological, social, physical, cognitive, and/or behavioral domains.
Process	Grief is characterized by phases or clusters of activity moving toward some goal or outcome.
Normative	Distinctions can be made between normal and abnormal or pathologic grief.

Note: Derived by the author from Cowles, K. V., & Rodgers, B. L. The concept of grief: An evolutionary perspective. In B. L. Rodgers & K. A. Knafl (Eds.), *Concept development in nursing* (2nd ed., pp. 103-118). Copyright 2000 by Saunders.

Attachment Theory

One of the most influential theories in explaining human responses to loss is Bowlby's (1969, 1980) theory of attachment and loss. Bowlby (1969; 1980) defined grief as a response to the disruption of attachments, or bonds of affiliation between human beings. He based his theories on observations of humans and other animals, particularly interactions between mothers and offspring. According to Bowlby (1969; 1980), attachment behaviors are activated by states of need, such as fear, anxiety, or pain. Attachment and caregiving describe a complex, dynamic relationship between parents and children that is adaptive and meets a basic survival need.

The attachment relationship is based on *internal working models* (IWMs). IWMs consist of expectations about the self, significant others, and relationships between them (Bowlby, 1988). They are flexible and dynamic, evolving with experience and development. IWMs include details about interpersonal experiences and emotions associated with those experiences, stored within organized representational structures (Mikulencer & Shaver, 2007). There is evidence that IWMs are biophysically based: that is, that humans are "hard-wired" to create internal models and attachments in order to meet basic survival needs (Mikulencer & Shaver, 2007).

Bowlby's original conceptualization of attachment is not directly applicable to perinatal loss because the kinds of interactions described by classic attachment theory, such as expressing states of need and responding by caregiving, are not possible between a mother and fetus or a mother and a deceased infant. However, many authors,

including Bowlby himself, reconceptualized attachment to include a wide variety of responses, processes, and emotions characteristic of close affiliative bonds between individuals. Bowlby (1980; 1988) described attachment relationships between adults, including adults' responses to the loss of attachment figures. Other authors have described the formation of attachments between mothers and fetuses during pregnancy (Condon, 1985; Cranley, 1981; Muller 1992). Robinson, Baker, and Nackerud (1999) outlined the application of attachment theory to perinatal bereavement, and argued that the nature and intensity of prenatal attachment influences characteristics of grief responses with perinatal loss. Attachment theory also heavily influenced the development of theories such as caregiving, continuing bonds, and meaning reconstruction, which are discussed subsequently.

Elements of attachment theory may be applicable to perinatal loss and PH. The concept of IWMs and their role in the formation of attachment may be relevant to how women develop emotional bonds with their offspring prior to birth. This concept of prenatal attachment is discussed more fully in a subsequent section (*Transition to Motherhood*, p. 39). Bowlby (1980) also described patterns of responses that occur after the loss of an attachment figure, including (a) shock or numbness, (b) searching and yearning, (c) disorganization and despair, and (d) reorganization. Of particular interest to health professionals interested in facilitating clients' recovery from loss is reorganization. According to Bowlby (1980; 1988), reorganization includes the adjustment of working models, restoration of functioning, adjustment to life without the deceased, and renewed interest and engagement in activities.

Caregiving

Complementary to attachment is the concept of caregiving. Caregiving is not generally regarded as a bereavement theory, but because of its relationship to attachment and significance for mothers, I considered it potentially relevant to this inquiry.

Bowlby (1969; 1988) originally conceptualized caregiving as parental behaviors involved in nurturing and protecting a child. Subsequent researchers have developed theories of caregiving that describe complex interactions between biology and experience (George & Solomon, 1999). Caregiving has been researched both qualitatively and quantitatively (George & Solomon, 1999; Limbo & Pridham, 2007; Pridham, Brown, Clark, Sondel, & Green, 2002; Pridham, Saxe, & Limbo, 2004), but has not previously been studied in relation to PH.

George and Solomon (1999) posited that the caregiving system is activated during pregnancy and undergoes substantial development during pregnancy, birth, and the postpartum periods due to physiologic, psychologic, and social influences. Caregiving IWMs reflect a mother's evolving expectations and intentions about herself, her baby, and the relationship between them (Limbo & Pridham, 2007).

Until the present study, concepts related to caregiving had not been investigated in the context of perinatal loss. Even prior to the findings of the present study, it was possible to speculate that one consequence of perinatal loss could be a mother's need to

deconstruct and reconstruct her working models related to herself, her baby, and their relationship.

Meaning Reconstruction

Adapting or reconstructing working models in the aftermath of significant losses has become a major focus of some bereavement theorists. According to this school of thought, bereavement entails the disruption of the bereaved person's meaning constructions, especially constructions of identity and relationship (Niemeyer, 2001, 2002). Post-loss meaning reconstruction can include making sense of the loss, drawing important life lessons, and assimilating the loss into the bereaved person's conceptions of the world and his or her role in it.

Rituals are one way human beings can construct meaning, create order, and find comfort when faced with loss (Kobler, Limbo, & Kavanaugh, 2007). They can be extemporaneous or part of an established tradition, secular or religious (Kobler et al., 2007). The lack of ritual validation has been recognized as problematic for parents who experience pregnancy loss (Kobler et al., 2007; Malacrida, 1999). For rituals to be effective in helping bereaved parents to reconstruct meaning, they must be active participants and the ritual must be facilitated in a way that respects their experiences, background, and perspectives (Kobler et al., 2007). This observation reflects the constructivist theme that meaning cannot be passively absorbed from others, but must be actively constructed by the individual.

Another important process of meaning construction is *narration*; creating and

relating one's life story (Gilbert, 2002; Niemeyer, 2001; Walter, 1996). Walter (1996)

proposed a biographical model of grief that emphasizes the importance for the bereaved

of re-authoring their life stories to accommodate and incorporate their experiences of

loss. Through a process of social negotiation involving sharing stories of the deceased,

the bereaved can construct a stable, shared, and tested account of the deceased and find

a secure place for the deceased in their ongoing lives (Walter, 1996).

Continuing Bonds

Recognition of the ongoing significance of attachment relationships after death

has prompted some bereavement theorists to focus on the concept of continuing bonds

between the bereaved and the deceased (Klass & Walter, 2004). This approach rejects

detachment, or the cessation of emotional involvement, as a desirable bereavement

outcome. According to this view, bereaved people often maintain significant bonds with

the deceased. These bonds can continue for decades and are not associated with

pathology (Klass & Walter, 2004). Some ways the bereaved may maintain bonds with

the deceased include sensing the presence of the deceased, talking with the deceased,

and relying on the deceased for moral guidance (Klass & Walter, 2004). This approach

also highlights the importance of narrating stories about the deceased to share their

'extraordinariness' with others and to reconstruct healthy relationships with the

deceased (Klass & Walter, 2004).

Post-traumatic Growth

One commonality between the meaning reconstruction and continuing bonds perspectives is an acknowledgement of the human capacity to cope with adversity, and grief's power to act as a catalyst for change and growth (Riley, LaMontagne, Hepworth, & Murphy, 2007). Post-traumatic growth is an emerging concept in bereavement theory that emphasizes positive personal transformations in the aftermath of loss (Tedeschi & Calhoun, 2008). Some individuals' understandings and sense of purpose in life may be experienced as transcending beyond the loss. This transcendence may be more satisfactory than previous constructions (Tedeschi & Calhoun, 2008). While emphasizing positive potentials after loss, it should be noted that some individuals do not experience post-traumatic growth. Among those who do, this does not preclude or negate experiences of grief and suffering (Tedeschi & Calhoun, 1996).

Growth experiences following bereavement may include positive changes in relationships with others, new possibilities, an increased appreciation for life, a greater sense of compassion and connectedness to others, or a sense of intimacy with others who shared the loss (Riley et al., 2007; Tedeschi & Calhoun, 2008). For some, losses that are sudden or unexpected, such as infant deaths, may be more likely to lead to rumination about causes, reasons, purposes, and existential meaning of the loss. These are ruminations that can in turn act as catalysts for existential or spiritual growth (Tedeschi & Calhoun, 2008).

Multi-Theory and Multi-Process Approaches

The concept analysis and the theories reviewed above emphasize the complexity of bereavement responses. The qualitative literature on perinatal loss, reviewed below, suggests a wide variety of different bereavement responses. Cowles and Rodgers (2000) identified multiple dimensions and four attributes of grief. All of these theoretical perspectives, including attachment, caregiving, meaning reconstruction, continuing bonds, and post-traumatic growth, seemed intuitively plausible to me. These approaches reasonated with responses I have personally experienced or seen in others. I believe there is some truth in each of these theories. Still, complex experiences like bereavement seem to defy encompassment by any one theoretical approach. All of these theories seemed to have some ring of truth to them, but none seemed, by itself, capable of completely explaining the wide variety of responses and processes that human beings experience in response to significant losses. The limitations of individual theories in fully explaining such complex phenomena may be part of what has motivated some bereavement theorists to develop multi-theoretical or multi-process approaches.

Rubin (1999) proposed a *two-track model* to incorporate the concepts of continuing bonds and meaning reconstruction along with other aspects of bereavement response. Track one, focusing on functions and symptoms, included psychiatric symptoms, functioning in relationships, personal meaning structures, and investment in life tasks. Track two focused on the bereaved person's ongoing relationship to the deceased, which could include images and memories, emotional distance or closeness,

impact of the relationship on self-identity, memorialization, and preoccupation with the loss. Regarding Track one, the functional/symptomatic track, Rubin emphasized human adaptability and noted that most bereaved people return to normal functioning relatively quickly. Track two, the ongoing relationship to the deceased, by contrast, may be a constantly evolving lifelong process (S. S. Rubin, 1999).

In view of the uni-dimensional focus and emphasis on psychiatric outcomes found in much of the perinatal bereavement research literature (see *Quantitative Research on Perinatal Loss*, p. 70), recognition of another dimension of bereavement experience was a strength of the two-track model. However, the wide variety of experiences evident in the qualitative literature (see *Qualitative Research on Perinatal Loss*, p. 83) suggested that there may be more than just two dimensions of bereavement response. Furthermore, subsuming meaning reconstruction into the functional/symptomatic track seemed conceptually awkward: these processes may be complex and significant enough to form a third dimension or 'track' of their own. These criticisms aside, it does seem clear that bereavement is a multi-dimensional phenomenon and an approach confined to any one theoretical perspective is likely to neglect significant aspects of women's experiences with perinatal loss.

There is some research evidence to support a multi-theoretical approach to perinatal bereavement. Uren & Wastell's (2002) theory-testing study examined the experiences of 109 female participants, 78 of whose losses were due to stillbirth and 31 due to neonatal death. The time interval post loss ranged from 2 to 204 months, with over half of the participants within 24 months of their losses. Using a battery of

psychometric instruments and open-ended items, the researchers examined the participants' bereavement experiences and found evidence to support more than one theoretical perspective. Responses predicted by attachment theory, such as shock/numbing, searching/yearning, disorganization, despair, and reorganization were prevalent among the participants. Seventy-seven percent of the participants experienced significant impairment in daily functioning. Participants demonstrated ongoing relationships with their deceased children, as evidenced by mothers' tenacity in maintaining emotional connections and relationships to their lost infants and valuing grief experiences as a way of staying connected. Searching for meaning was also a common finding, although many participants reported that they were not able to find meaning in their losses. Some participants reported finding meaning in terms of favorable changes in self-identity.

Uren and Wastell's (2002) study was significant because it supported the applicability of both attachment and meaning reconstruction theories to perinatal bereavement. Although the concept of continuing bonds was not a major focus of the study, the findings support this conceptualization as well. The authors' successful use of more than one theoretical perspective demonstrated that, in this case at least, multiple theories could inform the same inquiry and contribute to a coherent and compelling account of the findings. Based on my review of the literature and my clinical experience with PH mothers, I believed that a multi-theoretical approach was most likely to be helpful in understanding the complexity of PH mothers' experiences.

In addition to approaches informed by multiple theories, some bereavement experts have suggested an approach that recognizes more than one process. Stroebe and Schut (1999) argued that much of the bereavement literature was based on an unacknowledged, perhaps unrecognized, single-process model. They coined the term *grief work hypothesis* to describe this model and its constituent assumptions about what is the most adaptive way for an individual to respond to bereavement. These assumptions include the importance of confronting rather than avoiding painful affect, the belief that suppressing painful emotions is pathological, the necessity of active ongoing attempts to come to terms with one's loss, and the desirability of returning to normal functioning and a positive state of mind as soon as possible (Stroebe & Schut, 1999). In contrast to the grief work hypothesis, these authors proposed a *dual process model* based on theories of stress and coping. The two processes referred to in the name of the model are confrontation and avoidance. According to the dual process model, oscillation between confrontation and avoidance is normal and adaptive. Extremes of confrontation or avoidance, such as intrusive or obsessive thoughts, or persistent denial of the loss, may be harmful. However, these authors argue that most bereaved individuals appropriately self-regulate their 'dosage' of grieving to strike an adaptive balance between confrontation and avoidance (Stroebe & Schut, 1999). Presumably, individuals may differ in their optimal balance and the balance may change at different stages of the grieving process.

The dual process model contradicts underlying assumptions of symptom-oriented bereavement research; that grief symptoms are undesirable or pathological and

returning rapidly to a symptom-free state is optimal. In choosing to continue a

pregnancy affected by a lethal anomaly, PH mothers are choosing to continue a difficult

and painful experience. Research and clinical approaches to PH should recognize the

possibility that confronting painful affect and experiencing distressing symptoms may

be part of an adaptive process for some mothers.

Summary of Contributions from Bereavement Theory

A few summary points can be drawn from this review of theoretical approaches

to grief and bereavement. Bereavement appears to be a complex, multidimensional

phenomenon with ongoing, possibly lifelong, impact on the life of the bereaved.

Approaches that focus only on symptoms and functioning probably will not be adequate

to explain PH mothers' experiences, which are likely to be complex, varied, and unique.

The purpose of the present research study was to understand PH mothers'

experiences from their points of view, respecting their needs, perspectives and priorities.

It would be inconsistent with this purpose to impose a theoretical perspective on the

data based on a researcher's preferences or preconceptions. One potential strength of a

multi-theoretical approach was that familiarity with a variety of different theorized

phenomena could help sensitize the researcher and facilitate recognition of these

phenomena if they were present, while avoiding a prejudicial commitment to any one

particular theory. For this reason, I decided that an approach which accommodates more

than one theoretical perspective was most appropriate for this research. My goal was to

be prepared to recognize many different kinds of phenomena in the experiences of PH

mothers, while avoiding the presupposition of their presence or significance in advance of supporting evidence.

<div align="center">Review of Health Care Literature</div>

Little has been published in the health care literature specific to PH. However, there is a substantial body of qualitative and quantitative research on perinatal loss and much of this work has potential implications for understanding and studying PH. Additionally, literature on parents' experiences of attachment prior to birth and their responses to abnormal fetal diagnoses could be germane to the study of PH. The following sub-sections are devoted to review and critical analysis of the research literature on PH and related areas that informed this inquiry, including PPC, women's transitions to motherhood, responses to abnormal fetal diagnoses, and perinatal loss.

Perinatal Hospice and Perinatal Palliative Care

There has been scant study of PH, with only seven articles in the health care literature since the term was introduced by Hoeldtke and Calhoun (2001). Six of these articles were not based on PH-specific research data, but rather on authors' experiences and opinions and research from related areas. Two articles proposed models of care for PH (Hoeldtke & Calhoun, 2001; Roush, Sullivan, Cooper, & McBride, 2007). Three articles described the implementation and outcomes of PH care programs (Calhoun et al., 2003; D'Almeida et al., 2006; Leuthner & Jones, 2007). One case study was published, describing the process of formulating and implementing a PH plan of care for one family (Ramer-Chrastek & Thygeson, 2005). Just one article (Chitty, Barnes, & Berry,

1996) was based on research data collected from PH mothers and families, and is discussed subsequently below.

In addition to these articles on PH, a body of literature has recently emerged on *perinatal palliative care* (PPC). Some authors have used PH and PPC as interchangeable terms (Limbo et al., 2008). One author has used PPC as a broader term, encompassing previable premature newborns and newborns with overwhelming illnesses not responsive to treatment, in addition to newborns with lethal anomalies (Leuthner, 2004a). Since models of PH and PPC share many commonalities, they will be discussed together and the term PH will be used preferentially, unless distinguishing PH from PPC is germane to the subject of discussion.

A literature search did not find any PPC research in which data on parents' experiences were analyzed. A recently published article on the state of the practice of PPC noted a dearth of research and called for nurse researchers to explore the needs of families, how best to deliver care, and how to design and implement effective policies (Sumner, Kavanaugh, & Moro, 2006). The present study addressed these issues, particularly exploring the needs of PH mothers and families and how providers can help to meet them.

Models of care that have been proposed or described for PH/PPC have emphasized the need for a global, holistic approach addressing quality of life for the newborn (Leuthner, 2004b) and physical, emotional, and spiritual support for the mother and family (Leuthner, 2004b, Hoeldtke & Calhoun, 2001; Roush, Sullivan, Cooper, & McBride, 2007). It has been emphasized that in this context, hospice refers to a

philosophy of care, not a physical location or a particular program (Roush et al., 2007).

There is a consensus that PH care requires a multidisciplinary team approach (Hoeldtke

& Calhoun, 2001; Leuthner & Jones, 2007; Limbo et al., 2008; Roush et al., 2007). One

article described the central role of a nurse coordinator who works with the family to

create a plan of care, gather information, present options, and act as a liaison between

health care disciplines (Leuthner & Jones, 2007).

Birth planning is a major element of PH care (Leuthner & Jones, 2007; Roush et

al., 2007; Sumner et al., 2006). Planning can enhance the mother's and family's sense of

control and help make the best of the limited time they may have with their fetus or

newborn (Roush et al., 2007). It has been emphasized that the birth plan is not a legal

document and can be changed as needed (Roush et al., 2007). Birth planning for PH can

be especially difficult because mothers and families may have to plan for a range of

possible outcomes. For instance, a family may have to simultaneously consider nursery

care and funeral planning (Roush et al., 2007). The birth plan encompasses the obstetric

care plan, including the mode of delivery and responses to fetal distress or preterm

labor, as well as delivery room management, plans for attendance and participation by

family members and visitors, plans for rituals and creating mementoes, and newborn

care including possible home care if the newborn survives to discharge (Limbo et al.,

2008; Roush et al., 2007). The need for after care of the surviving family is widely

recognized as an important element of PH care (Hoeldtke & Calhoun, 2001; Leuthner &

Jones, 2007; Limbo et al., 2008; Roush et al., 2007). Lack of awareness of these needs and

PH care options to meet them have been identified as major barriers among the general public and providers (Sumner et al., 2006).

These articles represented a wealth of knowledge based on the wisdom and skills of experienced PH care providers from multiple disciplines. They provide a valuable overview of the landscape and major features of PH care and the needs of families. While these authors' observations and their approaches to care have been based on and modified by feedback from PH mothers and families, there has so far been little confirmation of these models or elements of care by research evidence conducted with the recipients of PH services.

In the only published article based on data from PH mothers and families, Chitty, Barnes, and Berry (1996) interviewed five British couples who chose to continue their pregnancies after lethal anomalies were diagnosed. The interviews were semi-structured and took place one week to eight months after the conclusion of the pregnancies. Interview findings were summarized in five categories. The first category *negative experiences,* included insensitivity or miscommunication by health professionals, which were common. Secondly, some couples reported *positive experiences*, such as improved communication or compassion by health care providers. The third category of experiences was *seeing the baby*. Three of the five couples had contact with the baby after delivery and reported this as a valuable experience. One couple expressed relief that the appearance of their infant was less distressing than they had imagined. One woman expressed intense resentment that her baby was taken away from her shortly after birth. The fourth category was labeled *retrospective feelings about knowing*. The couples were

unanimous that knowing about their infants' conditions prior to birth was helpful. The

final category was labeled *what would have made things easier*? Continuity of health

providers and improved communication among providers predominated in this

category. The need for specialized care by a small team of providers was emphasized.

This study represented a beginning attempt to study phenomena relevant to PH.

It was informative as a beginning, but there are some significant limitations. Although

qualitative research does generally involve small sample sizes (Morse & Richards, 2002;

Sandelowski, 1995), a sample of five couples suggests that further exploration among

more participants might be fruitful. The time limitation of one to eight months following

conclusion of the pregnancy may be too restrictive considering the insights of emerging

grief theories previously discussed, particularly those that emphasize the ongoing,

evolving impact of a loss in an individual's life. Finally, the lack of theory-based

qualitative methodology and formal analysis of the data may have limited the depth of

the analysis: the conclusions of the study, while clinically significant, seem to lack the

depth and richness evident in other qualitative studies (see *Qualitative Research on

Perinatal Loss*, p. 83). Despite these limitations, the findings supported further research

about the experiences of women who continue pregnancies after receiving lethal fetal

diagnoses, particularly in the areas of health provider responses and parents'

experiences of contact with their affected infants.

Although Chitty and colleagues (1996) focused their study on participants who

continued pregnancies after the diagnosis of a lethal anomaly, they did not use the term

perinatal hospice. I was unable to find any references to the term prior to Hoeldtke and

Calhoun's (2001) article which proposed a model of care for PH. The title of Chitty and colleagues' article, "For Debate: Continuing with Pregnancy after the Diagnosis of Lethal Abnormality," (1996) suggested that the authors anticipated or had encountered controversy or resistance. In contrast, Leuthner and Jones' (2007) program description article depicted well-established interdisciplinary cooperation and institutional support, with little to suggest that the program operated in a climate of controversy or resistance. It may be that the concept of PH and support for women's and families' choices have gained some acceptance in the last decade.

Chitty and colleagues' (1996) paper represented a starting point for PH research, and some recognized elements of PH care models were supported, such as the desirability of continuity among providers and the benefits of specialized PH care services. Given the limitations of Chitty and colleagues' (1996) study, a more systematic and rigorous process of collecting and analyzing data from PH mothers was indicated, which the present study represents. More in-depth PH research has the potential to confirm or modify existing concepts in PH care and to identify important issues that have not previously been recognized.

Due to the overall paucity of literature specific to PH, the author sought to review literature from areas of research that seemed possibly relevant to the experiences of PH mothers. These areas of scholarship included women's psychosocial transitions to motherhood, responses to abnormal fetal diagnoses, and research on perinatal loss.

Transition to Motherhood

In addition to specific PH-focused research, there is a substantial body of literature on women's transitions to motherhood. Although there have not been any published studies of how lethal diagnoses might affect the transition to motherhood, it is potentially germane to understand the normal processes of maternal transition which may be affected by lethal diagnoses and foreknowledge of impending losses. Additionally, some of this literature examined how maternal transition was affected by pregnancy complications. It was recognized as a possibility that PH mothers may share some similarities with women experiencing complicated pregnancies in regard to maternal transitions.

The transition to motherhood is widely recognized as a major life event (Mercer, 2004), and most scholarship in this area has held that this transition begins relatively early in pregnancy (Limbo & Pridham, 2007; Muller, 1992; Nelson, 2003; R. Rubin, 1984). Since lethal conditions are usually ascertained in mid-pregnancy, it seems likely that most PH mothers have already begun the transition to motherhood by the time they learn of their fetuses' conditions. Understanding the process of becoming a mother, therefore, could provide insight to the transitions and processes that women are undergoing at the time they become PH mothers.

Rubin's (1984) classic theory of maternal role attainment described how mothers progress through various tasks during pregnancy to achieve maternal identity, a new self-identity that incorporates motherhood. Maternal identity includes a woman's ideals

related to motherhood, her feelings of confidence and competence as a mother, and her knowledge of and feelings of attachment to her fetus or infant (R. Rubin, 1984).

Rubin's work spawned a body of research on maternal role attainment, and its component concept of prenatal attachment. Maternal role attainment is influenced by a mother's age, socioeconomic status, perceptions of her birth experience, personality traits, self-concept, child rearing attitudes, perceptions about the infant, and health status (Mercer, 2004). Recognition of her status as a mother by others in her social surround also influences a woman's maternal identity (Mercer, 2004).

Nelson (2003) conducted a meta-synthesis of nine qualitative studies related to the transition to motherhood. Studies were selected for inclusion based on their relevance to the topic and the methodologic comparability of their findings. Studies involving special circumstances such as perinatal loss, premature birth, teen pregnancy, or maternal illness were not included. A comparative method of synthesizing qualitative findings was used that involved juxtaposition of key findings from the various studies and translating the studies into each other's terms. To conceptualize the transition to motherhood, the authors used a definition of *transition* that emphasized disruptions and responses to disruptions. Although the participants in the selected studies were dissimilar to PH mothers, examining the disruptions and responses involved in the normal transition to motherhood, separate from disruptions associated with an abnormal fetal diagnosis, could provide useful insights for understanding PH mothers.

Findings of the meta-synthesis included two major processes: *engagement* and *growth and transformation* (Nelson, 2003). *Engagement* included making a commitment to

motherhood, experiencing the presence of the child, and being actively involved in caring for the child. *Growth and transformation* described how women changed as they became mothers. Both of these major processes were underway prior to birth, and included such themes as making the decision to mother, feeling the maternal-child bond, accepting responsibility, adapting to changed relationships with partners and others, and coming to feel like a mom.

Because these phenomena were present during pregnancy, it seemed possible to me that PH mothers might experience them, possibly in altered form due to the impact of adverse diagnoses. Since women experiencing abnormal pregnancy conditions were excluded from Nelson's (2003) meta-summary, questions about which of these phenomena were relevant to PH mothers remained to be addressed by the present investigation.

Reid (2000) qualitatively investigated maternal identity among 40 women who delivered preterm infants less than 34 weeks gestational age. The mothers were interviewed while their infants were still hospitalized in a neonatal intensive care unit. Interviews were semi-structured: an interview guide developed from the maternal transition literature was used, but participants were also encouraged to talk about anything they wished to discuss (Reid, 2000). Interview transcripts were analyzed by categorizing responses according to maternal transition concepts. A second researcher coded 25% of the interviews, with 95% congruence in category assignment.

Eight categories were identified (Reid, 2000). Some of the categories, such as coping with preterm labor, or anxieties about long-term outcomes for surviving infants,

did not appear to be directly relevant to most PH mothers. Categories that did appear

relevant to PH included (a) holding and touching the infant, (b) maternal feelings, (c)

contact, rights, and obligations, and (d) caregiving competencies and sensitivities.

Participants positively valued holding and touching their infants. Holding and touching

was associated with the feeling of being a mother, which was in turn associated with

maternal identity. Mothers were concerned about their infants' well-being and care.

Spending time with their infants, comforting, touching, feeding and talking to them

were regarded by participants as actions that should be done by mothers rather than

health care professionals. Mothers expressed anxiety about their own competence to

properly care for their infants. All of these findings were well supported by participant

quotes.

There are a few significant weaknesses in Reid's (2000) approach. Foremost

among these was the decision to structure the interview guide and the analysis process

according to existing theories of maternal transition. This opens the question of whether

the author might have been intellectually committed to a pre-determined set of concepts

prior to data collection and analysis. The participants' quotes support the relevance of

these concepts, but one wonders whether the author might have discovered previously

unknown processes or concepts had she approached the study with more blank space

on her conceptual slate. The sample size of 40 participants also raises questions. Such a

large sample has the potential to represent a broader range of participant experiences

that could possibly be a strength of the study. However, it could also be that such a large

sample, and a potentially enormous amount of qualitative data, might have made it more difficult to perform in-depth analysis.

Because the participants in Reid's (2000) study experienced abnormal pregnancy and newborn conditions, their experiences could potentially be more relevant to those of PH mothers. The importance to Reid's participants of holding, touching, and caregiving, and the connection between these behaviors and their identities as mothers was striking. Another possible similarity to PH mothers was that Reid's participants described many positive experiences, although most strongly expressed feelings related to negative experiences in their own or their infants' care.

Of all the components of maternal transition, maternal-fetal attachment (MFA) has probably generated the largest volume of research in the nursing literature. MFA describes a mother's developing knowledge of, relationship with, and feelings for her fetus during pregnancy (Muller, 1992). MFA could be important in understanding PH mothers' experiences because it seems likely that their knowledge of, relationships with, and feelings for their fetuses could be significant in their experiences during pregnancy and after birth. If, as theorized by Bowlby (1980), attachment is a predicate of loss and grief, then attachments formed prenatally could affect PH mothers' experiences after the loss of their infants. It is also possible that knowledge of a lethal diagnosis might influence the character or degree of PH mothers' attachment to their fetuses.

Muller (1992) conducted a critical review of MFA research including 24 previously published studies. Eighteen of the included studies used quantitative

methods, six used qualitative methods, and one used a mixed methodological approach. Muller (1992) did not specify how the studies were selected for inclusion.

The qualitative literature reviewed by Muller (1992) supported the idea that pregnant women experienced interaction and communication with their children prior to birth. Ascribing individuality or personality to the fetus and expressing feelings of affection for the fetus, also were well documented (Muller, 1992). Quickening, the mother's first experience of fetal movement, featured prominently in both qualitative and quantitative research. In qualitative studies, feelings of love for the fetus were nearly universally documented among mothers after quickening (Leifer, 1980; Lumley, 1982). Quantitative studies showed positive correlations between quickening and MFA (Muller, 1992). Advancing gestational age and mothers' marital satisfaction were also well documented correlates of MFA (Muller, 1992).

The first widely-used instrument to measure MFA was Cranley's (1981) Maternal-Fetal Attachment Scale (MFAS). Based on a literature review, six dimensions of MFA were identified and incorporated into the instrument: (a) differentiation of self from fetus, (b) interaction with the fetus, (c) attributing intentions and characteristics to the fetus, (d) giving of self, (e) role taking, and (f) nesting. Items for each dimension were created by a panel of experts who produced a list of germane statements that mothers frequently make about themselves and their fetuses. Cranley selected 37 items for use in the instrument. Each item was rated on a five-option scale from "most of the time" to "never." The instrument was initially tested among 71 volunteer participants recruited from childbirth education classes. Statistical item analysis resulted in

elimination of 13 items, including the entire 'nesting' subscale. The resulting 24-item

instrument had an alpha coefficient of .85 for the whole scale and a range of .52 to .73 for

each of the five remaining subscales (Cranley, 1981).

The MFAS has been widely used. By 1992, the author of the MFAS had received

nearly 300 requests from researchers to use the instrument (Cranley, 1992). Most studies

have demonstrated the reliability of the overall instrument, with alpha coefficients

ranging from .80 to .87 (Muller, 1992). However, the individual subscales have not

proven reliable, so the author does not recommend the use of subscale scores in research

(Cranley, 1992). This, in turn, casts some doubt on the validity of the instrument as a

whole because the subscales represent the conceptual definition of prenatal attachment

underlying the instrument's design.

Use of the MFAS revealed further doubts about the reliability of the scale.

Although quickening, advancing gestational age, and marital satisfaction have been

consistently correlated with MFAS scores as noted above, other hypothesized correlates

such as social support and anxiety have produced conflicting results (Cranley, 1992;

Muller, 1992). Theorized propositions about a relationship between prenatal attachment

and self-esteem have not been supported (Muller, 1992). These inconsistencies may

reflect differences in study populations, limitations of the instrument, or lack of

conceptual clarity regarding the nature of MFA (Cranley, 1992; Muller, 1992).

These problematic findings from research based on the MFAS led Muller (1993)

to develop a new theoretical model of MFA and a new research instrument based on the

model. According to Muller's (1992) attachment model, women's initial attachment

experiences lead them to develop internal representations about the nature of the self, others, and relationships. These representations then influence pregnant women's attachments to families, partners, and friends. According to this view, internal representations and attachments to partners subsequently influence women's adaptations to pregnancy and their MFA (Muller, 1993).

Based on the model and a literature review, Muller (1993) developed an initial Prenatal Attachment Inventory (PAI) of 48 items. The items were then scored for relevance by an expert panel and the lower-scoring items were removed. This resulted in a 29-item instrument. Participants were asked to rate each item on a 4-point scale (4 = almost always, 3 = often, 2 = sometimes, and 1 = almost never). Examples of PAI items include "I feel love for the baby," "I imagine what part of the baby I'm touching," and "I think that my baby already has a personality" (Muller, 1993).

The PAI was tested in a convenience sample of 336 low-risk pregnant women. The instrument demonstrated an alpha coefficient of .81 (Muller, 1993). Participants also completed the MFAS, the Maternal Adjustment and Maternal Attitude scale (MAMA) which measures maternal adaptation to pregnancy, and the Kansas Marital Satisfaction Scale (KMSS). PAI scores were highly correlated with MFAS scores (r = .72), which the author interpreted as evidence of concurrent validity (Muller, 1993). However, it seems problematic to validate a new instrument by correlating it to an instrument of questionable reliability and validity. PAI scores also had significant correlations with the Body Image, Attitudes to Sex, and Attitudes to Pregnancy subscales of the MAMA. PAI scores did not correlate with KMSS scores.

Factor analysis was then conducted on the PAI scores using varimax rotation. A single factor, comprising 11 items, explained more than 50% of the overall variance. Items loading on this factor represented themes of Preparedness, Fantasizing, Affection, and Interaction. It is unusual for a single factor to contain four qualitatively distinct themes (Muller, 1993). The author hypothesized that this eleven-item factor, rather than representing a single dimension of prenatal attachment, may consist of the items which best represent prenatal attachment (Muller, 1993). This would presumably suggest that Preparedness, Fantasizing, Affection, and Interaction are the primary dimensions of prenatal attachment.

Recently, Yarcheski and colleagues (2009) conducted a quantitative meta-analysis of studies using measures of MFA, including both the PAI and the MFAS. From a comprehensive review of the literature, including 183 studies published between 1981 and 2006, 72 studies with adequate data for statistical meta-analytic methods were included. Among the included studies, 14 possible predictors of MFA were identified. Each predictor was analyzed for the magnitude of its effect on MFA.

Gestational age was the strongest predictor of MFA in the pooled data: increasing gestational age was associated with higher MFA. Social support and prenatal testing had moderate effect sizes. Ten predictors (anxiety, self-esteem, depression, planned pregnancy, age, parity, ethnicity, marital status, income, and education) had low but statistically significant effects on MFA. The effect of high risk pregnancy status on MFA was trivial (Yarcheski et al., 2009).

One strength of Yarcheski and colleagues' (2009) study is the authors' choice to examine predictors in terms of their effect size. This provides more information than simply reporting whether an effect is statistically significant, because effect size provides information about not just whether an effect is measurable, but the degree to which it is influences the variable of interest. The fact that gestational age was the strongest predictor may be relevant to PH, since mothers may have become more attached at the time diagnoses are made than earlier in pregnancy. The extremely small effect size of high risk pregnancy status in this pooled data is difficult to interpret. Clinical risk in pregnancy is not a homogenous entity: for example, it can be easily imagined that a diagnosis of gestational diabetes would have different effects on MFA than a diagnosis of a lethal fetal condition, despite the fact that both of these could be categorized as high risk pregnancy conditions.

Despite lingering questions such as this, quantitative research has validated the concept of MFA in my opinion. Instruments designed to measure MFA have demonstrated validity in multiple studies among different populations. Inconsistent or otherwise problematic research findings suggest relatively minor flaws in the conceptualization of MFA or operational definitions of its correlates, rather than invalidating the whole concept of MFA. My interpretation was that there was general support for the assertion that MFA is a significant experience for many women.

Of particular interest for PH research are questions about the possible influences of pregnancy risk status, pregnancy complications, or adverse diagnoses on MFA, and whether MFA might affect women's responses to adverse diagnoses. Prior to the present

study, MFA among PH mothers had not been examined. However, previous research in related areas suggested some potentially relevant concepts.

In a qualitative study, McGeary (1994) explored the concept of *guarding* among women experiencing high-risk pregnancies. The author defined *guarding* as protective strategies used by women at risk for adverse pregnancy outcomes, and one such strategy was to limit, avoid, or defer MFA. Fourteen women participated in the study. Risk conditions included advanced maternal age (with a corresponding risk of chromosomal abnormalities), gestational diabetes, premature labor, twin pregnancy, and maternal renal disease. Uncertainty about the outcome of their pregnancies, including whether or not their infants would survive and whether or not they would be normal, characterized these women's experiences. Although all of the women were at risk for a variety of adverse outcomes, all eventually safely delivered healthy newborns.

McGeary's (1994) analysis of interview data revealed processes of *raising guard* and *lowering guard*. *Raising guard* described protective strategies employed by mothers in response to perceived threats to themselves or their fetuses. These strategies included modifying activities for greater safety, seeking reassurance, and *holding back,* which referred to mothers' attempts to avoid becoming emotionally involved with their fetuses and limiting or deferring MFA. One participant expressed fear that if she became too attached, she would not be able to cope if her pregnancy resulted in a loss (McGeary, 1994). *Lowering guard* referred to women's responses after they perceived that the threat to their pregnancies had passed or that the outcome seemed less uncertain. Most of the women described a significant turning point in their pregnancies after which they felt

they had reached a safe stage and were able to move toward connecting with their

fetuses (McGeary, 1994). When they lowered their guard and moved toward connecting,

participants experienced prenatal attachment phenomena such as identifying the fetus

as a baby with an individual personality, communicating with the fetus, and imagining

their post-birth relationship.

The concept of guarding is intriguing in the context of PH. None of the women

in McGeary's (1994) study had abnormal fetal diagnoses or lethal anomalies and all of

them went on to have favorable pregnancy outcomes. Because lethal diagnoses are not

subject to change throughout the course of pregnancy, it seems unlikely that PH mothers

would experience turning points or decrements of perceived threat in the same way that

McGeary's (1994) participants did. The possibility that PH mothers might continue

guarding and avoiding emotional attachment throughout the course of pregnancy was

recognized. However, this possibility was not consistent with my clinical experiences

and deserved further study.

Armstrong and Hutti's (1998) study of MFA among expectant mothers with

previous losses provided some support for the notion that an actual or anticipated

perinatal loss could affect attachment during pregnancy. Thirty-one women who were

greater than 20 weeks pregnant at the time of the study participated. Sixteen of the

participants had experienced miscarriage, stillbirth, or neonatal death in a previous

pregnancy. The other 15 participants had experienced no previous perinatal losses.

Measures included the PAI and the Pregnancy Outcome Questionnaire (POQ), an

instrument designed to measure pregnancy-related anxiety. Women with previous

losses had significantly higher anxiety scores and significantly lower attachment scores.

A non-significant association between higher anxiety and lower attachment was noted

within the previous loss group (Armstrong & Hutti, 1998). Although the participants

were not PH mothers, and did not have lethal diagnoses in their pregnancies during the

study, these findings suggest that apprehension of an adverse pregnancy outcome may

be associated with decreased prenatal attachment. This provides some quantitative

validation of guarding and holding back as described by McGeary (1994).

The concepts of guarding and holding back are also reminiscent of Stroebe and

Schut's (1999) dual process model of bereavement. As outlined previously, the dual

process model proposed that individuals self-regulate grieving by balancing

confrontation and avoidance, and that oscillation between these two processes is healthy

and adaptive. According to this model, only extremes of confrontation or avoidance are

unhealthy or maladaptive. If this is true, then some degree of guarding or holding back

could be a healthy coping strategy for women anticipating adverse pregnancy outcomes.

Prior to undertaking the present study, I recognized that it might generate

findings about MFA among PH mothers. If, as suggested by continuing bonds theory

(Klass & Walter, 2004; Walter, 1996), bereavement is characterized by an ongoing and

possibly lifelong relationship with the deceased, then MFA could influence PH mothers'

lives long after the deaths of their infants. The significance of MFA among PH mothers

needed investigation.

Women's Responses to Abnormal Fetal Diagnoses

A central element of PH experiences is receiving the diagnosis of a lethal fetal anomaly. Previous studies on women's responses to abnormal fetal diagnoses have included quantitative descriptions of psychological distress, qualitative descriptions of experiences, and investigations of the decision whether to terminate or continue affected pregnancies. All of the studies subsequently reviewed were conducted with participants who differed fundamentally from PH mothers, because they included either women who terminated their pregnancies or those whose fetuses had non-lethal diagnoses. Despite these differences, many of the themes and experiences documented in these studies did seem potentially relevant to PH and the studies were therefore included in this review.

Hunfeld, Wladimiroff, and Passichier (1997) conducted a longitudinal study of 46 mothers who received the diagnosis of a fetal anomaly at 24 weeks gestation or greater. Lethal anomalies, and anomalies likely to result in severe physical or mental disabilities, were included. Thirty of the participants terminated their pregnancies, and 16 continued. Standardized instruments such as the Perinatal Grief Scale (PGS), the Impact of Event Scale (IES), and the General Health Questionnaire 28 (GHQ-28), along with a clinical interview, were used to evaluate mothers' responses at 2-6 weeks after the diagnosis, three months later, and 4 years after the loss of the pregnancy or infant. At the time of the first evaluation, 45% of the mothers experienced severe psychological instability as indicated by GHQ-28 scores and clinical interviews. At 3 months post

diagnosis, 22% had severe psychological instability by the same criteria. At 4 years post loss, 38% of participants still had clinically significant psychological distress. Grief symptoms as measured by the PGS persisted, with no significant decrease in despair or difficulty coping subscales over the 4-year duration of the study.

These authors acknowledged that their study likely underestimated participants' long-term psychological distress, because only 29 of the original 46 participants were available for the four-year follow up and attrition may have been higher among the most severely affected women. The small sample size and high attrition did not allow comparison of outcomes between women who continued and those who terminated. Another limitation of this study is the imprecise definition of terms such as "severe psychological instability" and "significant psychological distress" and the reliance on clinicians' judgment to determine whether these conditions were present. If this were a study comparing psychological outcomes between two different groups or two different treatments, this imprecision would be a fatal flaw in the study design. However, as a purely descriptive study, these findings do support the general conclusions that women experience distress following the diagnosis of fetal anomalies, that some women experience very severe distress, and that such distress can persist for at least four years.

After receiving an abnormal fetal diagnosis, women may face the decision whether to terminate or continue their pregnancies. Several studies have investigated this decision and various factors that may influence it.

Sandelowski and Jones (1996) interviewed 15 women and 12 of their male partners to explore their responses and decisions after receiving an abnormal fetal diagnosis. The

diagnoses included fetal demise (n = 2), lethal fetal anomalies (n = 4), and non-lethal

anomalies (n = 9). The two women who learned their fetus had died terminated their

pregnancies. Five women terminated pregnancies after the diagnosis of non-lethal fetal

abnormalities. Eight chose to continue their pregnancies after receiving abnormal

diagnoses, including four non-lethal and four lethal. The primary focus of the study was

the parents' stories of choosing: how they created personal narratives to come to terms

with their experiences and their choices of whether to terminate or continue their

pregnancies.

Ten of the women and couples were interviewed multiple times, once or twice

during their pregnancies and one to four times after delivery. Six of the couples were

interviewed both individually and together. Initial interviews took place within 11 days

to 2 months of receiving the abnormal diagnosis. Interviews were minimally structured,

allowing participants to order their stories according to their own priorities

(Sandelowski & Jones, 1996). Narrative analysis techniques were used. The authors

described an experimental process of "playing with" various combinations of data

elements in order to discern patterns among them (Sandelowski & Jones, 1996, p. 355)

Emphasis was less on the content of the stories and more on how the stories were

constructed.

The authors identified five *emplotments*, or distinctive types of stories,

differentiated by the way the storytellers attributed moral responsibility for their choices

(Sandelowski & Jones, 1996). *Nature's choice* was an emplotment characterized by

parents' perception that the choice to terminate had been made for them, either because

the fetal anomaly was lethal or because the fetus had already died. *Disowned choice* was a type of story told by parents for whom the locus of moral agency was God's will. *Choice lost* referred to narratives of women who did not have the option to terminate, due to incorrect diagnosis or diagnosis too late in pregnancy. One woman and one couple who had difficulty deciding whether to terminate or not, and who recognized reasons to continue as well as reasons to terminate, constructed narratives of *close choice*. Both of these pregnancies were terminated. *Choice found* described the story told by one woman who continued her pregnancy as long as she was emotionally able to do so, then terminated when it became too difficult for her to continue.

In my view, some of the findings related to these emplotments are unclear or problematic. The only participants whose choices were recognized as being informed by their religious views were those in the *disowned choice* category. The authors seemed to be implying that people who make important life decisions based on religious beliefs are abdicating moral agency or responsibility for their choices. This was a potentially controversial assertion for which the authors did not provide supporting evidence. The *choice found* category also seemed unclear. From the description of this participant's story, it seemed that she initially wanted to continue her pregnancy but later felt emotionally unable to continue. The authors' label seemed to imply a discovery or reclaiming of lost agency, but the participant's story seems more like a change of choice, or a realization that she was unable to implement her original choice. A third questionably labeled category was *close choice*. The label "close" implied equal likelihood among multiple outcomes, but all the participants who told these kinds of stories

decided to terminate. Perhaps "ambivalent choice" would have better described a decision in which one recognized reasons both for and against the choice that was ultimately made. Overall, the authors' analysis of the data in terms of emplotments was interesting, but some of the emplotments did not seem to be as clearly conceptualized as others.

In addition to the five emplotments of choice operating on the level of individuals and couples, the authors identified larger narrative contexts operating on a cultural level. For example, the idealized "story" of the prevailing medical-obstetrical culture is one of patients making active, informed, and voluntary choices to undertake prenatal testing (Sandelowski & Jones, 1996). Findings from this study undermined this prevailing cultural narrative. Participants described "backing into" testing, undertaking "routine" or "standard" tests that they often did not understand, and consenting to tests out of a nonspecific and uninformed desire "to do everything for our baby" (Sandelowski & Jones, 1996, p. 355).

This insightful critique of the prevailing cultural 'story' of prenatal testing is germane to the study of PH. The majority of PH mothers probably 'back into' testing in much the same way these participants described. It is unclear whether or not the other findings of this study, such as the five distinct emplotments, would apply to the experiences of PH mothers. The heterogeneity of Sandelowski and Jones' (1996) sample, representing lethal and non-lethal diagnoses and both continuations and terminations of pregnancy, may have generated some narrative types that might not be represented among PH mothers.

The narrative approach to qualitative research, further discussed below, was fruitful for this study. The researchers were able to synthesize the data in understandable ways, while retaining a distinct diversity of voices. The five emplotments and the participant verbatim quotes supporting them illustrated profoundly different participant perspectives and experiences. The ability to portray different perspectives and values within a coherent overall account is a strength of qualitative research approaches.

One of the interesting findings of this study was that different participants 'storied' the same or similar events in very different ways. For instance, one couple who had a fetus diagnosed with Down syndrome considered their child a blessing from God and constructed a *disowned choice* narrative. They continued their pregnancy. Couples with the same diagnosis who constructed *close choice* narratives perceived Down syndrome as a negative or stigmatized condition and elected to terminate (Sandelowski & Jones, 1996). This exemplified the fact that narrative constructions do not simply reflect how individuals described their life experiences. Rather, they reflect and to some extent may determine how individuals made choices and organized their lives.

Sandelowski and Barroso (2005) integrated the findings of 15 qualitative studies in another investigation of expectant parents' responses to abnormal fetal diagnoses. Any qualitative study of parents living in the United States who learned during pregnancy of a fetal impairment was eligible for inclusion. Both metasummary (quasi-quantitative analysis of findings) and metasynthesis (qualitative integration of findings)

techniques were used to synthesize the qualitative studies in this area (Sandelowski & Barroso, 2005).

Included studies were analyzed using a 14-item reading guide developed specifically for the study (Sandelowski & Barroso, 2005). The metasummary procedure involved extracting relevant statements of findings from the 15 included studies, paraphrasing them into meta-findings, and then calculating the frequency for each meta-finding. In the process, the authors analyzed 39 meta-findings. Metasynthesis consisted of identifying the prevailing topics and themes among the meta-findings.

The four most prominent meta-findings were (a) time-sensitive decisions the parents were forced to make, (b) parents' efforts to both obtain and avoid information in making decisions, (c) greater devastation felt by women than men following the diagnosis, and (d) the traumatic and reverberating effects of the diagnosis (Sandelowski & Barroso, 2005). Time-sensitive decisions referred to in the first meta-finding included whether to terminate or continue the pregnancy, how to terminate if that option was chosen, how to handle fetal remains, and how to tell others. The second meta-finding reflected the fact that parents seeking to obtain information to assist in decision making, and avoiding information that might undermine or contribute to regret about a decision already made, were both commonly reported. The third meta-finding, that women experienced greater distress than their male partners, was common to all of the studies that compared men's and women's responses. The fourth meta-finding emphasized the fact that adverse prenatal diagnoses were experienced as traumatic life events with ongoing effects in subsequent pregnancies and beyond (Sandelowski & Barroso, 2005).

In the studies reviewed by Sandelowski & Barroso (2005), the certainty of fetal death was identified as a factor associated with the decision to terminate. The decision to continue an affected pregnancy was influenced by unavailability or unacceptability of termination and/or the hope that the baby might be normal. The desire to see or hold the fetus, mourn his or her death, and preserve mementoes of his or her existence was also commonly reported. Not doing these things was reported as a source of regret. Diagnoses of fetal impairment were seen as traumatic life events with long-lasting effects, both positive and negative (Sandelowski & Barroso, 2005). The authors noted that the most prevalent topical focus of the included studies was termination of pregnancy following a positive genetic diagnosis (Sandelowski & Barroso, 2005). It may be that the predominance of parents who terminated, as opposed to the participants in the present study who planned to continue their pregnancies, would result in different findings.

Integration or synthesis of qualitative findings, whether by metasummary, metasynthesis, or other methods, is a promising development in health research. The ability to systematically incorporate the results of multiple studies into an organized body of knowledge has the potential to increase the utility of qualitative research. The approach used by Sandelowski & Barroso (2005), incorporating both qualitative and quasi-quantitative methods to summarize and synthesize the findings, provided more perspectives on the data than either approach would independently.

Another qualitative study, published subsequently and thus not included in Sandelowski and Barroso's (2005) meta-study, explored decision-making and

bereavement experiences among 30 women who terminated pregnancies after receiving

abnormal fetal diagnoses (McCoyd, 2007). Participants were women, 21 to 45 years of

age, who each had a desired pregnancy within a committed relationship, received the

diagnosis of a fetal anomaly, and terminated their pregnancies. Originally the author's

intent was to limit participation to women who had terminated within the last year, but

this limitation was dropped in response to interest from potential participants whose

experiences were more than one year past. Information about the time intervals between

termination and participation for these additional participants was not reported.

Interviews were transcribed and analyzed for themes that characterized the women's

experiences.

The two major themes McCoyd (2007) identified were *mythic expectations* and

excruciating dilemmas. Both of these major themes were complex and incorporated a

number of sub-themes.

Sub-themes comprising *mythic expectations* reflected societal messages and

participants' comforting beliefs about their own pregnancies. For example, the sub-

theme *our baby would be fine* was characterized by the participants' tendency to negate

the possibility of problems in their pregnancies. Rather than regarding prenatal

screening as part of a process designed to detect fetal abnormalities, they thought of

screening as part of 'good prenatal care,' a process designed to ensure the delivery of a

healthy, normal newborn. Because they had participated in 'good prenatal care,' the

women felt they were entitled to healthy offspring. Another aspect of *our baby would be*

fine was the belief that fetal abnormalities only "happened to other people" (McCoyd,

2007, p. 39).

These findings are reminiscent of Sandelowski and Jones' (1996) critique of the

prevailing cultural stories about prenatal testing. Like the participants in the earlier

study, McCoyd's (2007) participants' perceptions about prenatal screening were

incongruent with the medical culture's presumption of informed patients undergoing

testing for rational diagnostic reasons. McCoyd's (2007) participants were

predominantly highly educated, and even those participants with advanced biomedical

education still exhibited mythic expectations. This fact further undermined the implicit

assumption about informed consent in the prevailing medical cultural story; that

information leads to reasonable expectations and rational decisions about medical

procedures and tests.

Because McCoyd's (2007) participants elected to terminate their pregnancies,

they differ from PH mothers, who by definition, choose to continue. It is not clear,

therefore, whether her findings would be applicable to PH mothers. If, for instance, PH

mothers' decision to continue rather than terminate is related to different expectations

about prenatal screening, then McCoyd's (2007) observations about the expectations of

women who decided to terminate may not apply. If, however, women's expectations

about prenatal screening are largely determined by societal and/or cultural messages

(McCoyd, 2007; Sandelowski & Jones, 1996), or by women's desire to believe they will

have healthy pregnancies (McCoyd, 2007), then it seems likely that PH mothers

undertake prenatal screening with similar expectations.

Participants in McCoyd's (2007) study also demonstrated mythic expectations after termination, particularly in their expectations related to grief. Although the women did expect to experience grief, they expected their grief feelings to follow a set of stages and proceed quickly to resolution. This sub-theme was labeled *the healing would all be done by then*, reflecting an expectation that grief would be resolved by the time for the first post-termination provider visit. The persistence, complexity, and intensity of their grief contradicted these women's expectations. This finding suggested that there may be commonalities between McCoyd's participants and women experiencing PH.

The second major theme McCoyd (2007) identified was *excruciating dilemmas*. Participants in the study reported experiences of bonding and identifying their fetuses as their babies. One participant reported "When we found out we were having a son at 19 weeks, he became part of our family. He was given a name and we bonded with him" (McCoyd, 2007, p. 42). The experience of bonding exposed the women to grief and guilt regarding the decision to terminate. Choice, in the context of continuation or termination, was perceived as a dilemma because neither option allowed the woman's goal of a healthy child.

Choice was also identified as a dilemma in the context of the polarizing societal debate over abortion. Participants in the study were acutely aware of this ongoing debate and felt alienated by both the pro-life and pro-choice "camps" (McCoyd, 2007, p. 43). They felt alienated by the pro-life ideology because it did not condone their willingness to terminate their pregnancies. They felt alienated by the pro-choice

ideology because they felt it rejected their emotional attachment to what they identified as their "babies" (McCoyd, 2007, p. 44).

Another dilemma was that of identity. The women felt they had to choose either the identity of the mother of a disabled child or the identity of a bereaved mother (McCoyd, 2007). Participants also felt alienated by a social context in which they were not regarded as mothers of infants, despite the fact they identified themselves as mothers. This theme echoed constructivist insights about a person's need for social validation of his or her constructions of identity.

The *dilemma of disability* was also identified as characteristic of participants' experiences. A prevailing cultural context claims acceptance of all people, including those with disabilities, but stigmatization of disabled people persists. Women expressed feelings of guilt for not accepting a disabled child or for believing they would not be able to parent a disabled child. They also expressed concerns about potential negative experiences a disabled child might face in life, as well as concerns about the impact on their lives and families of raising a disabled child (McCoyd, 2007).

Some of these dilemmas do not appear to be applicable to the decisions PH mothers face. For instance, a lethal diagnosis might diminish concerns about the long-term consequences of living with a disability. Neither, presumably, would PH mothers experience the kind of bilateral alienation from both sides of the abortion debate that these participants reported since PH mothers have chosen to continue rather than terminate.

Despite the differences between McCoyd's (2007) study population and PH mothers, the latter may experience some similar dilemmas. One relevant theme could be lack of social support and validation when they are not recognized as "real mothers". McCoyd's (2007) participants also described conflicts faced by their male partners between social expectations of masculine stoicism and their own feelings of grief and their need to express emotions. It is possible that male partners of PH mothers could experience similar conflicts, but this was not a focus of the present study.

McCoyd's (2007) findings may also be relevant to understanding PH mothers' decisions to continue their pregnancies. One possible hypothesis, that the decision to continue or terminate could be explained by differences in MFA between women who terminate and women who continue, is refuted by these women's reportedly intense feelings of bonding prior to diagnosis and their decision to terminate. Rather than a dynamic whereby prenatal attachment is significant for mothers who continue, but less significant for mothers who terminate, these findings suggested that MFA is probably a significant factor in the experiences of women who receive abnormal fetal diagnoses, irrespective of the decision to continue or terminate.

Factors influencing the decision to terminate or continue were the focus of a retrospective study of women whose fetuses were diagnosed with one of seven common chromosomal abnormalities (Shaffer, Caughey, & Norton, 2006). A retrospective review including all 833 women from one perinatal center who received such diagnoses over a 20-year time span was undertaken to identify possible predictors of the decision to terminate. The type of abnormality, timing of diagnosis during pregnancy, and maternal

age and ethnicity were abstracted from medical records. The diagnoses included both lethal and non-lethal abnormalities. Chi-square tests were used to identify differences between women who terminated and those who continued, and multiple regression was used to control for potential confounds.

The difference of greatest magnitude between the groups was the severity of the anomaly. Anomalies with worse prognosis (lower developmental potential and/or shorter life span) were more prevalent in the termination group. Hispanic women were less likely to terminate than women from other ethnic groups. Maternal age was a factor in the one statistical interaction that was identified: older women were more likely to terminate for anomalies with worse prognosis, but the age difference was not significant when the anomalies were associated with a less severe prognosis (Shaffer et al., 2006).

Descriptive, retrospective studies of this kind sometimes can raise more questions than they answer, such as possible factors influencing termination in the Hispanic culture or the impact of maternal age with diagnoses of severe anomalies. Apropos of PH, it is possible that the construct 'anomalies with worse prognosis' could influence a woman's termination decision differently if she were contemplating a long lifetime with severe disability for her child, versus a radically shortened lifespan characteristic of lethal anomalies. In this sense, 'anomalies with worse prognosis' does not seem to be a homogenous entity. The strength of Schaffer and colleagues' (2006) methodology was its ability to include all women from a particular center, thus reducing selection biases related to willingness to participate in research. However, the lack of depth of the findings limits explanatory power.

Korenromp and colleagues (2007) explored in somewhat greater depth women's decision to terminate after the diagnosis of Down syndrome. Seventy-one participants from a medical center in Holland completed a questionnaire 4 months after termination. Those who agreed to participate represented 77% of all potentially eligible participants. The questionnaire included items related to women's motivations for the decision to terminate, reasons for doubt about their decision, and perceived influence and/or pressure in decision-making. The questionnaire was developed based on responses to open-ended discussions in a pilot study group of 40 women and consisted of 27 items. Each item was a statement about the decision to terminate. Participants were asked to rate whether each item was applicable to their decision to terminate, on a scale ranging from 1 (very much) to 5 (not at all). Responses of 1 (very much) or 2 (to some extent) were considered positive and expressed as percentages. For example, the item "I believed the child would never be able to function independently" generated positive responses from 92% of participants (Korenromp et al., 2007).

Two major classifications of motivations were identified: those related to the child's interests and those related to the interests of the mother and/or her family. Examples of these motivations are provided in Table 3. Participant responses indicated that most women considered the affected child's interests, the interests of their families, and their own interests in making their decisions. There was remarkably high agreement between participants regarding motivations to terminate, with several items scoring 70 to 90% positive responses (Korenromp et al., 2007).

Another set of items addressed possible reasons women may have doubted their decisions to terminate. Most of the participants reported some doubt about the decision to terminate, with only 35% reporting no doubts at all. The doubt-related items generating the most positive responses were "My reason was in conflict with my feelings" (49%), "I had the feeling of killing a child" (43%), and "My partner and I disagreed" (38%) (Korenromp et al., 2007). Regarding influences on their decisions, results indicated that partners were most influential and physicians second most influential, followed by family and friends and other health providers. Despite these findings related to influences on their decisions, very few of the women (13%) reported feeling pressured in their decision.

One potential weakness of this study design was the possibility that the list of items on the questionnaire might not have included every motivation or reason for doubt among the participants. In particular, the fact that the highest scoring doubt-related item only rated 49% positive responses suggested the possibility that some of the participants may have had reasons for doubt not represented by any item on the questionnaire. The fact that the items were developed from responses to open-ended questions in a pilot study only partially ameliorated this concern, because the pilot group may not have represented the full range of experiences present in the study group.

It is not clear how Korenromp and colleagues' (2007) findings among women with a fetal diagnosis of Down syndrome might or might not be applicable to PH mothers. Absent additional complications, Down syndrome is not a lethal anomaly.

Table 3

Motivations for Termination after Diagnosis of Down Syndrome

Type of Motivation	Statement	Percentage of participants ($n = 71$)
Related to the child	I believed the child would never be able to function independently	92
	I considered the abnormality too severe	90
	I considered the burden for the child itself too heavy	83
	I worried about the care of the child after my (our) death	82
Related to the mother or family	I considered the burden too heavy for my other children	73
	I considered the burden too heavy for myself	64
	I did not want a disabled child	63
	I thought I would become unhappy at having this child	61
	I considered the burden too heavy for my relationship	55

Note: Percentage of participants includes those who agreed that the statement was "very much" or "to some extent" applicable to their decision Eighteen motivations were documented. Motivations scoring less than 50% are not listed. From Korenromp, M. J., Page-Christiaens, G. C. M. L., van den Bout, J., Mulder, E. J. H., & Visser, G. H. A. Maternal decision to terminate pregnancy after a diagnosis of down syndrome. *American Journal of Obstetrics and Gynecology, 196*, 141e1-149e11. Copyright 2007 by Elsevier, Inc. Adapted with permission.

The anticipation of a relatively normal lifespan, albeit with significant limitations, could well influence a woman's decision differently than a shorter life followed by death in hospice care. Like these Down syndrome mothers, PH mothers may indeed consider their own interests and the interests of their families, as well as the interests of their affected offspring, in making their decisions.

Understanding PH mothers' decision making processes, and how they arrive at the decision not to terminate their pregnancies after the diagnosis of a lethal anomaly, is potentially important for health professionals. Whatever factors affect their decisions, they probably reflect what is most important to PH mothers. Their reasons for continuing their pregnancies may reflect their perceived needs, their values, the interests of their families, or possibly even their deeply held beliefs about life and death. Any or all of these factors could be important for health providers seeking to understand PH mothers and help meet their needs.

Despite the lack of studies specific to PH prior to the present study, the literature on women's responses to abnormal fetal diagnoses supports some broad generalizations that could potentially apply to PH mothers. Receiving such a diagnosis is deeply shocking, likely in part because women do not seem to anticipate the possibility of abnormal findings when they undergo testing. They are likely to face difficult and unanticipated decisions that may involve dilemmas or conflicts. An abnormal diagnosis is profoundly distressing, and this emotional distress probably has long-term as well as

immediate effects. All these factors could influence the experiences of PH mothers-and warranted further study.

Generally, the body of knowledge related to women's responses to abnormal fetal diagnoses prior to the present study was developed in populations that differ from PH mothers in potentially significant ways. Of particular concern were the inclusion of non-lethal diagnoses and the preponderance of women who chose to terminate in these study populations. These inclusions brought into question the applicability of previous research findings to PH mothers. Such limitations of previous knowledge highlighted the need for PH-specific research and supported the potential utility of the present study.

Quantitative Research on Perinatal Loss

There is a substantial body of literature on women's responses to perinatal loss, including different kinds of losses such as miscarriage, previable birth, stillbirth, and neonatal death (see *Definition of Terms*, p. 10). None of these variants encapsulates all the experiences of PH mothers, but there are some possible commonalities between PH these other kinds of losses. Since the experiences of PH mothers have not been extensively studied, reviewing the literature on other variants of perinatal loss could help to anticipate some of the responses that PH mothers are likely to have.

Much of the quantitative literature on perinatal loss is descriptive, and most of these studies focus on psychiatric phenomena such as depression, anxiety, and post-traumatic symptoms. Exemplary of these generalizations is Stirtzinger and colleagues'

(1999) study of women's responses to spontaneous miscarriage. The participants were 294 women who had experienced a miscarriage. Standardized psychometric instruments were used to assess symptoms of depression, self-esteem, guilt, stress, and intimate relationship adjustment at intervals of three months and one year following their miscarriages.

Results suggested a prevalence of distressing symptoms among the participants (Stirtzinger et al., 1999). Participants' mean depression scores were in the "at risk" or "in need of treatment" ranges at both time intervals, and were nearly double the general population mean for the depression instrument that was used. Measures of intimate relationship adjustment indicated that relationship problems were common. Nearly half of the participants believed that they were partly or totally at fault for their miscarriages. Women who had high conflict in their relationships and those who believed that they were at fault had higher depression scores. At both time intervals, about 90% of the women rated the miscarriage as being stressful or very stressful, with about 35% reporting that the miscarriage was more stressful than any other life event. Women who had multiple miscarriages and those with no living children had the lowest self-esteem scores. Participants' scores on all the measures were generally stable over time. The only time effect noted was an interaction between participant age and time post miscarriage: compared to older women, younger women were more symptomatic at the 3 month interval but less so at the one year interval, while older women continued to be equally symptomatic at both time periods.

Stirtzinger and colleagues (1999) did not address a number of factors that could possibly influence women's response to miscarriage, such as gestational age at the time of the loss and the degree of maternal attachment to the pregnancy or fetus. The fact that no main time effects and only one interaction time effect were noted suggests that either (a) the time interval of the study was too short to detect changes that do exist in women's symptoms over time, or (b) women's symptoms do not change with time post miscarriage. The depression instrument used in this study does have established norms for the general population, allowing the very germane observation that these participants had much higher depression scores than the general population. Similar observations could not be made for other constructs measured in the study. For instance, although relationship conflict was common among these participants, one does not know whether it was more prevalent than in the general population. The use of normed instruments, or inclusion of a comparison group of women who had not had miscarriages, would have contributed to a better understanding of women's responses to miscarriage. The effect of participant age on symptoms was intriguing and suggested that closer study of the experiences of women in different age groups is warranted.

Wheeler and Austin (2000) studied the responses of single adolescent women ages 12-19 to perinatal loss (miscarriage, stillbirth, or neonatal death). A 102-item Loss Response List (LRL) was developed based on a review of the literature on adolescent grief. For each item, participants were asked to select one of five Likert-type responses ranging from *not like me* through *like me all of the time*. To test the instrument, a cross-sectional comparison design was used: the instrument was administered to 23

participants who had experienced perinatal loss and a comparison group of 17 who had not.

Based on the observed Cronbach's alpha coefficient and inter-item correlations, the instrument was revised to 83 items divided into four subscales: physical responses (27 items), emotional responses (25 items), social responses (11 items), and cognitive responses (20 items). In a follow-up study (Wheeler & Austin, 2001), the revised instrument was administered to 164 adolescent females in four groups: (a) never pregnant (n = 62), (b) currently pregnant without history of pregnancy loss (n=50), (c) history of pregnancy loss (n=31), and (d) currently pregnant with history of pregnancy loss (n=21). The four groups were comparable in terms of demographic variables. A depression instrument well-validated in non-adult populations, the Children's Depression Inventory (CDI), was also administered.

Analysis showed that the instrument and the four subscales were reliable, with alpha coefficients of .98 for the overall instrument and .88-.96 for the four subscales. ANOVA was used to compare scores on the LRL and CDI between the four groups. Participants with a history of pregnancy loss had higher LRL total, LRL emotional, LRL cognitive, and CDI scores than those without pregnancy losses. The pregnancy loss and pregnant groups had higher LRL physical scores than the never pregnant group. All of the subscale comparisons demonstrated statistical significance, with observed inter-group differences and significant correlations with depression scores.

The findings of Wheeler and Austin's (2000; 2001) studies support some basic conclusions about the nature of responses to perinatal loss. As reported by Stirtiznger et

al (1999), the generalization that perinatal losses are associated with significant distress was supported. For these adolescent participants at least, perinatal loss was a multi-dimensional experience with distressing effects in the social, cognitive, physical, and emotional domains. Although none of these participants met the definition of PH, the adolescents' experiences were similarly complex and multi-dimensional.

A few studies have compared psychiatric outcomes between mothers experiencing different variants of perinatal loss. Zeanah, Dailey, Rosenblatt, and Saller (1993) used a matched groups design to compare grief intensity and depression among women who terminated pregnancies due to abnormal fetal diagnoses and women who experienced spontaneous prenatal losses. Twenty-three women were included in each group. Fetal diagnoses included lethal and non-lethal anomalies. The groups were matched for socioeconomic status, education, number of children, and gestational age at the time of the loss or termination. The Beck Depression Inventory (BDI) and Perinatal Grief Scale (PGS) were administered 2 months subsequent to the loss. The PGS is discussed further below.

Symptoms of depression and grief were prevalent in both groups, but there were no statistically different differences between the two groups (Zeanah et al., 1993). A methodologically similar matched groups study (Peppers & Knapp, 1980) found no differences in symptoms between women who experienced miscarriage, stillbirth, and neonatal death. Both of these studies were limited by the short time interval between loss and measurement, and by the narrow range of outcomes measured. The latter limitation is critical. It seems unlikely to me that there are no meaningful differences in

women's experiences of these very different kinds of pregnancy loss. The fact that

measures of distress or psychiatric symptoms do not demonstrate any differences

suggests that these are probably not the salient variables for understanding different

kinds of loss. The general observation that all variants of perinatal loss are associated

with quantifiable distress is worthy of note.

Zeanah and colleagues' (1993) study used the PGS instrument to distinguish

grief from other measures of psychological distress. Indeed, the PGS was originally

developed to address the need to measure grief as a construct distinct from other

bereavement-related symptoms such as depression and anxiety (Toedter, Lasker, &

Janssen, 1988). The original PGS consisted of 104 Likert items (Toedter et al., 1988), later

revised to 33 items (Potvin, Lasker, & Toedter, 1989). The PGS has three subscales:

Active Grief, Difficulty Coping, and Despair. Table 4 includes examples of items

corresponding to the three subscales.

The PGS has been well-validated in numerous studies. In a retrospective review

of 22 studies using the PGS, Cronbach's alpha values ranged from .88 to .93 (Toedter et

al., 2001). In the same review, convergent validity was demonstrated by associations

with grief-related constructs such as depression. The PGS performed well in multiple

perinatal bereavement populations, including both mothers and fathers who had

experienced miscarriage, stillbirth, or neonatal death (Toedter et al., 2001).

There are some weaknesses of the PGS. The instrument was developed

empirically, not from a clear conceptual or theoretical definition of perinatal grief. I find

that this lack of clarity on the conceptual and theoretical levels makes it difficult to

interpret the meaning or significance of the PGS score. Additionally, despite the authors' effort to distinguish between perinatal grief and psychiatric symptoms, the PGS reflects only limited dimensions of bereavement responses and process. In terms of Rubin's (1999) two-track model, the PGS items and subscales all fall within track one; psychosocial functioning and symptoms of grief. The PGS does not address dimensions of meaning reconstruction, social negotiation, personal growth, or ongoing relationship to the deceased as suggested by developments in bereavement theory.

Janssen and colleagues (1997) prospectively examined predictors of grief intensity in another study using the PGS. A battery of well-validated psychometric instruments measuring physical and psychological symptoms, personality factors, intimate relationship quality, and social support were administered to a cohort of 2140 women in the first trimester of pregnancy. 227 of these women subsequently experienced pregnancy losses at various stages of gestation. The women who experienced pregnancy losses were assessed longitudinally using the PGS over four measurement periods: (a) as soon as possible after the loss, and (b) 6 months, (c) 12 months, and (d) 18 months post loss. There was very little attrition for a longitudinal study: of the 227 post-loss participants, 94% completed all four questionnaires.

Gestational age at the time of the loss, psychiatric symptoms prior to the loss, and absence of living children were all associated with higher grief intensity. Grief intensity decreased over time. One significant interaction between time and predictor variables was identified: women with more pre-loss psychiatric symptoms had a more

Table 4

Sample PGS Items

PGS Subscale	Sample Items
Active Grief	"I am grieving for the baby."
	"I cry when I think of him/her."
	"I can't avoid thinking about the baby."
Difficulty Coping	"I feel I have adjusted well to the loss."
	"I find it difficult to make decisions since the baby died."
	"I can't keep up with my normal activities."
Despair	"The best part of me died with the baby."
	"I try to laugh, but nothing seems funny anymore."
	"I feel worthless since he/she died."

Note: Derived by the author from Potvin, L., Lasker, J. N., & Toedter, L. J. Measuring grief: A short version of the perintal grief scale. *Journal of Psychopathology and Behavioral Assessment 11*(1), 29-45. Copyright 1989 by Springer Inc.

intense initial grief response, but this difference diminished over time (Janssen et al., 1997).

The prospective design, particularly the measurement of predictor variables prior to the pregnancy loss, is a strength of this study because this design ensured that psychological effects of the pregnancy loss itself did not influence the values of the predictor variables. Since the pregnancy losses had not occurred at the time of baseline measurement, independent measurement of predictors and outcomes was achieved.

The finding of this study that is most relevant for the study of PH was the positive association between grief intensity and gestational age at the time of the loss. Unlike mothers experiencing most other kinds of perinatal losses, mothers who are diagnosed with lethal fetal anomalies are presented with some degree of choice about the gestational age at which their losses will occur. Those who choose PH over termination are essentially opting for their losses to occur at a later stage of pregnancy or in the newborn period. If the findings of Janssen and colleagues (1997) are applicable to PH mothers, they would presumably experience more grief intensity than mothers who chose to terminate.

This raises a conceptual question, however; one that makes the significance of Janssen and colleagues' (1997) study difficult to interpret. Recalling Stroebe and Schut's (1999) dual process model, and the observation that individuals seem to self-regulate their "dosage" of grieving to achieve an optimal balance of confrontation and avoidance, it is unclear whether the higher grief intensity noted by Janssen and colleagues (1997) would be a desirable, undesirable, or neutral outcome. If grief is truly an experience

subject to gradations of "too much," "too little," and "just right," then simply quantifying grief without comparison to some optimal standard is meaningless. The likelihood that differences in the optimal balance between confrontation and avoidance exist between individuals, and within the same individual at different times, further complicates this question. Indeed, without clarification of this issue on the conceptual-theoretical level, the value of measuring grief intensity is open to doubt.

Another area of inquiry where questions have been raised about the desirability of exposure to, versus protection from, grief-provoking experiences is the question of contact between mothers and their dead or dying infants. Perhaps as a backlash against previous health care practices that discouraged such contact, emerging clinical wisdom throughout the 1980s and 1990s was to encourage bereaved parents to hold, touch, and talk to their infants. This practice was supported by some research evidence: in one study, half of mothers who did not see their infants later wished they had done so, and women who had mementoes of their lost infants such as photos, footprints, or a lock of hair reported less anxiety than those who did not have mementoes (Rådestad, 2001).

However, encouraging mother-infant contact in perinatal bereavement has been called into question by the findings of a study of psychiatric symptoms among women with a history of stillbirth (Hughes, Turton, & Evans, 2002). Sixty-five women with a history of stillbirth in their previous pregnancies were assessed in the third trimester of their viable subsequent pregnancies. Participants were categorized into three groups based on their own recollections: (a) those who saw and held their stillborn infants, (b) those who saw but did not hold them, and (c) those who neither saw nor held them.

Depression, anxiety, and post-traumatic symptoms were measured with standardized instruments including the Beck depression inventory, the Spielberger state anxiety scale, and the PTSD-1 interview (Hughes et al., 2002). Women who had held their stillborn infants were most likely to be depressed, and had higher anxiety and post-traumatic symptoms. Women who neither held nor saw their infants were least likely to be depressed.

In a second phase of Hughes' and colleagues (2002) study, Turton, Evans, and Hughes (2009) followed up with 52 of the original 65 participants who had experienced previous stillbirths. At the time of the first phase described above, the participants were experiencing normal pregnancies subsequent to previous stillbirths. At the time of the second phase, the offspring of those normal subsequent pregnancies were 6 to 8 years old. The outcome variables in the second phase included psychological morbidity as assessed by a structured clinical interview, and whether or not the participants had experienced partnership breakdown (i.e., dissolution of the relationship between the parents of the normal pregnancy represented in the first phase). Predictor variables included sociodemographic factors, history of psychological problems, and factors related to the stillbirth experience, including whether the mother held or saw her stillborn infant. In this phase of the study, women who held their stillborn infants were more likely to have experienced partnership breakdown than those who did not. Women who held their infants also had higher post traumatic symptoms.

In contrast to the findings of these studies which suggested that such contact may be harmful, Rådestad and colleagues (2009) found beneficial effects of contact

between mothers and their stillborn babies. Their study included a nationwide cohort of women who lost infants to stillbirth in Sweden in 1991. Of 380 stillbirths recorded in Sweden that year, 309 (81%) of the mothers were represented in the study. Data collected included factors related to their stillbirth experiences, anxiety as measured by the Spielberger's State and Trait Anxiety Inventories, depression as measured by the Center for Epidemiologic Studies Depression Scale, and an inventory of somatic symptoms created by the researchers based on review of the literature on perinatal loss.

A majority of women in this study (68%) had held their stillborn infants. Mothers' perceptions that care providers were supportive of them holding their infants were the strongest predictor of whether or not they did so. Outcomes were assessed separately for women whose stillbirths occurred at greater than 37 weeks and those that occurred between 28 and 37 weeks. There were no losses prior to 28 weeks gestation represented in the study (Rådestad et al., 2009).

For women who had stillbirths at greater than 37 weeks, those who had not held their infants were significantly more likely to experience headaches and sleep disorders. Women who had stillbirths between 28 and 37 weeks and did not hold their infants were more likely to have stomach complaints. Neither gestational age group demonstrated statistically significant differences in symptoms of anxiety or depression between women who held versus those who did not hold their infants (Rådestad et al., 2009).

These studies by Hughes and colleagues (2002), Turton and colleagues (2009), and Rådestad and colleagues (2009) have generated controversy among researchers and

clinicians interested in perinatal bereavement, but they are limited in some important

ways. As Rådestad and colleagues (2009) noted, the stillbirths represented in the Hughes

and Turton studies occurred in the 1980s and early 1990s due to the time intervals

between the stillbirths and the subsequent pregnancies which were actually studied. The

1980s and 1990s were times of great change in providers' attitudes and approaches to

women experiencing stillbirth. In light of Rådestad and colleagues' (2009) findings about

the influence of women's perceptions of provider supportiveness, differences in

provider attitudes and approaches between the 1980s and early 1990s versus today

could be significant. Perhaps more important is these studies' focus on symptoms of

psychological or psychiatric distress as their main outcome variables. As noted above,

emerging theories of grief suggest that reconstruction of meaning and ongoing

attachment to the deceased may be important phenomena in bereavement processes and

outcomes. If these are significant aspects of grief recovery, the failure to assess them in

studies of perinatal bereavement outcomes is a major limitation.

Additionally, emerging insights about personal growth in the aftermath of

bereavement suggest that grief-related distress may trigger reflections, re-evaluations, or

spiritual seeking which can contribute to desirable changes in self-concept and

interpersonal relationships (Wright & Hogan, 2008; Tedeschi & Calhoun, 2008). If this is

the case, it may be erroneous to define desirable bereavement-related outcomes solely by

the absence of distressing symptoms.

The question of contact between mothers and their infants in perinatal loss, and

the effects of this contact on bereavement experiences, is an important one in the context

of PH because PH is essentially a choice for more contact and interaction throughout

pregnancy, childbirth, and the newborn period. In my opinion, it is critical to address

the full dimensions of post-loss experiences in the context of mothers' ongoing lives,

rather than just the presence or absence of grief-related symptoms.

Qualitative Research on Perinatal Loss

In addition to the quantitative literature, there is a substantial body of qualitative

research on perinatal loss. Like the quantitative literature, the qualitative literature

includes research on different variants of perinatal loss and different aspects of mothers'

responses. Unlike the quantitative literature, qualitative studies suggest a much broader

range of responses than psychiatric symptoms. Again, none of these studies specifically

addressed the experiences of PH mothers, but research in related aspects of perinatal

loss suggested some likely aspects of the PH experience.

Swanson's (1986) landmark study examined women's experiences of caring from

health providers, particularly nurses, following miscarriage. Twenty women were

interviewed for the study. The findings were later synthesized with the findings of two

other qualitative studies; one focusing on the experiences of parents and professionals

caring for infants in a neonatal intensive care unit, and another focusing on the

experiences of young mothers in a mental health intervention project (Swanson, 1991).

A common theme in the women's accounts in all three studies was their need to

find and maintain structures of meaning in life that made sense to them. The women

wanted to be cared for as persons whose experiences had unique meanings in the

contexts of their own lives (Swanson-Kauffman, 1986). Care that was based on such

understanding was regarded as personalized, comforting, supportive, and healing

(Swanson-Kauffman, 1986). Based on these insights, the author developed a theory of

caring that included five caring processes: *knowing*, *being with*, *doing for*, *enabling*, and

maintaining belief (Swanson-Kauffman, 1986; Swanson, 1991)

    Knowing was striving to understand events as they have meaning in the life of

the other, and thoroughly assessing all aspects of his or her condition and reality

(Swanson, 1993). *Being with* was being emotionally present, conveying availability, and

sharing in the feelings and meanings of the other (Swanson, 1991). *Being with* also

entailed avoidance of burdening the other with one's own meanings and feelings

(Swanson, 1991). *Doing for* described actions that are performed on behalf of the other's

long term well being. *Doing for* also meant protecting the other and preserving the

other's wholeness and dignity (Swanson, 1991). The process of *enabling* was defined as

facilitating the other's passage through life transitions and unfamiliar events (Swanson,

1993). *Enabling* also included informing and explaining, supporting and allowing,

validating and giving feedback, and helping the other to think things through (Swanson,

1991). *Maintaining belief* consisted of holding the other in esteem, believing in the other,

and sustaining faith in his or her ability to get through a difficult life transition and face

a future with meaning (Swanson, 1991).

    Swanson's work, particularly her original study on women who had

miscarriages (1986) was limited due to inadequate description of central research

processes such as participant recruitment, data collection techniques, and analysis of

data. It was difficult to critically evaluate the study's findings when one did not know how the findings were generated. Extensive use of participants' quotes and examples of their experiences ameliorated this limitation to some extent. Despite the lack of research methodology description, the findings were plausible and "rang true" to me, based on my clinical experience with women who have experienced perinatal losses. It was unfortunate, however, that Swanson did not better describe her methods to guide future qualitative researchers exploring related topics.

Despite these limitations, Swanson's work appeared to be relevant to the study of PH mothers in two important ways. Firstly, it supported the choice of a constructivist epistemology for the study of women's experiences around significant life-events. Swanson's findings regarding respect for the participating women's own perspectives and meanings were consistent with constructivist insights about the way knowledge and meaning are generated. A constructivist approach highlights individual agency and self-authorship of one's life story. Swanson's findings emphasized that health professionals can assist and support these individual processes, but that attempting to usurp the individual's autonomy was incompatible with caring.

Additionally, Swanson's work demonstrated that qualitative research on women's experiences generated insights into the actions of health care providers and how these actions were perceived and experienced by the women receiving care. By listening to women talking about their experiences in their own words, rather than exploring their experiences according to the researcher's priorities, qualitative researchers can learn what is important to women and what is helpful to them.

Trulsson and Rådestad (2004) used a phenomenologic methodology to investigate the experiences of 12 women participants before, during, and after stillbirth. Data collection interviews were conducted 6 to 18 months after the delivery. One of the issues participants were asked about was their experiences in the time between the diagnosis of fetal death and the delivery of the stillborn infant, which ranged from 24 hours to 2-3 days in this group.

The findings were particularly rich and complex. One overarching theme was identified: *the silent child*. This theme encompassed both the shock of the infant's death and mothers' difficulty relating to a newborn who lacked one of the most basic expectations of newborn behavior; crying. Women described needing help to "dare" to look at their newborns. Despite such distressing experiences, none of the participants regretted seeing their babies and all expressed gratitude for the experience. All of the women eventually realized that this was their beloved child (Trulsson & Rådestad, 2004).

Trulsson and Rådestad (2004) identified a number of additional themes common to the participants' experiences. Most of the women experienced *premonition* that something was wrong with their babies prior to diagnosis. Several women reported *cessation of verbal communication* by the staff at the time of diagnosis, though they could tell something was wrong by staff members' body language. When they were told of their diagnoses, women reported *unreality and numbing*. Several were shocked to learn that they would have to go through the birth process and expressed an appalling sense of meaninglessness at the idea of giving birth to a dead baby. At the time, a *desire to get*

rid of the dead child immediately was common. For a variety of reasons, however, most of the women had a delay of 24 hours or longer before labor was induced. This waiting time was described as very difficult, but most of the women experienced a cognitive or emotional change as their foci shifted from reacting to the diagnosis to going through the process of labor. Ultimately most of the women recognized the need for this time to prepare themselves for the birth (Trulsson & Rådestad, 2004).

Participants' reports of their experiences in this study translated directly into recommendations for care. The need for mementoes, and the need for staff to offer them, were affirmed. Most of the women felt that they had not had enough time with their babies and wished they had had more guidance about what they could do in the time they did have to gather as many memories as possible. All the women emphasized the importance of providing information both verbally and in writing and the importance of clarity in the information that is given. Regarding the silent baby theme, mothers expressed the importance of caregivers providing anticipatory guidance about experiences with their newborns.

Trulsson & Rådestad's (2004) study demonstrated the value of qualitative research in perinatal bereavement. The rich descriptions of these women's experiences provided health professionals with a far deeper understanding of what their clients were going through and what they needed than could be achieved by quantitative description of psychiatric phenomena alone. Clearly, the participants in their study had experiences that were much more complex than unidimensional constructs such as depression or anxiety. The study demonstrated that qualitative research methods could generate

concrete and practical recommendations for improvement of care. The authors' decision

to use a phenomenologic approach, given the strengths of this method in generating

insights about the nature of participants' experiences, was a fruitful one for

investigation. As with the Swanson-Kauffman (1986) study, it was unfortunate that

these authors did not provide more details about their data analysis processes as a guide

to future researchers.

Insights about the time between diagnosis and delivery as reported by Trulsson

& Rådestad's (2004) are particularly suggestive for the scholar investigating PH. The

women's initial desire to get rid of the dead child immediately echoes one rationale for

termination of pregnancies affected by lethal anomalies: the desire to "get it over with"

(Hoeldtke & Calhoun, 2001). Just as participants in Trulsson and Rådestad's (2004)

study needed the time between diagnosis and induction to prepare themselves, so may

PH mothers experience some valuable process or change in perspective in the time that

they continue their pregnancies after learning of their fetuses' lethal conditions. These

authors' findings suggested that the impulse for immediate resolution in the aftermath

of an abnormal diagnosis may not represent the best choice for all women.

Another dimension of perinatal bereavement that has been of interest to

qualitative researchers is mothers' social experiences, interactions, and support, or more

often, lack of social support. Doka (1989) coined the term *disenfranchised grief* to describe

parents' burden of grieving a death that is real and salient to them but not necessarily so

to others. Because perinatal loss involved the death of one who was not yet a recognized

part of a community, there was little social sanction for parents' feelings, recognition of

their loss, or support for their recovery (Doka, 1989).

Malacrida (1999) explored the social experiences of 16 women and 6 men who

had a perinatal loss at 20 weeks gestational age or greater. Participants' interactions with

social institutions such as family, social and religious communities, health professions,

and the workplace were emphasized. Participants were initially encouraged to tell their

stories with little prompting or guidance, then were encouraged to expand on the social

phenomena that were the focus of the study. A grounded theory methodology was used

to analyze the interview data. A theory of complicated mourning (Rando, 1993),

focusing on factors that inhibit resolution of grief, guided the data analysis.

A primary finding of Malacrida's (1999) study was that the social support

received by parents was not commensurate with their own valuation of the losses they

had experienced. Even within their own families, normal practices surrounding births

and deaths such as financial contributions, cards, gifts, flowers, visits, phone calls, and

providing simple services such as meals and housework, were conspicuously absent.

Parents did not receive sufficient support or explanations from health professionals.

Parents noted the absence of gestures of support and formal rituals or memorials

typically provided to bereaved individuals by their religious communities. These

absences were interpreted by parents as a tacit message that the loss they had

experienced was not important, despite their own profound feelings to the contrary

(Malacrida, 1999). Profound discordance between their own internal experiences and

their social surround made it difficult for parents to find meaning or sense in what they

regarded as the lives and deaths of their children (Malacrida, 1999). In conclusion, the

author encouraged the early development and implementation of legitimating social

practices surrounding perinatal death.

Malacrida's (1999) study provided insights that could be relevant to the care of

PH mothers. I recognized the lack of legitimization and social supports noted by

Malacrida's (1999) participants as potentially relevant to PH. Her findings were highly

compatible with constructivist insights into the way people create sense and meaning

from their experiences. The process of testing one's own experiences and

understandings against the understandings implicit in one's social surrounds is

considered a fundamental process of meaning construction (von Glaserfeld, 1991). That

the inability to reconcile one's internal models with socially constructed meanings will

likely compromise one's ability to make sense and meaning of one's life experiences was

an essentially constructivist observation.

There are methodological limitations of this study that to some extent

undermined the credibility of the findings. Malacrida's (1999) decision to consciously

adopt a theory of complicated mourning, and to interpret participant data in light of that

theory, openned the possibility that the theory could have prejudiced her interpretation

of the data. There would be a natural tendency to emphasize data consistent with the

theory and de-emphasize data that were not. This concern, however, must be balanced

by the fact that theoretical understandings can usefully sensitize the researcher to

significant phenomena that might not otherwise be apparent. Furthermore, this theory's

consistency with the author's extensive clinical experience was probably a factor in her

choice to adopt it. Ultimately, the reader of qualitative research evaluates the credibility

of a study's findings based on the support from direct participant quotes and

consistency with the reader's own experiences with the phenomenon being investigated.

By these standards, I considered Malacrida's (1999) findings credible.

Generally, the qualitative literature identified a broader range of experiences and

processes than the psychiatric outcomes emphasized in the quantitative literature.

Qualitative research poignantly illustrated experiential themes, such as Trulsson and

Rådestad's (2004) evocative description of the silent child. Qualitative research also

seemed to address more fluently than quantitative research such seeming paradoxes as

the coexistence of a need to resolve a painful situation immediately and a need for more

time to process events and prepare oneself for such resolution. Qualitative approaches

also attended to subtle differences in women's experiences with different variants of

perinatal loss, while the quantitative literature tended to emphasize commonalities such

as depression and anxiety. My overall impression of this body of literature is that

qualitative research gave voice to women's experiences and perspectives, rather than

focusing on constructs selected by researchers.

<div align="center">Summary of Literature: Limitations and Possibilities</div>

The most glaring absence in the literature is the paucity of research specific to

PH prior to the present study. Ample literature existed in related areas such as abnormal

fetal diagnoses, prenatal attachment, perinatal loss, and grief theory. As illustrated

above, these related bodies of knowledge provided a basis for many plausible

suppositions about what kinds of experiences, responses, and needs PH mothers might be likely to have. This background was helpful in planning the present study and preparing me as a researcher for data collection and analysis.

The quantitative literature supported the generalization that receiving a lethal fetal diagnosis and experiencing the death of one's fetus or newborn involved profoundly distressing experiences. The quantitative literature also suggested the prevalence of psychiatric problems such as depression, anxiety, and post-traumatic symptoms. The qualitative literature supported a broader conceptualization of experiences, needs, and outcomes. Although the literature did not support quantitative differences in the degree or magnitude of distress between different variants of perinatal loss, the qualitative literature supported differences in the subjective dimensions of loss. To me, it appeared that PH mothers were likely to have some commonalities as well as some differences with women who experience other variants of perinatal loss.

These suppositions and generalizations helped to provide a basis for PH research, and served to sensitize me as a researcher to promising avenues of exploration. It was not a goal of this study to confirm or deny the relevance of any particular theoretical perspective or previous research finding to the experiences of PH mothers. However, familiarity with these concepts and findings could be helpful in recognizing and exploring significant phenomena if they manifested in the participants' experiences in the present study.

Qualitative research has produced findings and insights that are particularly germane to the investigation of PH. Swanson's (1986; 1991) and Malacrida's (1999)

studies echoed constructivist themes such as the individual, idiosyncratic nature of meaning construction and the need for such constructions to be validated in a supportive social milieu. These parallels between constructivist epistemology, meaning-making theory, and evidence from qualitative research on perinatal loss supported the use of research methodologies sensitive to individual processes of meaning construction. Swanson's (1986; 1991) findings suggested that effective care for women experiencing perinatal loss must attend to their own perspectives and meanings. The present study was conducted under the assumption that the same attention would be beneficial in PH research.

Another theme that emerged from the theoretical literature and the qualitative research is multidimensionality. Experiences of grief and loss appear to be highly complex, with many different ongoing processes and multiple experiential themes, such as confrontation, avoidance, continuing bonds, personal growth, meaning-making, disruption of functioning, symptoms of grief and depression, and social alienation. The complexity and individuality of grief responses, and the need for a flexible and sensitive approach, were major factors in the choice of a research method for the present study (see *Decision to Use Qualitative Method*, p. 97)

The critical roles of health providers generally and nurses in particular were evident in this body of literature. Trulsson and Rådestad's (2004) participants emphasized the importance of anticipatory guidance from health providers. Chitty and colleagues' (1996) study of PH mothers emphasized the importance of a small, consistent team of providers with specialized knowledge in PH care. Another key finding was the

distressing effects that were reported when providers demonstrated miscommunication, insensitivity, or ignorance in delivering their care (Chitty et al., 1996). Swanson's (1986; 1991) research highlighted the roles of caregivers and the profound impact of their attitudes and approaches to women experiencing perinatal losses. Malacrida's (1999) analysis concluded that women did not receive sufficient support or explanations from health providers, and suggested that the resulting lack of legitimization could contribute to complicated grief outcomes. All of these studies emphasized the need for sensitive care from informed providers.

Questions about contact between mothers and their dead or dying infants remain unanswered. Two studies associated such contact with worse psychiatric outcomes (Hughes et al., 2002; Turton et al., 2009), but other studies suggest that women were grateful for the time they spent with their stillborns (Trulsson & Rådestad, 2004) and that women who had ample contact had less subsequent anxiety (Rådestad, 2001) and somatic symptoms (Rådestad et al., 2009). It is likely that there are more complexities to this question than existing research has explored. Given this gap in the literature, the best that could be said is that time spent with the fetus during pregnancy and with the infant after birth is probably a sensitive period with the potential to influence subsequent bereavement experiences for good or ill, or possibly both. These questions about mother-infant contact are particularly salient to the subject of PH, because the choice to continue a pregnancy after a lethal fetal diagnosis is essentially a choice of more contact and interaction during the remainder of pregnancy, labor and delivery, and after birth

Another aspect of PH that differs significantly from the bulk of the literature relates to the different variants of perinatal loss. Most of the literature reviewed above was specific to one variant or another, such as miscarriage, previable birth, stillbirth, or neonatal death. PH mothers are at risk for all of these variants of loss, but the majority will experience stillbirth or neonatal death, about 30% and 65% respectively in one published series of 20 affected pregnancies (D'Almeida et al., 2006). The experiences of PH mothers, therefore, do not fit neatly into the well-researched categories of perinatal loss. I recognized in planning the present study that some previous research findings might apply to some PH mothers but not to others or not to any of them, and that some issues might be common to all variants of perinatal loss, including PH. Additionally, I recognized that there might be significant phenomena specific to PH that were not revealed by previous research. Again, this realization was one of the motivations for research specific to the experiences of PH mothers.

The purpose, therefore, of the proposed dissertation research was to broadly explore the experiences of PH mothers according to their own perspectives. The aims of the study were to gather knowledge useful to nurses and other health professionals providing PH care, and to guide future research as necessary. The research question for the study was as follows: What do mothers who have received lethal fetal diagnoses and decide to continue their pregnancies, report about their experiences?

The preceding discussion reviewed and analyzed what was known prior to the present study that was potentially relevant to understanding PH mothers' experiences, as well as gaps and limitations in the existing state of knowledge. Existing knowledge

supported the relevance and significance of the aims, purpose, and possible areas of

exploration. Additionally, the gaps and limitations of existing knowledge identified

above suggested that research designed to meet the purpose, aims, and possible areas of

exploration here identified was likely to generate knowledge that was not previously

available.

III. RESEARCH DESIGN AND METHODS

Just as the purpose, aims, and areas of exploration for the present research were consistent with the existing state of knowledge relevant to PH, I considered it desirable that the research design and methods be consistent with what was known and what was not known prior to this study. My goal for this study was to formulate a design and select methods appropriate for the study's purpose and aims, and to the state of existing knowledge.

Decision to use Qualitative Method

A basic methodologic decision in designing PH research was whether to use qualitative or quantitative methods, or a combination of both. To achieve as complete an understanding of PH mothers' experiences as possible, I believe it would eventually be desirable to study PH using both quantitative and qualitative methodologies. Prominent bereavement researchers have advocated 'methodological pluralism,' using both qualitative and quantitative approaches to achieve the broadest possible understanding (Niemeyer & Hogan, 2001).

At present, however, major theoretical concepts of grief such as ongoing relationship with the deceased and meaning reconstruction are not addressed by existing quantitative instruments. Furthermore, premature quantitation of research approaches in areas where little is known can constrain research into avenues determined by researcher preconceptions (Niemeyer & Hogan, 2001). For these reasons,

I judged that the most appropriate initial approach to PH research was to broadly

explore PH mothers' experiences using qualitative methodology. Morse and Richards

(2002) described five conditions for the use of qualitative research methods. According

to these researchers, a qualitative approach should be considered if any of the five

conditions are present. In Table 5, five conditions needed for qualitative research are

outlined, including how they applied to the state of knowledge regarding PH at the time

this study was designed.

<div align="center">Narrative Analysis</div>

Narrative analysis is a qualitative methodology particularly well-suited for

bereavement research (Gilbert, 2002; Niemeyer, 2001). In this context, the term *narrative*

is synonymous with 'story' (Gilbert, 2002). Creating and relating personal stories about

significant life events is a basic means by which individuals organize their experiences

and construct sense and meaning (Gilbert, 2002; Riessman, 1993). Narratives do not

simply describe significant events: they provide structure to experience and establish

meaning in what may seem to be meaningless situations (Gilbert, 2002).

Recognizing that narratives are representational in nature, and that they are not

to be interpreted as exact replicas of events, is key to the analysis of narratives (Gilbert,

2002; Sandelowski, 1991). The literal historical truth of an account is not the concern:

instead, narrative researchers concern themselves with the ways participants organize

the events of their lives and derive meaning from them (Riessman, 1993). Narratives

Table 5

Conditions for Qualitative Research

Conditions for Qualitative Research	Relevance to State of Knowledge regarding Perinatal Hospice prior to Present Study
The inquiry is in an area where little is known, or the researcher does not know what he or she is likely to find	Paucity of previous research on the experiences of PH mothers
The purpose is to make sense of complex situations, and a way of simplifying data without destroying complexity is needed	Complex, multidimensional phenomenon of perinatal bereavement; need to explore various dimensions of PH mothers' experience
The researcher hopes to learn from the participants the way they experience the phenomenon, the meanings they attribute to it, and how they interpret their experiences	For appropriate care, it is necessary to understand PH experiences from the perspective of participants' meanings and interpretations
The goal of the study is to construct a theory or theoretical framework	Formulation of grand theory is not a proximal research goal, but theory testing and exploring the applicability of various theories are relevant
There is a need to understand phenomena deeply and in detail; to discover central themes and core concerns	Discovery of central themes and core concerns may help determine whether hypothesized phenomena such as attachment, meaning reconstruction, caregiving, and continuing bonds are relevant to PH

Note: Conditions for qualitative research (left column) derived by the author from Morse, J. M., & Richards, L. (2002). *Read me first for a user's guide to qualitative methods.* Copyright 2002 by Sage Inc. Information in the right column are the author's observations.

continually evolve, changing with each telling and with the influence of new

information and experience (Gilbert, 2002; Riessman, 1993). Thus, narration is a cyclical

process whereby stories provide structure for individuals' lives and constructions of

reality, while individuals' experiences and constructions of reality provide structure and

context for the creation of stories (Gilbert, 2002).

Social context is important to the creation of narratives, just as the social

dimension plays a key role in construction of knowledge and meaning. We learn about

our social world through narratives, and are shaped by the narratives of our culture

(Gilbert, 2002). Narratives are constructed in conversation with a real or imagined

audience, and story telling is a social act of negotiating meaning (Gilbert, 2002).

Consistent with constructivist assertions about the social dimensions of knowledge and

meaning construction, narratives are tested and explored and meanings are negotiated

in relation to the views and responses of others (Gilbert, 2002).

There is no single defined methodology for conducting a narrative study.

Methods of analyzing narratives can be adopted and adapted to suit the nature of the

phenomenon being investigated and the narratives that are collected. In general terms,

the process of narrative research consists of the researcher asking participants to tell

their stories, then constructing a meta-story that transcends and binds together the

individual stories and explains what has been found (Gilbert, 2002). A variety of

techniques were employed in the analysis process for this study (see *Data Analysis*, p.

117).

Narrative research may result in multiple views of 'the truth' rather than a single 'true' account (Appleton & King, 1997; Gilbert, 2002). Rather than correspondence to an external objective reality, narrative truth is evaluated according to whether it is lifelike, plausible, and intelligible (Sandelowski, 1991). Narration reconstructs events and experiences within the framework of the narrator's current frameworks of meaning and understanding and reflect how the event is now being interpreted, rather than interpretations held at the time the events occurred (McCreight, 2004). Rather than being concerned with consistency or the objective accuracy of an account, narrative researchers look for clues to how meanings and understandings evolve over time.

Narrative analysis has been specifically advocated as a methodology for bereavement research (Gilbert, 2002; Niemeyer, 2001). The impulse to construct narratives is particularly strong when one is confronted with death, loss, and grief (Gilbert, 2002). Reading participants' stories serves to engage the audience and personalize the phenomenon being described (Gilbert, 2002). Narrative analysis addresses the emotional as well as the intellectual experiences of the participants (Gilbert, 2002). The open-ended, participant-driven nature of narrative research ensures that participants will have the opportunity to relate core concerns and major themes in their experiences.

Although narrative research methods have not been applied to the study of PH prior to the present study, they have been successfully used in related areas of research interest. As previously noted, Sandelowski and Jones (1996) used a narrative approach to explore experiences of choosing among couples who received abnormal prenatal

diagnoses. Analysis of birth stories has been used to explore the interplay of forces in women's labor experiences (VandeVusse, 1999b), decision making in labor (VandeVusse, 1999a), and the professional socialization of student midwives (Ulrich, 2004). One researcher noted that sharing birth stories provides an opportunity for integration of a major event into the framework of women's lives (Callister, 2004). Narrative research methods have also been used to explore women's transitions to motherhood (Carolan, 2004; Klingberg-Allvin et al., 2008). These examples illustrate the applicability and successful use of narrative methods for exploring women's experiences around pregnancy and childbirth, and experiences related to the diagnosis of fetal anomalies. These previous narrative studies in topical areas most closely related to PH were undertaken by researchers in the nursing profession. Narrative methods are also widely used in psychology and the social sciences. Much of the research in the psychological literature on emerging theories of bereavement, such as meaning reconstruction and continuing bonds, has employed narrative methods (Gilbert, 1996; Niemeyer, 2001; Walter, 1996).

The emphasis and goals of narrative research are consistent with the nature of perinatal bereavement and PH experiences. Narrative methodology is also consistent with the state of knowledge related to PH. The narrative research approach shares a common constructivist philosophical foundation with theories of grief and bereavement that are likely to be relevant to PH research. Narrative methods have been successfully employed in areas of research interest related to PH, such as maternal transition (Carolan, 2004; Klingberg-Allvin et al., 2008) and child birth (Callister, 2004,

VandeVusse, 1999a; 1999b). Together, these factors suggested that narrative analysis would be an appropriate methodology for PH research.

<div align="center">Participants and Recruitment</div>

Participants for the proposed study were women, age eighteen years or older at the time of the affected pregnancy, who received the diagnosis of a lethal fetal anomaly during pregnancy and continued the affected pregnancy until spontaneous labor, spontaneous fetal loss, or delivery for maternal indications. Participation was limited to women only, because although experiences of other family members are important, mothers are the central focus of perinatal nursing and nurse-midwifery care. Additionally, mothers' accounts were considered likely to include information that could help direct future study of fathers, siblings, and other family members. Participant age was limited to eighteen years or older at the time of the affected pregnancy, because studies of adolescents' responses to perinatal loss suggest that their responses may be different than those of adult women (Wheeler & Austin, 2001).

Participants were also limited to those who experienced the delivery or death of their PH infants at least one year and no greater than 12 years in the past. I decided on the lower limit of one year because the short term, acute responses to perinatal loss have been relatively well-studied and I believe there is a greater need to study longer term adaptation. The upper limit of twelve years was decided upon because the widespread availability of accurate prenatal diagnosis for lethal anomalies is relatively new, and women's and families' decisions and experiences were likely different prior to the

advent of technologies allowing diagnosis and treatment decisions before birth.

Additionally, there has been a trend through the 1990s of increasing awareness of

women's and families' needs when experiencing perinatal losses and greater respect for

their autonomy and preferences. Women whose losses occurred in the more remote past

likely encountered a very different health care environment than women whose

experiences are more recent. Research has documented the vividness and accuracy of

women's birth memories after 15-20 years (Simkin, 1991; 1992), so 12 years is not too

remote in time for participants to provide rich and relevant narrative accounts.

For this initial research, participants were limited to those who are fluent in

English and residents of the continental United States. These limitations may have

excluded important cross-cultural perspectives, but simplified data management and

analysis and reduced travel costs. Factors related to cultural diversity are important to

address in future research, but may have over-complicated this first formal inquiry into

women's PH experiences.

Narrative research typically involves small sample sizes because narrative

analysis generates large amounts of in-depth data from each participant (Gilbert, 2002).

The focus is on the depth of the analysis rather than a large sample size. A sample size

no larger than 15 participants was anticipated for the present study. Sampling is guided

by emerging insights about the study topic (Appleton & King, 1997), so the final number

of participants was determined by observations about the data already collected

(Sandelowski, 1995).

In order to account for the possibility that one or more participants might decide to withdraw from the study, the study protocol allowed for recruitment of up to 20 participants. A total of 17 women signed contact consents (see Appendix B; Contact Consent) and were in initial contact with me. One of these women did not meet the eligibility criteria and one was not able to schedule an interview due to time conflicts. The other 15 women who made initial contact did complete the consent process and participate in data collection.

Participants were initially recruited from two perinatal bereavement support agencies: Alexandra's House in Kansas City, Missouri, and The Haven Network in Rockford, Illinois. After 9 participants had been recruited and data had been collected, I recognized that 7 of the 9 participants were recruited from Alexandra's House. In order to balance the sample and avoid over-representation of this one program, the research protocol was revised to allow for word-of-mouth recruiting among my professional contacts. Of the additional 6 participants recruited in this way, 5 had received care from one perinatal bereavement support service. One of the additional participants did not receive specialized PH care, but discovered the concept of PH and designed her birth plan using internet resources.

Since data analysis was concurrent with recruitment and data collection, it was possible to evaluate the completeness of the data while recruitment and collection were still underway. Saturation, the point after which no new information or themes were observed in the data (Guest, Bunce, & Johnson, 2006), was achieved by the fifteenth interview.

An important tool for recruitment was the initial recruitment announcement (see Appendix A; Initial Recruitment Announcement). This announcement was written in the form of a letter to potential participants. The text of the announcement included a description and the purposes of the proposed research. The volunteer nature of participation was discussed, along with the study's inclusion criteria, participants' right to withdraw, and the right to decline participation without affecting care or services from the support agency from which they are recruited. A description of participation, including specifically what participants would be asked to do and possible emotional risks of participation, was also included. Attached to the announcement was a contact consent (see Appendix B; Contact Consent) and a pre-addressed, postage-paid envelope.

The designated contact persons from Alexandra's House and The Haven Network (and later, word-of-mouth contacts) gave the initial recruitment announcement to current or former clients who met the inclusion criteria, either by mail or in person. Potential participants then had the option of completing the contact consent form, thus indicating their willingness to be contacted. Completed contact consent forms were placed in pre-addressed postage-paid envelopes that were provided and then mailed back to me. Only those potential participants who completed and signed the contact consent were contacted.

After receiving the contact consent form, I made contact according to the potential participant's preferences indicated on the contact consent. Potential participants were invited to ask any questions they had about participation. If the potential participant indicated that she wanted to participate in the study, the

participant and I agreed on a mutually convenient date and time to meet for the

informed consent and data collection processes.

Human Participant Protection

Protection of participants was ensured by a variety of means. The study

underwent primary review by the Marquette University Institutional Review Board.

Secondary review was conducted by the agencies from which participants were

recruited according to their own internal policies regarding human participant research.

Participant confidentiality was protected by assigning each participant a number. A

password-protected computer spreadsheet file constituted the only linkage between

participants' names and their data.

Study consent forms and descriptive data forms were stored in a combination-

protected safe. Computer-based data, including electronic audio recording files, digital

photographs of mementoes, and interview transcripts, were stored on password-

protected computer files. The e-mail account used for study correspondence was also

password-protected. Study consent forms and descriptive data forms will be destroyed

by shredding 3 years after the conclusion of the study. The e-mail account associated

with the study will be terminated and its data erased three years after the conclusion of

the study. The audio recordings will be erased electronically three years after the

conclusion of the study. Computer files of the interview transcripts, which will not

include any participant identifying data, will be maintained indefinitely. Although there

are no plans at present for secondary analysis of the interview transcripts, this may be

done. Photographs of mementoes, which did not include any participant identifying information, may be included in presentations of the study findings and will be retained indefinitely, according to the participants' consents.

An important ethical concern was the possible emotional risks of participation in research involving sensitive or difficult topics such as PH. I recognized the possibility that participants relating the loss of a fetus or infant might become emotionally upset. However, Corbin and Morse (2003) observed that persons who are highly emotionally fragile and unprepared to talk about a sensitive subject usually do not volunteer to be interviewed. Interview techniques that allow participants to control the pacing and content of the interview are more likely to be emotionally beneficial and less likely to be distressing (Corbin & Morse, 2003). Emotional benefits of participating in research may include catharsis, self-acknowledgment and validation of feelings, increased self-awareness, a sense of empowerment, promotion of healing, and giving voice to the disenfranchised (Corbin & Morse, 2003). One research team that has conduced extensive narrative research with bereaved parents noted that their approach has not caused distress among participants, but rather has helped to ameliorate it (Riches & Dawson, 1996). Additional protection for participants was provided by the fact that they were being recruited from support organizations, bereavement counselors, and women's health nurses, and therefore had some support services available to them. The fact that the interviewer was an experienced women's health clinician with a background in perinatal bereavement is another factor that safeguarded participants' emotional well-being. All participants were offered a list of national organizations providing perinatal

bereavement as an additional resource (see Appendix C; Perinatal Bereavement Support Organizations).

Informed consent was obtained from participants immediately prior to the data collection interview. A copy of the informed consent document (see Appendix D; Text of Informed Consent Document) was mailed to each potential participant prior to meeting to allow review of the document at the participant's leisure. An opportunity was afforded for participants to ask any questions they had about the study, the informed consent document, or their participation. Those who agreed to participate were asked to sign the informed consent document and did so.

The informed consent document contained the following elements: purpose and description of the study, description of participation and process, voluntary nature of participation, right to decline participation without consequences, right to withdraw without consequences, possible risks and benefits of participation, and protection of participant confidentiality. Some optional items related to participation were included on the informed consent document. Participants had the opportunity to accept or decline follow-up contact by the researcher after initial data collection and photographing of mementoes related to their narratives (see below). All 15 of the participants accepted follow up contact to review the study results. Nine of the participants consented to photography of their mementoes.

Data Collection

Data collection took place subsequent to obtaining informed consent. Eight of the data collection interviews were conducted in private rooms at the facilities of the community based bereavement support agencies affiliated with the study. Three participants requested that their interviews take place in coffee shops. Another three participants preferred to be interviewed in their homes. For one of the participants, meeting at my home was most convenient. In general, the choice of interview location was determined by the participants' preferences and convenience. Facial tissues and bottled water were provided for all participants during their interviews. Audio recordings were made electronically, using a digital voice recorder.

Data collection began with a broad opening question (Chase, 2003) designed to elicit the participant's personal narrative: "Please tell me your story in your own words, any way you want to tell it." Participants were not given any direction about the subject matter of the interviews other than what they ascertained from the recruitment and the eligibility criteria for the study. Narrative researchers have noted that very little prompting is required (Riches & Dawson, 1996), and this proved to be the case for the participants in this study. Interview approaches were intended to minimize interruptions, and questions were asked only to encourage elaboration or clarification when necessary (Sandelowski & Jones, 1996), and only after the participant has an opportunity to relate events in her own words (Stevens, 1993; 1994). I monitored the participants' emotional status throughout the interviews. If a participant had become too

distressed to continue, I had planned to offer her the opportunity to pause or

discontinue the interview. Services of the bereavement support agencies affiliated with

the study were available had any participant required further care. In the unlikely event

that a participant became suicidal or otherwise dangerously unstable, I had planned to

call 911 to engage locally available emergency services. None of these adverse events

occurred and none of the anticipated responses were required.

After the interviews, I audio recorded field notes to note details such as the

participants' body language, display of mementoes, or other non-verbal aspects of story

telling. The employment of mementoes such as pictures of infants, locks of hair, and

footprint impressions in meaning-making and storytelling is well documented in the

bereavement literature (Gilbert, 1996; Riches & Dawson, 1996; Rubin, 1999). Again, this

proved to be the case in the present study. Several participants used their mementoes to

illustrate their stories and provide visual representation of the people and events

described. Often, a memento seemed to serve as a memory cue, leading the participant

to tell a part of her story that she had not previously discussed. If a participant agreed to

photographic documentation of mementoes, this was done after the interview was

completed. No photographs were made that included any personal identifying

information.

At the conclusion of the interview, participants were asked to fill out a form

containing participant descriptive information (see Appendix E; Descriptive Data Form).

No participant identifying information was included on this form. Some of the

descriptive items were included because they were identified in the literature review as

possibly influencing individuals' responses to perinatal loss, such as age, relationship

status, pregnancy history, and history of other losses. Some items were included because

they represented significant dimensions of participant diversity, such as race,

educational level, income, and religious affiliation. I hoped that the participant sample

would reflect sufficient diversity on these dimensions because I recognized that if the

sample was relatively homogenous with respect to one or more of these dimensions, this

could represent a limitation on the interpretation of the findings. The sample was

relatively homogenous in some respects, including age, race, religion, education, and

income. These and other characteristics of the sample are displayed in Table 6.

Limitations related to the sample are discussed below.

The descriptive data form also included information about fetal diagnoses and

outcomes, which is summarized in Table 7. Trisomy 18 was the most common of the 8

diagnoses represented. For fetuses deceased prior to birth ($n = 7$), the gestational age at

the time of fetal death ranged from 28 to 36 weeks. For live born infants ($n = 9$), the

duration of survival ranged from 30 minutes to seventeen months.

One of the participants had two affected pregnancies. Because of this, 16 fetuses

and 16 pregnancies were represented in the sample, despite the fact that there were only

15 participants. In order to preserve this participant's confidentiality, her fetuses'

diagnoses will not be disclosed. This participant related her narrative as a single,

connected story, frequently moving back and forth between her two pregnancies in her

account. For this reason, her data was treated as a single narrative for analysis purposes.

Participant numbers were included on the form, so that the descriptive data could be

Table 6

Characteristics of Particpants (n = 15)

Characteristic	Categories (where applicable)	Value n (%)
Age at time of affected pregnancy	18-25	1 (7)
	26-30	4 (27)
	31-35	4 (27)
	36-40	5 (33)
	41+	1 (7)
Interval since delivery (years)	1-2	5 (33)
	2-4	3 (20)
	5-8	6 (40)
	9-12	1 (7)
Relationship status	Single	1 (7)
	Married to father of affected baby	14 (93)
Race/ethnicity	African-American	1 (7)
	White/Caucasian	13 (86)
	Hispanic	1 (7)
Religious affiliation	Catholic	4 (27)
	Other Christian	11 (73)

(continued on next page)

Table 6

Characteristics of Participants (continued)

Characteristic	Categories (where applicable) *	Value[†] n (%)
Religious attendance	More than once per week	5 (33)
	Once per week	6 (40)
	More than once per month	1 (7)
	Once per month	1 (7)
	Special events or holidays	2 (12)
Education	Did not respond	1 (7)
	High school or equivalent	1 (7)
	Some college	3 (20)
	Technical School graduate	1 (7)
	Undergraduate college degree	4 (27)
	Graduate degree	5 (33)
Annual family income	Did not respond	4 (27)
	Full-time students < $10,000	2 (12)
	$46-60,000	1 (7)
	$61-80,000	1 (7)
	Over $80,000	7 (47)

Note: This table omits categories to which no participant belonged. One participant had two affected pregnancies and two affected infants. Her age, interval, and pregnancy history data reflect the more recent of her two pregnancies.

Table 7

Fetal Diagnoses and Outcomes

Diagnosis	Weeks gestation (deceased prior to birth)	Duration of life (deceased after birth)
Anencephaly	28	
Anencephaly	34	
Mosaic Trisomy 16	28	
Trisomy 18	28	
Trisomy 18	35	
Trisomy 18	36	
Trisomy 18	Not disclosed	
Trisomy 18		8.5 months
Trisomy 13		1 hour 10 min
Osteogenesis Imperfecta Type II		1 hour
Osteogenesis Imperfecta Type II		3 hours
Renal agenesis		30 minutes
Renal agenesis		1 hour
Holoprosencephaly		7 hours 5 minutes
Holoprosencephaly		17 months
Urorectal septal malformation sequence		46 minutes
	(n = 7)	(n = 9)

Note: One participant had two affected infants.

linked to the interview transcripts (edited to remove identifiers) to aid in data analysis.

At the conclusion of the interview, participants were each given a $20 gasoline card to

compensate them for expenses incurred by travel to the interview location.

<div align="center">Terminology Related to Data Management and Analysis</div>

The literature on narrative analysis describes a variety of analytic techniques.

Definitions of analytic terminology are not standardized. In order to facilitate

description of the data management and analysis processes, I chose to use the following

definitions of terms.

Affinity group: a cluster of paraphrases that are thematically or functionally

related

Coding: the process of assigning passages of participant text to appropriate nodes

(QSR, 2008)

Node: a group of passages of participant text that have a common theme or

subject matter (QSR, 2008)

Passage: a segment of participant text relating an event, thought, feeling, or

experience

Paraphrase: a phrase created by the researcher or adopted from participant(s) that

represents a main idea from a passage of text (Haglund, 2003; Hall, Stevens, & Meleis,

1992).

Reference: a passage of text that is assigned to a node (QSR, 2008).

Theme: an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations (DeSantis & Ugarriza, 2000). Clarification of these terms was important to understand the data analysis.

Data Analysis

The goals of data management and analysis were to organize data from the participant interviews and to identify themes that captured the participants' experiences. A variety of techniques described in the narrative research literature were adopted and adapted for use in this study. For much of the time while the study was being conducted, processes of data collection, data management, and data analysis were occurring simultaneously so that the results of each process could inform the other processes.

Transcription was the first task in data analysis. A professional transcription service that is credentialed to handle confidential research data provided transcription of the audio recordings into word processing files. After transcription, I reviewed the transcripts for accuracy and to remove potential identifying information. Non-verbal utterances, such as "er" and "uh" were not included in the transcriptions, but the texts were otherwise verbatim transcriptions.

Initially, analysis focused on each participant's narrative individually (Haglund, 2003). In order to focus on each individual participant, the researcher reviewed field notes to recall circumstances and impressions from the time of the interview. For the first reading of each transcript, I listened to the audio recording simultaneously

(Haglund, 2003). The intended purpose of this was to check for transcription accuracy, gain an overall impression of the narrative, and remove any potential identifying information (Haglund, 2003). An additional advantage of this technique that became apparent throughout the analysis process was that I could listen for emotional cues and clues to meaning, such as the participant's tone, emphasis, and pacing.

Next, each participant's transcript file was imported into NVivo8, a software program designed to facilitate qualitative data management and analysis (QSR, 2008). Field notes were also imported, along with the participant's descriptive data.

Coding was the next step in data analysis. The participant's narrative text was reviewed closely to identify passages, and each passage of text was assigned to a node or nodes. If a passage contained an account of an event, thought, feeling, or experience that did not fit in to an already existing node, a new node was created. Some passages were as short as one sentence, but the majority consisted of several sentences that together formed an element of the participant's story. Each node was given a title that described its contents. Most passages of text were assigned to multiple nodes. For example, a sentence such as "Every Monday, Wednesday, and Friday my mother takes me to the gym" could have been assigned to various nodes such as *Weekly Routines*, *Activities with My Mother*, and *Regular Exercise*.

After each participant's narrative text was coded, those data were temporarily set aside while my attention was focused on the next participant. When coding for all the participants' texts was completed, there were 121 nodes and 2,740 references.

In the second stage of analysis, I turned my attention to consider the data set as a whole. Descriptive data were reviewed and summarized in writing, a process that served to focus my attention on the participants as a group.

Next, I examined the nodes that had been created in the coding process to identify those most relevant to the purposes of the study. Statistics generated by the NVivo8 software (QSR, 2008) allowed me to identify nodes that contained references from a large number of participants, and those that contained large numbers of references. This was helpful in identifying experiences or concepts that were predominant in the participants' narratives.

I also tried to identify nodes that contained passages that the participants emphasized as particularly important, either explicitly (for example, "It was a really big deal to me") or implicitly, as evidenced by emotional cues such as crying, pausing, or speaking in an emphatic tone. Since the ability to examine atypical or outlier experiences is a strength of narrative research (Chase, 2003), I also paid attention to nodes that represented very small numbers of participants or contained very few references, and passages that described experiences markedly different than those that were predominant in the sample. Finally, I reviewed the nodes to look for themes or experiences that were directly related to study goals or important issues identified in the literature review.

Each time I examined the nodes according to these different approaches, I made lists of those that were prominent, such as ones with large numbers of references, others representing atypical or outlier experiences, still others relevant to study goals, and so

forth. It quickly became apparent that some nodes appeared on more than one of these lists. Ultimately, I identified 25 nodes that appeared to be prominent in two or more ways of comparing the nodes. Since these nodes appeared to be particularly important, they became the foci for further analysis.

The next stage of data analysis was to analyze each of these 25 selected nodes in detail. This involved paraphrasing the main ideas from each coded passage of participant text, and arranging the resulting paraphrases into affinity groups in order to identify themes.

Paraphrasing is a technique employed in previous studies using narrative and life history methodologies (Eaves, 2000; Haglund, 2003; Hall, 2000; Hall et al., 1992; Stevens, 1995). To facilitate the paraphrasing process, I created a two-column grid for each node. Every passage of participant text coded into each respective node was entered verbatim into the right hand column of the grid for that node. In the left hand column, paraphrases were created adjacent to the original participant text to represent the main ideas in each passage quoted.

Each paraphrase served as a shorthand or code for an idea expressed by one or more participants. Key words or phrases used by participants were often incorporated into the paraphrases. For example, the following quote,

> …that's why we were so careful to… plan out… the whole … birth experience because… we wanted to be able to use that time to do all those things that we wanted to do for our daughter, so… it was really nice… we bathed her and…we did a lot of just… holding her.

yielded the paraphrases: 'birth planning', 'desire to do things for the baby,' 'bathing the baby', and 'holding the baby.' Paraphrases were used as code words to allow clustering like concepts together and comparing them in various combinations during analysis.

In order to sort, arrange, and summarize the ideas represented by the paraphrases, an affinity grouping technique was used. For each node, a list of all the paraphrases corresponding to that node was printed out using a large type font size. The print outs were cut, so that the paraphrases were separated into individual pieces of paper. The separated paraphrases were arranged and re-arranged on a large table, so that paraphrases could be clustered into groups of related ideas. By examining these groups of paraphrases and referencing the original participant text passages, I was able to identify themes that captured the nature of recurrent participant experiences and their variants (DeSantis & Ugarriza, 2000).

During this process, it became evident that some nodes were linked by shared themes and large numbers of overlapping references. There were two strongly inter-related groups of nodes. When I applied the paraphrasing and affinity grouping process to nodes containing passages about maternal identity, maternal-fetal attachment, caregiving, touching, validation, and invalidation, I identified a group of themes that I titled *Maternal Related Themes*. The constituents of *Maternal Related Themes* were *Motherhood*, *Invalidation*, *Validation to Self*, *Validation through Caregiving*, *Validation from Others*, and *Validation from Health Professionals*. When essentially the same process was applied to nodes related to anniversaries, continuing bonds, positive meanings, looking back, saying goodbye, and how experiences changed over time, I identified a group of

themes that I titled *Temporal Related Themes*. These themes were *Continuity*, *Evolving Changes*, *Transient Phases*, and *Connecting Past to Present*.

The recurrent experiences and variants represented by *Maternal Related Themes* are discussed in detail in the subsequent manuscript titled "Affirming Motherhood: Validation and Invalidation in Women's Perinatal Hospice Narratives" (see Chapter IV, p. 127). The recurrent experiences and variants represented by *Temporal Related Themes* are discussed in detail in the subsequent manuscript titled "Continuity and Change in Mothers' Narratives of Perinatal Hospice" (see Chapter V, p. 156).

Maintaining Analytic Rigor

There has been considerable debate in the literature about what criteria should be used to evaluate qualitative research and how to ensure its quality, including debate about what terminology should be used to define and describe analytic quality in a way that is appropriate for qualitative inquiries (Golafshani, 2003; Rose & Webb, 1998; Sandelowski, 1993; Whittemore, Chase, & Mandle, 2001). Terms such as *reliability* and *validity* rely on positivist and realist assumptions that may conflict with the nature and aims of qualitative studies (Guba, 1981; Lincoln & Guba, 1985; Whittemore et al., 2001). A variety of concepts and terms have been proposed, such as truth value, applicability, consistency, neutrality (Guba, 1981; Lincoln & Guba, 1985), credibility, fittingness, auditability, confirmability, creativity, and artfulness (Sandelowski, 1993).

Whittemore and colleagues (2001) published a helpful taxonomy of quality-related concepts and terminology, distinguishing between *criteria* (quality-related ideals

that researchers strive to meet) and *techniques* (methods employed by researchers to ensure that criteria are met). *Rigor*, in this analysis, referred to the degree to which researchers adhered to the quality-ensuring methods chosen for the inquiry (Whittemore et al., 2001). Although this analysis is helpful in clarifying terminology, it still does not offer any definitive system of quality criteria or standardized set of techniques: it is left to the researcher to select the criteria and techniques best suited for the purposes and aims of the inquiry.

As previously discussed, the purpose of this inquiry was to broadly explore the experiences of PH mothers according to their own perspectives, and the aim of the study was to develop knowledge useful to nurses and other providers involved in PH care. Based on Whittemore and colleagues' (2001) taxonomy, I considered *authenticity* and *credibility* to be the most important quality-related criteria for this study. *Authenticity* is the degree to which participants' experiences and perspectives are accurately represented by the analysis (Whittemore et al., 2001). This is an important criterion for this study, because if participants' experiences and perspectives were not accurately represented, the inquiry would have failed its stated purpose. *Credibility* is the degree to which the study's findings are trustworthy and that they reflect the experiences of the participants in a believable way (Lincoln & Guba, 1985; Whittemore et al., 2001). This criterion is important to the stated aim of the inquiry, because if its results are to be useful to nurses and other health professionals, they must find the results trustworthy and believable. Among the techniques identified by Whittemore and colleagues (2001) for ensuring authenticity and credibility were (a) demonstrating persistent observation,

(b) articulating and recording analytic decisions, (c) member checking, (d) expert

checking, (e) providing an audit trail, and (f) providing evidence to support

observations.

In order to perform persistent observation, I audio-recorded detailed field notes

from each interview. I transcribed these field notes immediately before working with

each participant's interview transcript, thereby serving to refresh my interview

observations in my mind at the time of analysis. I also kept a detailed journal of analytic

processes and decisions throughout the analysis. This journal, along with the detailed

node summaries, the grids containing verbatim quotes adjacent to the corresponding

paraphrases, and records of each affinity group with its constituent paraphrases, serves

as a detailed audit trail of the analytic process.

The analysis methods, process, and results were reviewed by an expert panel.

The panel was composed of three members with expertise in their respective fields of

qualitative women's health research, narrative research, and perinatal bereavement

research. This panel had opportunities to review the project and make recommendations

at multiple stages throughout the research process. The fact that all three panel members

were female provided alternative perspectives to any unrecognized gender-related

biases.

For further assurance of authenticity, a member check was conducted. An

extended abstract of the study's findings was prepared and e-mailed to every

participant who agreed to follow up contact ($n = 15$). Participants were invited to

comment on the findings by return e-mail. To date, none of the participant replies has suggested any disagreement with any of the study's findings.

To enhance credibility, ample evidence was provided for study observations and findings in the form of direct quotes from participants. The findings and supporting participant quotes are located in Chapter IV (p. 127) and Chapter V (p. 156) below.

Limitations

Despite these efforts to maintain rigor and ensure credibility and authenticity, this study does have some important limitations. Most of these limitations relate to the homogeneity of the sample.

Participants were relatively homogenous in several dimensions: Caucasians, high family income, high educational level, and older maternal ages were over-represented. These and other characteristics of the participant group are represented in Table 6. The sample was composed entirely of women who identified themselves as Christians, and 14 of the 15 participants were married.

My experience is that these characteristics, although not representative of the childbearing population as a whole, are representative of the PH mothers with whom I have worked as a clinician. It may be that some of these characteristics could influence the decision whether to continue an affected pregnancy and thus become a PH mother, but the sample and methods of this study did not examine these descriptive factors. Additionally, women from less advantaged socioeconomic backgrounds or from

different ethnic or cultural groups may have different perspectives and different needs

than those represented in this sample.

Another dimension of homogeneity was the result of recruiting from perinatal

bereavement support agencies: all of the participants but one had access to specialized

PH care, either at the time of their affected pregnancies or subsequently. The experiences

of women without such support were not represented, so the study provided no basis

for evaluating the effects of such services or their absence.

The fact that all the participants chose to continue rather than terminate their

pregnancies represents yet another kind of homogeneity. For this reason, the study

provides no basis for comparison of the effects of continuation versus termination.

The study is also limited in that there is no direct inclusion of the experiences of

PH fathers or other family members. As previously explained, this study focused on the

experiences of PH mothers because pregnant women are the primary recipients of

perinatal nursing and midwifery care. The family and cultural contexts and experiences

of family members also are important to providers, therefore, research that investigates

these aspects of PH care could be a valuable contribution to the literature.

IV. AFFIRMING MOTHERHOOD: VALIDATION AND INVALIDATION IN WOMEN'S PERINATAL HOSPICE NARRATIVES

Abstract

Perinatal hospice (PH) is an option for women who learn during pregnancy that their fetuses are affected by terminal conditions and choose to continue their affected pregnancies. These women face emotional pain and the impending loss of their fetuses or infants. There is a paucity of evidence-based literature to inform PH care. METHODS: Narrative analysis was performed using the personal stories of 15 women who continued pregnancies affected by lethal fetal anomalies. RESULTS: The participants identified themselves as mothers and their fetuses or newborns as babies. Mothers valued caring for and interacting with their babies. Health professionals who affirmed their status as mothers, the value of their babies, and the significance of their losses were perceived as supportive. Invalidating attitudes and behaviors caused significant distress. CONCLUSION: Optimal care of PH mothers supports the development of maternal identity and contact between mothers and newborns when desired. Professionals who care for PH mothers can affirm their motherhood through their behaviors and attitudes.

Affirming Motherhood: Validation and Invalidation
in Women's Perinatal Hospice Narratives

Birth defects and pregnancy losses have always been part of the human

childbearing experience. Some of the earliest known human writings, 4000 years old,

contain references to birth defects (The Teratology Society, 2007) and stillbirth (Black et

al., 2006). In the past three decades, technological advances have enabled health

professionals to detect many fetal anomalies prior to birth and presented women with

the choice whether to continue or terminate affected pregnancies. In the same three

decades, there has been an increasing recognition of the emotional and psychological

effects on women of pregnancy losses (Malacrida, 1999; Stirtzinger et al., 1999; Toedter,

et al., 2001; Trulsson & Rådestad, 2004) and abnormal fetal diagnoses (Hunfeld, et al.,

1997; McCoyd, 2007; Sandelowski & Jones, 1996).

Fetal anomalies are fairly common. Each year in the United States, approximately

120,000 infants are born with anomalies, about 8,000 of whom die within the first year of

life (Centers for Disease Control and Prevention, 2007). *Lethal anomalies* are a

classification of birth defects characterized by a radically shortened life expectancy. In

2005, the most recent year for which data are available, there were 6,925 fetal and infant

deaths in the United States attributed to lethal anomalies (Centers for Disease Control

and Prevention, 2007).

Perinatal Hospice (PH) describes a care option for women who learn during their

pregnancies that their fetuses have lethal anomalies and choose to continue their

pregnancies. The term *hospice* reflects the fact that an individual and a family have

learned of a lethal condition, and that the goal of care is to optimize their experiences

according to their priorities and values rather than seek a cure (Calhoun et al., 2003).

Perinatal reflects the fact that these events occur in the context of pregnancy, childbirth,

and the postpartum period. In one published series, 49 of 61 women (75%) who were

offered PH care after receiving a lethal fetal diagnosis chose to continue their

pregnancies (D'Almeida, et al., 2006).

There is very little existing research specific to the experiences of mothers who

choose PH. In the absence of research specific to this population, few evidence-based

practice recommendations can be made. The purpose of this study was to broadly

explore the experiences of PH mothers, according to their own perspectives. The aims of

the study were to gather knowledge useful to health professionals and to guide future

research.

<div align="center">Background</div>

Quantitative research has documented the prevalence of grief, depression, and

anxiety symptoms among women who experience pregnancy losses (Stirtzinger et al.,

1999; Turton et al., 2001; Wheeler & Austin, 2001). Psychological distress has also been

documented among women who receive abnormal fetal diagnoses (Hunfeld et al., 1997).

Qualitative researchers have identified a wide variety of distressing responses

associated with perinatal loss, including effects on the individual, family, and social

levels (Malacrida, 1997, 1999; Swanson, 1999; Trulsson & Rådestad, 2004). Women who

experience the loss of a pregnancy or newborn are particularly distressed when the significance of their losses is not recognized by others (Malacrida, 1999). The actions and attitudes of health providers can have a tremendous impact on women's experiences of pregnancy loss, both positive and negative (Chitty, Barnes, & Berry, 1996; Swanson-Kauffman, 1986; Trulsson & Rådestad, 2004).

The psychosocial transition to motherhood begins during pregnancy (Mercer, 2004), before abnormal fetal conditions are usually ascertained. *Maternal identity* refers to the incorporation of motherhood into a woman's concept of her self (Rubin, 1984). The development of maternal-fetal attachment, including feelings of affection for the fetus, has been documented early in pregnancy (Muller, 1992). *Caregiving* is a behavioral system that is complementary to attachment and includes maternal behaviors that meet infant needs (George & Solomon, 1999). Caregiving also encompasses the development during pregnancy of a mother's intentions and expectations about herself, her infant, and the relationship between them (Limbo & Pridham, 2007). Recognition by others of a woman's status as a mother plays a role in developing maternal identity (Mercer, 2004). Maternal identity and attachment are mediated by biophysical as well as psychosocial factors (George & Solomon, 1999). Pregnancy complications and anxiety about fetal or infant well-being can affect the transition to motherhood (McGeary, 1994; Mercer, 2004; Muller, 1992). Prenatal attachment and threats to maternal identity are significant for women who receive abnormal fetal diagnoses (McCoyd, 2007), but these phenomena have not been previously been studied in the context of lethal anomalies or PH.

Methods

A qualitative approach using narrative analysis was chosen because this method is well-suited to exploratory research on personal experiences, including bereavement (Gilbert, 2002; Niemeyer, 2001) and transition to motherhood (Klingberg-Allvin, et al., 2008). The study protocol was approved by the Marquette University institutional review board.

Participants and Recruitment

A purposive sample of 15 participants was recruited from three perinatal bereavement support agencies and by word of mouth. English-speaking women who were (a) at least 18 years old, (b) had received the diagnosis of a lethal fetal anomaly during pregnancy, (c) chose to continue the pregnancy, and (d) had an interval of 1 to 12 years since delivery, were eligible to participate. The participants were aware of the inclusion criteria.

The average age of the participants at the time of their affected pregnancies was 33.2 years (range 25 to 43), and the average interval since delivery was 4 years (range 1 to 9). Fourteen of the participants were married, and with the same husbands they had been with at the time of their affected pregnancies. One participant was single at the time of her pregnancy and at the time of the interview. All of the participants identified themselves as Christians. Thirteen of the participants identified themselves as white/Caucasian, one as African-American, and one as Hispanic.

Data Collection

Data were collected in face-to-face audio-recorded interviews. Data collection

began with the opening question: "Please tell me your story in your own words, any

way you want to tell it." No direction about the subject matter of the interviews was

given, other than what participants ascertained from the recruitment process and

eligibility criteria. The interviewer only asked questions for clarification or amplification

of details after the participant finished telling her story. Interviews were 1.5 to 3 hours in

length. Field notes and researcher impressions were recorded at the end of each

interview.

Interview recordings were professionally transcribed, and the transcriptions

were compared to the recordings by the researcher for accuracy and to eliminate

identifiers. Other than the elimination of non-verbal utterances, transcriptions were

verbatim. NVivo8 software (QSR, 2008) was used to facilitate data management and

analysis.

Data Analysis

Data were analyzed in a multi-stage process. *Passages* - segments of interview

text relating an event, thought, or feeling - were gathered into groups called *nodes*

according to subject matter and content. Nearly every passage of text was assigned to at

least one node, and most were assigned to multiple nodes. This process generated 121

nodes and 2,740 assigned passages of text.

Next, nodes were compared in a variety of ways, such the number of passages contained in them and the number of participants represented. Nodes that had direct implications for PH care, that represented atypical experiences, and that were identified by participants as important were also closely reviewed. Through this process, 25 nodes were selected for further detailed analysis.

Detailed analysis included writing a summary of each node and a paraphrasing and affinity grouping process used to identify themes. Paraphrases were constructed to represent the main ideas of each passage of text (Haglund, 2003; Hall, 2000). Related paraphrases were then arranged in affinity groups. Examination of the grouped paraphrases, comparison to original verbatim quotes, and reflection facilitated the identification of key themes in the participants' experiences.

Analytic rigor was ensured by maintaining an audit trail, expert checking, and member checking (Whittemore, Chase, & Mandle, 2001). To maintain an audit trail, analytic processes and decisions were recorded in a detailed journal. Three experts from the fields of women's health research, narrative research, and perinatal bereavement research provided critical review and made recommendations at various stages throughout the research process. Member checking was performed by distributing a summary of the findings among those participants who consented to be recontacted for this purpose (n = 15).

Results

The themes identified in the analysis process were *Motherhood*, *Invalidation*, *Validation to Self*, *Validation through Caregiving*, *Validation from Others*, and *Validation from Health Professionals*. These themes and the participant experiences they represented are described in the following sections.

Motherhood

Participants' stories revealed a variety of perceptions and emotions relating to their pregnancies, their fetuses, and their own identities as mothers. They consistently used the words *mother* to describe themselves and *baby* to describe their fetuses or newborns. *Mother* and *baby* will be used hereinafter to facilitate understanding the participants in their own terms.

Developing maternal identity was evident in the mothers' stories. They described their conscious intentions to be mothers. After the initial shock of her baby's diagnosis, one mother said "I went through the first two or three days… and I thought through everything, and yeah; I was her mom from that point on." Three mothers used the term 'emergency bonding' to describe their urgent need to form relationships with their babies in a limited amount of time.

Fetal movement was frequently cited as a factor in attachment between mothers and their babies. One mother "cherished" her baby's movements and stayed up late at night to feel him move. Others attributed spirit, personality, or intentionality, such as "dancing," to their babies' movements.

Two of the mothers reported an initial self-protective desire to limit or deny their developing bonds with their babies. Both of these mothers reported that they did ultimately bond with their babies. Many mothers emphasized the association between learning their baby's sex and subsequent naming and bonding.

Naming was one of the ways the mothers recognized their babies as unique individuals. Every participant in this study named her baby. The names they chose reflected how the mothers valued and felt about their babies: Names were chosen for religious reasons, to honor family connections, or for their meanings, such as "gift from God."

The mothers in this study assumed maternal roles and responsibilities. They wanted to make the right choices for their babies' well being. One participant said that as a mother, she had innate "programming" to feel responsible for her baby's well being. Some reported feelings of inadequacy to meet their babies' needs and protect them from harm. For example, one mother felt that her baby was "safe" in her womb, but recognized that giving birth meant an end to that safety. As the time of delivery approached, she wrote a letter to her baby apologizing that she could not give her baby more time.

Mothers expressed a variety of hopes and dreams for their babies. Many reported telling their babies about these hopes and dreams: some that were shattered by their adverse diagnoses, while others focused on hopes that were still possible. One mother hoped her baby would have a pleasant appearance to facilitate interaction with

her other children. Another, whose baby lived for 8.5 months, wanted her baby to live up to his potential and to feel loved.

These passages described a variety of perceptions and emotions expressed by the mothers. Perceiving themselves as mothers and their fetuses as babies was central to these mothers' experiences. They valued their babies and expressed their love for them. In their stories, the mothers described various kinds of invalidation, or non-recognition, of their perceptions and feelings. In response, the mothers sought through their own actions, and interactions with others, to validate their perceptions and feelings.

Invalidation

The mothers' perceptions of themselves as mothers were threatened by the very deaths of their babies. Having a strong bond of attachment and an identity as a mother, in the absence of a living baby, created a sense of unreality and a tendency for mothers to doubt themselves. Additionally, many mothers perceived a social bias: an overt or unspoken tendency for others to devalue their babies or their status as mothers. For example, one mother was criticized at her workplace for taking maternity leave, since she had no living infant for whom to care. Others perceived a bias that because their babies were not expected to live very long, they were not expected to form strong attachments and should therefore "get over it" and recover quickly from their losses.

Implications that their affected babies were somehow less important than normal babies were particularly upsetting to mothers. For example, two mothers related stories about funeral arrangements that they perceived as inferior to those provided for normal

children. After working to make her daughter's funeral a suitably special occasion, "like, her prom, her wedding; everything combined," one mother was dismayed by the appearance of the coffin:

> I looked at it and I was like, "You're kidding me. This is what we're going to bury her in?" And I got really pissed. I was just like, "That's not even good enough… I've seen Igloo ice coolers that are nicer than that."

Mothers reported relatively few experiences of invalidation from health providers, but the prolonged negative impact of these incidents is evidenced by the intense emotions mothers showed when telling their stories, in some cases years after the fact. They explicitly identified invalidating incidents as important with phrases such as "that was offensive," and "it was a really big deal to me," and "at that point, I got angry at, like, the medical profession in general."

Because physicians have special authority in the health care setting, their invalidating comments or attitudes were especially painful to the mothers. One mother's physician commented that there was no reality-based reason for her to continue the pregnancy, and expressed his belief that she only continued the pregnancy because she irrationally thought the baby would somehow survive. Another physician prescribed a medication contraindicated in pregnancy, explaining that it did not matter because the baby was going to die anyway. Another implied that since the baby was not expected to live very long, the mother would not become too attached and therefore would not grieve as much.

Sometimes medical terminology was perceived as invalidating. 'Incompatible with life' is a phrase often used in counseling mothers and families when a lethal anomaly is diagnosed, but some mothers felt their experiences contradicted this term.

> Well, the doctor said we have to terminate: "It's non-compatible with life." …who are they to say that? You know what I mean? Who are they to take all this wonderful, beautiful experience that we had away just because they feel it's non-compatible with life?

Another mother acknowledged that 'incompatible with life' was accurate to the extent that her baby died, but noted "we did have a different journey than it sounded like they were telling us."

Other health care experiences were invalidating in subtle ways. Several participants were struck by how sonographers or physicians did not share images of their babies or reveal the babies' sex once anomalies were recognized. One mother described how she felt unable to fill out her obstetric history form because there were not any options listed that described her experience. Another was upset that she was not given a birth certificate for her baby, and sought out a special certificate given to mothers whose babies die prior to birth. The latter is one example of how mothers intentionally sought validation of their babies and motherhood.

Validation

Affirmation of their experiences and emotions was important to the mothers in this study. When mothers perceived actual or potential invalidation, they responded by asserting their perceptions and feelings about their babies and their own status as mothers.

The word *validation* is used in this report because it was used by several of the mothers to describe affirming experiences and interactions. Meanings of *validation* related to statistical or psychological literature are not implied for the purposes of this discussion.

Validation to Self

Mothers recognized their own doubts and feelings of unreality as potentially invalidating, and sought validation to themselves. One mother described how photographs helped her overcome self-doubt: "I'm so glad I have those pictures because otherwise I'd think that really didn't happen to me…. That was just a bad dream, you know. But the pictures are… proof that the baby did exist." All of the mothers in this study kept photographs of their babies and many used these photographs as aids when telling their stories.

Photographs were created in ways that validated mothers' perceptions or feelings about their babies. Mothers said they preferred black-and-white for photos of deceased babies because it minimized the appearance of pallor or lividity. One mother hired an artist to create a drawing that more closely matched her idealized image of her baby.

Tangible mementoes were another way that mothers sought to affirm their babies' reality. Hand and foot castings were treasured as physical reminders. "Anything tangible that you can get your hands on is so important," one mother said. "The one thing you want is already gone, and… you've got to have that piece of something for

comfort." Another mother expressed feelings of "mama bear" protectiveness toward her

baby's foot molds, and pointed out resemblances between her affected baby's feet and

those of her other, surviving children. A third explained how tangible mementoes can

overcome doubt: "You're just kind of trying to hold onto something, because

everything's slipped away and that's all you have now. And so, if you're ever in doubt

of what you went through, you can just go back and revisit."

Some mementoes combined tangibility with photographic images. For example,

several mothers showed the researcher pictures depicting their babies in physical

contact with some special object, such as a necklace or a blanket made by a family

member. The special object was kept as a tangible memento, and the photograph

documented the touch connection between the baby and the object.

Fading of memories could also be seen as an invalidating threat, so mothers

cultivated their memories. One mother described how visiting her baby's grave site

"makes it real, and not a distant memory. Something that helps you recall it... you don't

want to forget them. They're still your baby."

Validation through Caregiving

One of the most prevalent elements in the mothers' stories was their caring

behavior toward their dead or dying infants. Gestures of affection and closeness, such as

cuddling, hugging, holding, snuggling, and kissing, played a part in every mother's

story. One mother described the night she spent with her deceased infant:

> I slept with him. Just held him real close to me. Talked to him a lot, kissed him a
> lot, just tried just to savor every moment I could… I would put him down in his

little isolette… [then soon] I would pick him up again and just snuggle him real tight to me and talk to him and tell him about who loves him, and tell him about [his brother], and the things I would have wanted for him in his life. And it was like trying to live a lifetime with him.

Fourteen of the mothers described caregiving behaviors such as dressing, bathing, and swaddling their babies. This passage exemplifies the connection between motherhood and caregiving that was expressed by many of the mothers:

So we gave her the bath, we put her hat on, we put this little gown on her, and it was… nice to sort of feel like... you know, as a mother you want to take care of your baby. But when your baby dies…. You're not going to feed your baby and you're not going to get to do… all those things you do… when your baby is healthy and you bring it home… So to give her a bath and to dress her was really important to us.

Some mothers were frustrated by hospital practices that interfered with caregiving and other mother-baby interactions. One mother described how her baby was repeatedly taken away from her to the infant warmer to check his vital signs. Another mother, who delivered by cesarean section, never got to hold or see her baby while he was alive due to postoperative routines. The importance these mothers ascribed to caring for their babies, and their distress when they were unable to do so, highlight the affirming effects of these interactions.

Two mothers in this study had babies who lived much longer than expected: one for 8.5 and one for 17 months. These mothers were challenged to provide the special care their babies required. Because infants with these conditions usually do not survive long, mothers noted that health care providers lacked relevant care experience. These mothers received bereavement support, as well as outpatient hospice and pediatric care, but noted that none of these support sources were ideally suited to meet their or their

babies' needs. Both of these mothers found the most useful information through online

support networks comprised of other mothers with similarly affected babies.

Validation from Others

In addition to affirming their motherhood through caregiving, mothers were

validated by friends, family, and others in their social networks. A recurring theme in

the following passages is the importance of validating mothers' perceptions.

Family members were a particularly important source of validation. Mothers

wanted their babies to be recognized as members of the family. Some mothers showed

family pictures, drawn by their other children, that included the deceased baby as an

angelic figure. Many mothers were gratified that relatives came to visit them in the

hospital and held their babies, just as they would a surviving baby. Family photographs

that included the baby were treasured mementoes. One mother reported that her father

made her baby's coffin, while others described special blankets or clothing made for the

baby by relatives. These actions demonstrated that other family members shared the

mothers' perceptions of their babies as important.

Married mothers frequently used the word 'we' to include their husbands when

describing important emotions or perceptions, suggesting they felt these were shared.

One mother was touched that her "big, tough" husband shed tears at the time of her

baby's death, one of the few times she had ever seen him cry. Another described how

important it was for her that her husband had the opportunity to hold the baby while

she was still alive:

I got to hold her alive for nine months. I knew she was very real, very alive. I could feel her kicking… and I knew that she was a little human… a little person. But I didn't know how much my husband really felt that, and so I knew if he could hold her alive, he could have the same experience that I had gotten to have for nine months.

Mothers appreciated recognition of their status as mothers. One mother reported that she liked visiting the NICU where her baby stayed because she was recognized as a mother there: "I said 'Do you remember me?' And [the nurse] said 'Of course, you're [baby]'s mom.' And… I'm going to go back there just because I'm only [baby]'s mom. It's my identity and I like it."

Memorial services were important occasions for recognition and validation. Many mothers were touched by the sheer number of people who came to services. "We needed those people to acknowledge what was going on," one mother explained. Another, whose husband was a police officer, described how the memorial service was "a sea of blue" due to all the uniforms. One mother felt validated when people expressed their grief for the loss of her baby, as distinct from sympathy for her loss: "I think it just reconfirmed that she [the baby] was important to other people."

Talking about their babies was an important way for mothers to seek social validation. One mother said that participating in this study, and telling her story, was a way of validating her baby's life. Others found their usual social networks were not always receptive to stories about their deceased babies, but found the support they needed from other PH mothers:

…you're still a mom, and you have a need to talk about your baby. Well, everyone else who hasn't gone through that… really feels uncomfortable around you when you start talking about your baby; wants to shut you down and

change the subject… so you don't get the opportunity to talk about your baby… I've got all these pictures. To somebody in the outside world, that's gruesome…But you can come here [PH agency] and the… moms bring their photo albums, and we can show each other our babies. And we can fulfill the need that we have to talk about our kids. That they're real people.

Validation from Health Professionals

Health professionals played prominent roles in the women's stories. Supportive health professionals were well-situated to facilitate validating experiences for mothers. Table 1 is a compilation of all the validating and invalidating behaviors of health professionals described by the mothers in their narratives.

Many mothers expressed appreciation for the way nurses treated their babies. They told of nurses who called babies by their names, were attentive to their babies' needs, and treated deceased babies with affection and respect. One mother said her nurse seemed to have a connection with her baby, and this made her feel that her baby was "in good hands." Several mothers' nurses told them their babies were beautiful. Nurses who offered choices, followed birth plans, and facilitated mothers' interactions with their babies were perceived as supportive. Validation was apparent in these descriptions of supportive nurses, particularly validation of mothers' wishes and the worth of their babies.

Just as physicians' authority made their invalidating comments or attitudes especially painful, mothers were deeply affected by validation from physicians. One mother described how her obstetrician, who was not on call when she delivered, came to

Table 1

Validating and Invalidating Provider Behaviors in Mothers' Narratives

Subject of validation or invalidation	Validating	Invalidating
Baby	Called baby by name	Used insensitive terminology
	Treated baby like a person	Treated baby like an object
	Said baby was beautiful	
	Attended to baby's needs	
	Acknowledged value of baby's life	Emphasized futility of care and inevitability of baby's death
	Ultrasound: showed images of baby and told me baby's sex	Ultrasound: focused only on abnormal findings
	Provided hand and foot molds	
	Took or facilitated photographs	
	Attended memorial service	
Mothers' autonomy	Accepted decision to continue pregnancy	Pressured mother to terminate pregnancy
	Offered options	
	Followed birth plan	Followed routines
	Listened before telling	

(continued on next page)

Validating and Invalidating Provider Behaviors in Mothers' Narratives (continued)

Subject of validation or invalidation	Validating	Invalidating
Mother's autonomy (continued)	Respected parents' privacy	
	Allowed time to make decisions	
Mothers' caregiving	Provided unlimited time with baby	Interrupted time with baby for care routines
	Helped mother bathe baby	
	Helped mother dress baby	
	Trusted mother to take care of baby	
	Recognized mother as a mother	
		Provided inadequate information about baby's care at home
Mothers' feelings	Did not tell mother how to feel	Told mother how she should feel
	Acknowledged significance of mother's loss	Expected mother to "get over it" quickly
	Made human connection	Maintained clinical demeanor
	Seemed comfortable with tears	
	Treated parents like normal people	

the hospital on her day off to see and hold her baby. Another was moved to tears describing how her physician came back to the hospital several hours after the delivery to attend a bedside memorial service. One mother left a perinatologist's practice after he advised her to terminate her pregnancy, but found another who shared her belief in her baby's worth. "The second perinatologist, he was so cool. He was like, 'You're right. This life is of value, and every life has a value.'"

Health professionals who validated mothers' feelings were also perceived as supportive. One mother appreciated that her providers were "comfortable with tears." The director of a PH care program was remembered for how "she just validated all my feelings were okay feelings." Many stories echoed the sentiments of a mother who urged providers, "we need you to be real, and, you know, take off that white lab coat and become a human."

Discussion

Analysis of these women's stories revealed that they identified themselves as mothers and expressed love for their babies. The importance they ascribed to validation of their motherhood and attachment to their babies was also evident. Words and actions that validated their status as mothers, the value of their babies, and the significance of their losses were perceived as supportive. Invalidating words and actions caused anger and emotional pain.

Most instances of invalidation described by the mothers were related to lack of understanding. Mothers' comments often revealed fundamental discrepancies between

their own understandings and experiences and how they were perceived by others. In order to validate mothers' thoughts and feelings, it is necessary to understand them. Listening to mothers' stories was an effective way to achieve such understanding in this study, and seems likely to be an effective clinical approach as well.

Concepts from the literature on women's transitions to motherhood, such as maternal identity, maternal-fetal attachment, social recognition, and caregiving, were prominent in these mothers' experiences. It appears that some of the processes of maternal transition were either underway prior to the ascertainment of fetal conditions, or that they continued, possibly in an altered form, after diagnoses were made. Many of the mothers' comments emphasized similarities between their needs and desires and those of women experiencing normal pregnancies. In particular, these mothers' accounts revealed their need for caregiving of their own infants, either through gestures of affection or behaviors such as dressing, bathing, and swaddling. Some of the mothers' impressions, such as a sense of innate "programming" to feel responsible for their babies' well-being, could reflect the biophysical basis of maternal-infant caregiving and attachment (George & Solomon, 1999). Although the effects of bereaved mothers seeing or holding their infants have been studied in previous research (Hughes et al., 2002; Rådestad et al., 2009), maternal caregiving was not the primary focus of these studies. The importance that mothers in this study ascribed to cuddling, dressing, bathing, and talking to their babies suggests that further inquiry in this area could be fruitful. Implications that can be drawn for care based on the findings of this study are discussed subsequently.

Implications

The power of health care providers to validate or invalidate is particularly salient. The affirmation these mothers experienced from their health providers, and the resulting satisfaction they derived, are testament to the insight and understanding of those care professionals. When care was unsatisfactory, failure to understand mothers' experiences, perceptions, and needs often played a part. Listening attentively to mothers' accounts, and clarifying their thoughts and feelings prior to making clinical recommendations or decisions, is likely to foster better understanding and more satisfactory care. Table 1 can serve as a guide for behaviors to emulate and those to avoid.

These mothers' stories provided support for the established perinatal bereavement practices of creating mementoes and photographs. Understanding how mementoes can provide validation may help care professionals to suggest those that affirm mothers' thoughts and feelings about themselves and their babies. Planning for photographs and mementoes prior to birth can provide an opportunity to explore these thoughts and feelings. The tangible quality of hand and foot molds seems to make them especially validating.

Caregiving and other kinds of interaction with their babies were clearly valued by mothers in this study. Whether such interaction may be harmful has been a matter of controversy since the publication of Hughes and colleagues' (2002) study, which found higher depression and anxiety symptoms in subsequent pregnancies among women

who saw and held their stillborn infants than women who had no such interactions. The experiences recounted by the mothers in the present study suggest that benefits of mother-baby interaction could outweigh the negative effects described by Hughes and colleagues (2002). Until this question is investigated in ways that account for the potential benefits of mother-baby interaction, care is most appropriately based on the preferences of the mothers and families affected.

When mothers do express their desire for caregiving opportunities and contact with their infants, this should be recognized as a priority. It is difficult to imagine any possible clinical benefit to a terminally ill infant in the last moments of his or her life that could justify separating the infant from the mother and family. In such instances, care routines can be modified or performed at the bedside.

The mothers who participated in this study demonstrated conscious intention and active participation in decisions about their care. Helping mothers to define their wishes and formulate birth plans, and following those plans, demonstrates respect for their autonomy and is more likely to result in satisfactory care than clinical approaches based on established routines or provider preconceptions.

The narratives collected for this study supported the value of specialized PH care. Nurses and counselors experienced in caring for mothers of babies with lethal anomalies were able to anticipate possible needs, explore options, validate feelings, and make suggestions based on other mothers' experiences. Providing peer support groups composed of other PH mothers is a particularly important role for PH care agencies. The care of babies who survive longer than expected appears to be a gap in existing services

deserving of further attention. Specialized PH care is not available in every community: for example, a frequently updated online resource listed 79 such programs in the United States, mostly concentrated in major metropolitan areas (Kuebelbeck & Davis, 2009). Expanding access to specialized PH care is a pressing need.

Limitations

One limitation of this study is that women who chose to terminate affected pregnancies were not included. Emphasizing motherhood and attachment may or may not be appropriate for women who choose to terminate. Significantly, health professionals do not know at the time of diagnosis whether a woman will choose to continue or to terminate. Therefore, their approach at this vulnerable time is best informed by the *possibility* that she *may* consider herself a mother and her fetus a baby.

Additional limitations are due to the relative homogeneity of the sample and the fact that fathers and siblings were not included. It was evident from the mothers' accounts that fathers and siblings were deeply affected by their experiences. Mothers of different racial, ethnic, socioeconomic, cultural, or educational backgrounds may have significantly different experiences than those represented here. Research that includes more diverse participants and assesses the experiences of fathers and siblings is needed.

Conclusion

The findings of this study, derived from PH mothers' personal narratives, provided useful insights for professionals involved in the care of women faced with the loss of their fetuses or infants. Established care practices such as offering choices, birth planning, and making memories were supported. Additional insights about the importance of caregiving and validating motherhood may prove useful in planning care for PH mothers. Recognizing women who continue pregnancies affected by lethal anomalies as mothers, who can have meaningful relationships with their babies despite their impending losses, may be the most affirming and supportive basis from which to approach their care.

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V. CONTINUITY AND CHANGE IN MOTHERS' NARRATIVES OF PERINATAL HOSPICE

Abstract

OBJECTIVE: To explore and describe women's experiences after the continuation of pregnancies affected by lethal fetal diagnoses and subsequent loss of their infants DESIGN: Qualitative descriptive study using narrative analysis. PARTICIPANTS: 15 women who learned during their pregnancies of a lethal fetal diagnosis and chose to continue the affected pregnancies. METHOD: Participants' stories of their PH experiences were recorded in face-to-face interviews. Narrative analysis techniques were used to identify themes and develop suggestions for care. RESULTS: The element of time was prevalent in mothers' stories. Some aspects of mothers' experiences continued, particularly feelings of love and connection to their babies. Mothers also reported evolving changes in their thoughts and feelings. Personal changes, such as increased compassion, faith, and strength, were frequently mentioned. Mothers described transient phases of highs and lows. Drawing personal meanings or life-lessons was the main way mothers connected their past experiences to their present lives. CONCLUSIONS: Mothers' descriptions of their experiences can enhance nurses' understanding of perinatal loss. Established care practices, such as birth planning and creating mementoes, were supported. Nurses can help mothers experiencing loss by elucidating and reflecting their personal meanings.

Continuity and Change in Mothers' Narratives of Perinatal Hospice

Over the past 20 years, the care of women and families affected by perinatal loss

has become a major focus of maternal-newborn nursing. An electronic search of the

nursing literature using a widely-used search engine returned 4,498 articles on

miscarriage, stillbirth, neonatal death, and perinatal death. More recently, clinical and

scholarly attention has turned to the care of women and families affected by adverse

fetal diagnoses (Howard, 2006; Sandelowski & Barroso, 2005). The intersection of these

phenomena, the care of women who learn during pregnancy of a lethal fetal condition,

is the focus of a newly emerging body of literature on perinatal hospice (PH).

Fetal anomalies are fairly common. According to the Centers for Disease Control

and Prevention (CDC) (2009), about 120,000 infants are born with anomalies in the

United States each year. *Lethal anomalies* are birth defects characterized by a radically

shortened life span. In 2005, the most recent year for which data are available, there

were 6,925 fetal and infant deaths in the United States attributed to lethal anomalies

(CDC, 2007).

Technologic advances have made it possible to diagnose birth defects, including

lethal anomalies, prior to birth. Parents who receive a prenatal diagnosis of a lethal

anomaly are faced with the painful decision whether to terminate or continue the

pregnancy. Reasons to terminate may include a desire to avoid suffering, distressing

experiences, or possible maternal morbidity associated with continuation of pregnancy

(Calhoun, Napolitano, Terry, Bussey, & Hoeldtke, 2003). Recent trends such as

improved sensitivity to the bereaved and increased focus on client choice and involvement in decision-making have resulted in some parents choosing to continue pregnancies affected by lethal anomalies (Calhoun et al., 2003).

PH is a care option for mothers and families who choose to continue pregnancies affected by lethal anomalies. In one published series, 75% of women chose PH after receiving a lethal diagnosis (D'Almeida et. al, 2006). Women may choose PH for personal, ethical, or religious reasons, or simply to make the most of whatever time they have with their children. At the time of this publication, an online PH resource listed 79 PH programs in 29 different states of the USA, mostly concentrated in major metropolitan areas (Kuebelbeck & Davis, 2009).

There is a paucity of evidence-based literature to inform PH care. The purposes of this qualitative study were to broadly explore the experiences of women who choose to continue pregnancies affected by lethal fetal diagnoses and to develop knowledge useful to nurses and other health professionals who provide their care.

Background

Research on perinatal loss has demonstrated the prevalence of distressing bereavement-related experiences such as grief, depression, anxiety, post traumatic symptoms, guilt, and relationship difficulties (Hughes, Turton, & Evans, 2002; Stirtzinger, Robinson, Stewart, & Ralevski, 1999; Toedter, Lasker, & Janssen, 2001; Wheeler & Austin, 2000). The persistence of grief and other symptoms, especially through the first few years after a loss, has been documented (Hughes et al., 2002;

Stirtzinger et al., 1999; Toedter et al., 2001). Studies using a measure of grief intensity

have suggested a general trend of decreasing grief intensity over time (Janssen et al.,

1997; Toedter et al., 2001).

Beginning with Swanson's (1986) classic study of women after miscarriage, and

further explored by more recent works (Kobler, Limbo, & Kavanaugh, 2007; Swanson,

1999), the importance of personal meanings in the context of perinatal loss has been

recognized. Assessing mothers' intentions and promoting their active participation,

offering choices, assisting in the creation of memories and mementoes, supporting

physical contact and emotional attachment between family members and dead or dying

infants, and the importance of compassionate presence, have been recognized as

important elements in the nursing care of women and families experiencing perinatal

loss (Hutti, 2005; Kobler et al., 2007; Swanson, 1999; Trulsson & Rådestad, 2004).

Theories about human responses to loss have proliferated in the past 20 years

(Ayers et al., 2004). Classic approaches to bereavement focused on the grief work

hypothesis: the idea that recovery after a significant loss involves confronting the

emotional pain of grief, severing emotional ties to the deceased, and returning to pre-

loss functioning (Ayers et al., 2004; Wright & Hogan, 2008). Further developments

included theoretical models characterized by stages or phases. For example, Bowlby

(1980) described four phases of response to loss: (a) shock or numbness, (b) searching

and yearning, (c) disorganization and despair, and (d) reorganization. Research has

validated the clinical utility of stage approaches when used to describe and understand

responses to bereavement (Maciejewski et al., 2007).

Recent developments in bereavement-related theory have focused on meaning reconstruction, continuing bonds, and post-traumatic growth. *Meaning reconstruction* concerns the disruption of personal meanings entailed in loss, and the resulting need to make sense of the loss and restore one's sense of order or purpose in life (Niemeyer, 2000). In contrast to earlier perspectives that espoused the desirability of detachment, or cessation of emotional involvement with the deceased, *continuing bonds* describes how the bereaved may experience an ongoing and adaptive emotional attachment to the deceased (Klass & Walter, 2004). *Post-traumatic growth* is an emerging concept that emphasizes the potential for positive personal transformations in the aftermath of loss (Tedeschi & Calhoun, 2008). Table 1 includes an outline of the major concepts of these emerging bereavement theories. A common element in these theories is their emphasis on post-loss transformations of self and relationships, rather than a return to the pre-loss state.

There is an emerging literature on the care of women and families affected by lethal fetal diagnoses. Published articles have proposed models of care for PH (Hoeldtke & Calhoun, 2001; Leuthner, 2004; Roush et al., 2007) and described existing care programs (Calhoun et al., 2003; Leuthner & Jones, 2007). Authors have emphasized the need for a holistic approach to care that encompasses physical, emotional, and spiritual support (Hoeldtke & Calhoun, 2001; Leuthner & Jones, 2007). It has been emphasized that hospice is a philosophy of care, not a physical location (Roush et al., 2007). The

Table 1

Emerging Theories of Bereavement

Theory	Major Concept(s)	Examples
Meaning Reconstruction	Restoration of personal meaning in life after a loss	Finding a "silver lining" or higher purpose
		Attempting to make sense of the loss
		Creating comforting memories or symbols
		Identifying favorable changes in one's self resulting from the loss
Continuing Bonds	Ongoing significance of relationships after death	Sensing the presence of the deceased in daily life
		Talking with the deceased
		Comforting image of the deceased's existence after death
		Relying on the deceased as a moral example or guide
Post-Traumatic Growth	Changes in Relationships	Greater closeness or communication with others
		Strengthened empathy or compassion
	Personal Strength	Improved ability to cope with adversity
		Discovery of newfound strengths
	Spiritual Change	Enhanced religious faith
		Increased sense of spirituality
	Appreciation of Life	Feeling of gratitude for each day
		Change in priorities or what is regarded as important in life

goals of PH are to prevent suffering, preserve dignity, promote quality of life, and honor

parental preferences (Limbo, Toce, & Peck, 2008).

Consensus opinion supports the necessity of a multidisciplinary team approach

for PH care (Hoeldtke & Calhoun, 2001; Leuthner & Jones, 2007; Limbo et al., 2008;

Roush et al., 2007). One program description article emphasized the central role of a

nurse coordinator for effective PH care (Leuthner & Jones, 2007). A major element of PH

care is birth planning that helps parents prepare for possible outcomes, enhances their

sense of control, and makes the most of their limited time with their infants (Leuthner &

Jones, 2007; Roush et al., 2007; Sumner, Kavanaugh, & Moro, 2006). Aftercare of the

surviving family has also been advocated (Hoeldtke & Calhoun, 2001; Leuthner & Jones,

2007; Roush et al., 2007). Lack of awareness of PH has been identified as a barrier to

effective care (Sumner et al., 2006).

Methods

Narrative analysis is a research approach to exploration and understanding of

experiences through the study of participants' personal stories (Clandinin & Connelly,

2000). Narrative research has been advocated as a method particularly well suited to

bereavement research (Gilbert, 2002; Niemeyer, 2001).

Participants and Recruitment

Participants in this study were 15 volunteers recruited from perinatal

bereavement support agencies that provide PH services and by word of mouth. Eligible

participants were women who were at least 18 years old and had received the diagnosis

of a lethal fetal anomaly during pregnancy, chose to continue the pregnancy, and had an interval of 1 to 12 years since delivery.

The average age of the participants at the time of their affected pregnancies was 33.2 years (range 25 to 43), and the average interval since delivery was 4 years (range 1 to 9). Fourteen of the participants were married, and with the same husbands they had been with at the time of their affected pregnancies. One participant was single at the time of her pregnancy and at the time of the interview. All of the participants identified themselves as Christians. Thirteen of the participants identified themselves as white/Caucasian, one as African-American, and one as Hispanic.

Data Collection

Data were collected from participants in audio recorded interviews. There was no predetermined interview guide beyond a single opening question, "Please tell me your story in your own words, any way you want to tell it." Participants were not given any direction about the subject matter of the interviews other than what they ascertained from the recruitment process and the eligibility criteria for the study. The duration of the interviews was determined by the length of the participants' narratives, and ranged from 1.5 to 3 hours. Field notes of researcher impressions were recorded immediately after each interview.

Data Analysis

Interview recordings were professionally transcribed. The researcher reviewed transcripts of the interviews, simultaneously listening to the audio recordings to check

for accuracy and listen for tone, pacing, and other emotional cues. These impressions were compared to field notes made during the interviews. Potential identifiers were removed from the transcripts. NVivo8 software (QSR, 2008) was used to facilitate analysis.

The initial phase of data analysis focused on each interview separately and consisted of re-reading transcripts and assigning passages of text to nodes; groups of text passages with similar content or subject matter (QSR, 2008). This process yielded 121 nodes containing 2,740 passages of text.

Next, nodes were compared in a variety of ways, such the number of passages contained in them and the number of participants represented. Nodes that had direct implications for clinical care, that represented atypical experiences, and that were identified by participants as important were also closely reviewed. Through this process, 25 nodes were selected for further detailed analysis.

Detailed analysis included writing a summary of each node and a paraphrasing and affinity grouping process used to identify themes. Paraphrases were constructed to represent the main ideas of each passage of text (Haglund, 2003; Hall, 2000). Related paraphrases were then arranged in affinity groups. Examination of the grouped paraphrases, comparison to original verbatim quotes, and reflection facilitated the identification of key themes in the participants' experiences.

Analytic rigor was ensured by maintaining an audit trail, expert checking, and member checking (Whittemore, Chase, & Mandle, 2001). To maintain an audit trail, analytic processes and decisions were recorded in a detailed journal. Three experts from

the fields of women's health research, narrative research, and perinatal bereavement research provided critical review and made recommendations at various stages throughout the research process. Member checking was performed by distributing a summary of the findings among those participants who consented to be recontacted for this purpose ($n = 15$).

Throughout the analysis, attention was paid to how participants told their stories as well as to what was said. Participants consistently referred to themselves as *moms* or *mothers* and their fetuses or newborns as *babies*. In order to facilitate understanding the participants in their own terms, *mother* and *baby* will be used throughout this report.

<div align="center">Results</div>

The element of time was prominent in mothers' stories. Some of the most intense experiences reported by mothers were thoughts and feelings that persisted over time. Many of their comments contrasted how they felt or what they thought in the past with their current thoughts and feelings. Mothers also described transient phases or stages: periods of time during which one kind of experience was predominant. All of the mothers' stories included statements of summary or meaning through which they transitioned from their past experiences to their present lives. Details of the study findings are organized subsequently according to these various relationships between mothers' experiences and the passage of time, including *continuity*, *evolving changes*, *transient phases*, and *connecting past to present*.

Continuity

Many of the mothers experienced thoughts and feelings that continued despite the passage of time. These included ongoing, frequent thoughts about their babies, feelings of loss and pain, feelings of connection to their babies, and ongoing or recurrent feelings of grief. The common element in these experiences was that they continued through time, and mothers described them as still ongoing when they were interviewed.

Several mothers said that they still frequently think of their babies. "There isn't a day that goes by when you don't think of her," one mother said. The mother who had the longest interval of any participant since the loss of her baby said, "it's been nine years, but we still think of him every day and every time we say a prayer, we always say 'Give [baby] a hug and a kiss.' Every day." One mother described how she still reaches for her baby sometimes.

The emotional pain of mothers' losses was also persistent. One mother, a year removed from the death of her baby, noted "I do still have just those moments when… something snaps and I just remember that I don't have a baby, you know, and I never will have him again." Another who had a one year interval since her loss said, "it hasn't gotten any easier."

Many mothers expressed a sense of their babies' ongoing presence in their lives. Continuing feelings of love and connection to their babies were a prominent feature in mothers' stories, some many years removed from their losses. Most of the mothers

described pictures or other mementoes of their babies displayed in their homes. Some

described their babies' ongoing presence in spiritual terms:

> When someone passes through your life, they leave an imprint on you, and maybe that's what it is: maybe it's his spirit. Maybe it's an energy. Like my oldest daughter said, she has a big brother in Heaven, someone looking out for her, someone watching over her.

Five more mothers expressed similar thoughts of their deceased babies as

comforting, protective, or angelic presences. One mother said that she felt emotionally

supported by her baby's presence when talking about her loss, and believed that a

younger relative learning to be a pilot was protected by her baby's spiritual presence.

Including their babies in their prayers, or as intercessors, were frequently mentioned.

One mother, who lost her first baby after years of struggling with infertility, prayed to

her deceased infant to ask Jesus for a brother, and later, after her son was born, a sister.

Two mothers said that their babies' ongoing presence serves as a reminder to behave

more ethically. Several mothers thought of their babies as restored to wholeness and

health in an afterlife.

Recurrence, or the periodic renewal of grieving, was a variant form of continuity

in the mothers' stories. Anniversaries of the dates of diagnoses, due dates, dates of birth,

and dates of death were mentioned as times that thoughts about their babies were

especially present in mothers' minds. Many mothers continued to be reminded of their

babies at times they would have passed milestones, such as the first day of kindergarten.

Some of the mothers sought to make anniversary dates into special days of celebration

and remembrance.

> The 20 week sonogram anniversary, we… had some rose bushes put in for… a memorial rose garden… and we thought, "Well, let's have a rose garden blessing party on that anniversary date." And so we did that and we had over a hundred people in our front yard… and it was just really cool…That was really healthy for me to celebrate that… to celebrate her life and her memory on that date instead of thinking, "this is the day of that 20 week sonogram."

Evolving Changes

In contrast to the experiences of continuity represented above, mothers also reported evolving changes in their thoughts and feelings. Changes that occurred over time included decreasing intensity of grief, personal growth, and ambivalence about feelings of resolution.

Decreasing intensity was commonly reported. For example, most of the mothers reported that they were doing better at the time of their interviews than at the time of their losses. Mothers who had longer intervals since their babies' deaths generally reported that the most intense grief had passed. "I don't cry every day. Most of the time… it's always there, but it's not overwhelming grief in our life daily," one mother said. Another said "I just feel like I've been freed of the grief." Another mother described how her feelings changed over time:

> Well, I think like, with any death anyone would experience in their family, over time, the pain is – the intense pain has subsided… but you never forget them. You don't get over it, you get past; you get through it. But you don't get over it. But then, you're able to look retrospectively back and be at peace with everything… Until you reach that point, it's pretty difficult to talk about what you've been through… When you're in the middle of it, you just; yeah, I'd just sit there and cry the whole time.

Another mother described how when she was pregnant with her affected baby, she could not believe the pain would get better:

> I remember talking to [another PH mother] while I was pregnant… and, you know, it had already been a couple years for her to pass. And she goes, "just give it time. It'll get better." And I'm like, "I couldn't even begin to comprehend how in the world could all this pain actually get better." And it does.

Sometimes, mothers' internal processes of change were reflected externally. For example, one mother described how initially she had mementoes of her baby all over her house. As time passed, she felt that the constant reminders were detrimental to her healing. Now, she keeps mementoes of her baby together on one special shelf. This process of moving "the baby's things" from "everywhere" to one special place seemed symbolic of how she found a location for her baby in her ongoing emotional life.

One of the most prevalent experiences, described by thirteen of the fifteen mothers in the study, was personal change or growth in response to the loss of their babies. "I'll never be the same… it really made me a lot more compassionate person," one mother said. Many described a sense of increased personal or family strength. Greater compassion or empathy for others, and enhanced closeness to people who are suffering, were also frequently mentioned. Another prevalent kind of personal change was enhanced religious faith, as this mother exemplified:

> I just knew we would get through. A lot of people in this kind of situation or any kind of a terminal illness realize strength that they didn't know they had… When you're about to lose it, you don't think you can do it, it's there again for you. And so, my faith is stronger than it ever was because I felt *carried*. [participant's emphasis]

The absence of change, feeling stuck, was described by two of the mothers. One mother said she felt she stayed in "immediate crisis mode" for 3 months after her baby

was born, until she began taking antidepressant medication. Another felt she was able to get un-stuck when she reached out to support other PH mothers.

Within the overall trend of decreasing intensity and pain, some mothers encountered a paradox: regret for the healing or resolution they experienced. One mother described her mixed feelings the first time after the loss of her daughter that she felt joyful again: "The reason why I started crying was because I was so happy. I didn't feel the pain of that loss and I felt like I was forgetting her." Another said, "even the bad things, you feel guilty when you start to forget… you go back and forth, but I think you kind of want to remember the good things and maybe not so much the bad things."

Transient Phases

Mothers often used the terms *phase* or *stage* when describing their changing thoughts and emotions. None of the mothers' comments implied a linear progression of stages. Rather, they described transient periods during which one kind of emotion or experience was predominant, but later subsided. Phases described included numbness or unreality, most difficult or most painful times, "highs" or joyful phases, and "roller coaster" oscillation between highs and lows.

A majority of mothers, eleven of the fifteen in this study, described a phase of numbness or unreality. This usually occurred just after a major event such as an adverse diagnosis or the death of a baby. Mothers used phrases such as "a blur," "like a dream," "still in shock," "in a fog," and "didn't seem real." One mother described her response when her physician first told her about her baby's diagnosis:

> We were just… in complete shock; just complete shock, and I don't even remember how the rest of that conversation went. And I remember walking out just thinking, "Oh, my goodness, we're in a… really bad nightmare and I'm sure we will wake up."

Several mothers described a most difficult moment or most painful phase. One mother's most difficult time was when she felt guilty for her baby's condition. Some mothers' most difficult times were associated with finality. For example, one mother said her most painful time was when earth was placed on her daughter's casket. One mother treasured the time she spent with her baby, but dreaded the approaching time to hand her to the hospital staff:

> It was really nice just to hold her. It got harder as time went on because obviously she was dead, so her body became more and more stiff, and… we could tell that it was getting to be time to hand her over. But, Oh! That moment was just so hard, the moment of just handing her over to the nurse and, I think that was the, the hardest moment.

In contrast to the most difficult times, many mothers described a "high" or joyful phase. Memorial services, when babies' short lives were celebrated and mothers experienced outpourings of recognition and support, were frequently associated with highs. One mother described how she felt at her daughter's funeral:

> When I walked in, I was like, "I'm at my daughter's funeral and I'm supposed to be… horribly sad because she just passed away." I couldn't quit smiling. It was perfect. It was perfect. It was just kind of like, her prom, her wedding, everything combined.

Oscillation between joyful highs and painful lows was described by mothers as a "roller coaster." During pregnancy, especially as the time of delivery approached, was frequently described as an emotional roller coaster as mothers anticipated their babies'

births but dreaded their impending deaths. One described the highs and lows as a

"roller coaster in the dark:"

> And then you have this beautiful child and beautiful moments… and their life, even though it was incredibly short, was so meaningful and so profound... and knowing how proud you were of that baby… that just really gave us a high… where you're just happy and proud and… very, very relieved… And then that high, you know, it gradually goes down… It wasn't like I was always really, really down, but there were, I describe it as a roller coaster in the dark. You… have blinders on. And you don't know how long you'll have a medium level, when you'll have a dip, when you'll have another high.

Although composed of high and low phases, the roller coaster was itself a

transient phase. Rather than an abrupt end to the "ride," mothers described a gradual

leveling trend as the highs became less high and the lows not as low. One mother said

she feels she is off the roller coaster, but she "can still hear the rumble." This sense of

incomplete resolution is characteristic of mothers' descriptions of their various phases

and stages. That mothers spoke of phases in the past tense attests to their transitory

nature. No mother spoke of a phase in which she was still immersed or which still

predominated in her experience at the time of her interview.

Connecting Past to Present

Most of the mothers' stories contained statements or passages indicating a

transition or relocation to the present. Sometimes these were simple statements, such as

"I'm doing better now," or "that's still with me to this day." Other transitions were more

elaborate accounts connecting the experiences of the past to the present, such as

retrospective evaluations, personal meanings or life-lessons, and lasting emotions.

Several mothers adopted a retrospective point of view, looking back on their experiences. These mothers seemed to have evaluated their experiences and expressed a sense of having done the right thing or having no regrets:

> There was so much involved in having this special baby, and every time I think back to the times when I was pregnant with her, I would do it all exactly the same. I would make all of the same decisions again. So you know, I have no regrets on everything.

The most common form of transition to the present in mothers' stories was meanings or life-lessons drawn from their experiences that continued to inform their lives. Every participant had at least one such statement, one had 18, and the average number was 7. In all, there were 100 statements of meaning in the 15 women's stories.

Many of the mothers found meaning in the belief that their pregnancies, babies, and their losses served a higher purpose. Sometimes this purpose took the form of a direct benefit to some other party. For example, some mothers noted that their experiences motivated positive changes in health providers or institutions. Many told of how their babies touched the lives of others and inspired them. One mother noted that a relative who had previously been distant and isolated was so moved by her baby's life and death that she "totally changed" and became a compassionate hospice worker.

For mothers, belief in a higher purpose stood in contrast to medical or biological explanations of their babies' conditions, often expressed as developmental accidents or genetic errors. Some mothers explicitly rejected the implication that their babies resulted from a mistake:

We feel that [baby]'s life was not a mistake in any way, and… we do believe that she was put here for a reason… sometimes it's the most weak and innocent lives among us that can teach us the most.

Often, mothers' beliefs in a higher purpose were expressed in religious terms. Several mothers believed that their babies' conditions were part of God's plan and that they were chosen to be the parents of special babies. One mother reflected these ideas in her birth plan, which began: "This birth is sacred. This child is a gift from God, and we want to honor his life here."

Birth plans often reflected the intention of mothers to find or create meaning in their experiences. One mother described a process of talking to other PH mothers as well as her physicians in preparing her birth plan. "I just felt like the more information we had, the more power we had to make our time with her as meaningful as possible."

There is an important distinction between mothers' own meanings and the imposition of other people's beliefs or meanings. One mother recalled resenting being told that her loss was God's plan. At the time of her loss, she said, "it didn't feel like a very good plan." She did express her own meanings, in the form of learning important life lessons. These were meanings she drew for herself, not imposed by someone else.

In addition to drawing meanings, some mothers transitioned to the present through a predominant, lasting emotion. Gratitude and pride were frequently mentioned. "I just remember being so proud of him. That is probably the biggest thing that still stands out in my mind…I was just so proud of him. I still am," one mother said. Love was another emotion that mothers carried with them from the past to the present:

"His passing through our lives really brought out a lot of love in our family that remains to this day."

Whether in the form of a retrospective assessment, a personal meaning, or a lasting emotion, mothers' transitions to the present shared the common function of creating continuity between a past that included the pain of losing a baby and their ongoing lives in the present. Along with continuity, evolving changes, and transient phases, these transitions characterize how mothers moved through time, leaving the most intense pain of grief in the past while maintaining connection between past and present. One mother expressed it this way:

> I don't know if time heals, but I almost believe the other side of grief, like when you get healed to a point, that you start thinking of your loved one, then it's a happy thought instead of a sad. …you can think about something fun and happy and not cry, but smile. …that's what happens over time.

Discussion

The element of time was prominent in the mothers' stories, and understanding how mothers' experiences can both continue and change over time is potentially important for their care. The seeming contradiction between continuity and change was reflected in mothers' often paradoxical feelings: accounts of ongoing pain that will never go away yet decreases in intensity over time, feelings of sadness accompanying the first post-loss experience of joy, or a moment of joyful high occurring at the funeral of a beloved child.

Previous research in perinatal bereavement has suggested an overall trend of decreasing grief intensity over time (Janssen et al., 1997; Toedter et al., 2001). The

accounts of mothers in this study suggested trends not only of decrease, but also of

continuity and ongoing evolution. Mothers' stories showed that they valued, and

wanted to preserve, their feelings of family closeness, connection, and love for their

babies. The thought of "getting over it" or forgetting could be distressing in the context

of a mother's and family's love for their child. Although they wanted to hold on to some

thoughts and feelings, mothers wondered how it could be possible to live their lives

with grief and pain so overwhelming that they seemed to preclude any prospect of

resolution. The narratives represented here suggest that for these mothers, it was

possible to maintain meaningful emotional connections to their babies and to draw

enduring lessons and meanings, even as the intense pain of their losses subsided.

Transformation of self, relationships, and life-meanings in the aftermath of loss

was evident in these mothers' stories. This suggests that concepts of meaning

reconstruction (Niemeyer, 2000), continuing bonds (Klass & Walter, 2004), and post-

traumatic growth (Tedeschi & Calhoun, 2008) developed in the bereavement literature

are applicable to mothers' experiences of PH and possibly other kinds of perinatal loss.

Lack of conceptual clarity about the nature of recovery after bereavement has been

problematic for scholars and clinicians (Ayers et al., 2004). Theories that describe such

transformative post-loss processes may provide a useful guide for nurses to approach

perinatal bereavement in research and in clinical practice.

Although the mothers in this study did use the terms *stage* and *phase*, their

accounts are not consistent with conceptions of a linear progression through clearly

defined stages. Other than numbness and unreality, which were prevalent initial

responses, mothers' accounts of phases or stages were highly variable and individual, and did not seem to occur in any predictable order.

<div align="center">Clinical Implications</div>

Therapeutic communication can be enhanced by understanding clients' grief processes (Wright & Hogan, 2008), and guidance based on understanding mothers' thoughts and feelings over time may prove helpful. Suggested care approaches organized by the temporal themes identified in this study are listed in Table 2. Mothers who want to hold on to love and connection can be reassured that their emotional bonds to their babies can endure. Mothers facing the death of their babies may find hope in the fact that participants in this study emerged from their pain and were able to draw meaning from the seemingly incomprehensible. At the same time, these findings reinforce the admonition that approaches suggesting the prospect of rapid resolution of grief or returning to pre-loss 'normal' are unlikely to be helpful.

Describing various phases and stages may provide helpful guidance for bereaved individuals (Maciejewski et al., 2007), and such descriptions of phases or stages can help the bereaved anticipate and understand their experiences (Davies, Limbo, & Jin, 2010). Still, it is important to remember that although a bereaved mother may experience some commonalities with others, each mother's overall experience is unique. Nurses and other providers who care for mothers affected by perinatal losses are well advised to maintain and communicate flexible expectations.

Table 2

Temporal Themes and Corresponding Care Suggestions

Temporal Theme	Care Suggestions
Continuity	Avoid expectations of rapid recovery or resolution
	Recognize and affirm mother's ongoing attachment to baby
	Help mother create memories and mementoes
	Respect mother's desire to hold on or maintain connection
	Call mother or send card for support on anniversary dates
Evolving Changes	Acknowledge individual differences in grieving process
	Explore mother's perceptions of personal growth and change
	Refer for further care when mother feels "stuck"
	Anticipate resolution regret
Transient Phases	Describe different phases mothers *may* experience
	Assess mother's thoughts and feelings at each encounter
	Adjust agendas and expectations according to mother's needs
	Revisit important decisions and information in follow up visits
	Anticipate 'most difficult' moments

Temporal Themes and Corresponding Care Suggestions (continued)

Temporal Theme	Care Suggestions
Connecting Past to Present	Assist with birth planning, incorporating mothers' values and interpretations
	Listen to mother's personal stories about her baby and her loss
	Reflect and validate mother's meanings
	Provide or refer for after care
	Facilitate support and validation from other PH mothers

Because the phases mothers described were so variable and intense, it is important for nurses and other providers to assess how a mother is doing at each encounter and adjust their approaches to care accordingly. In particular, information provided to women experiencing numbness and unreality may not be retained or understood. Important information and decisions may need to be re-visited in future encounters. Nurses can also strive to be aware of mothers' "most difficult moments." An encounter or process that might seem routine to a nurse could be intensely painful for a bereaved mother and require the utmost sensitivity.

The ongoing nature of these mothers' experiences supported the emphasis on aftercare described in the emerging literature on PH (Hoeldtke & Calhoun, 2001; Leuthner & Jones, 2007; Roush et al., 2007). Organizing periodic gatherings of mothers and families is one way that PH programs can maintain contact and provide opportunities for ongoing affirmation and support. Formal bereavement support groups may also be valuable for some mothers.

Birth planning is another established care practice that is supported by these mothers' accounts. In addition to the obvious advantages of preparing for various outcomes and making the most of limited time, the birth planning process can provide a venue for mothers and families, along with their care providers, to assess intentions and explore meanings and feelings as they plan for moments, memories, and mementoes. For example, planning to take a family photograph that includes the baby could provide affirmation for the perception of a strong family bond. The goal of the nurse in such situations should be to elucidate and affirm the mother's or family's meanings.

Avoiding imposition of the nurse's own interpretations is preferable. Listening to mothers' personal stories is another important way nurses can validate mothers' experiences and interpretations.

<center>Research Implications and Limitations</center>

These mothers' accounts suggested both ongoing changes and continuation of some thoughts and feelings beyond the one or two year intervals frequently covered by longitudinal studies (Stirtzinger et al., 1999; Toedter, Lasker, & Janssen, 2001; Wheeler & Austin, 2000). To reflect bereavement outcomes in the long term, longitudinal research would optimally span longer time intervals. Additionally, measures of transformative processes such as the Post-Traumatic Growth Inventory (Tedeschi & Calhoun, 2008) could be employed to reflect a broader range of outcomes than focusing solely on measures of psychological symptoms or distress.

This study is limited in important ways, particularly the exclusion of fathers and other family members. These mothers' accounts suggested that fathers and siblings are profoundly affected by adverse diagnoses and the loss of infants. Future research should reflect the fact that PH involves the entire family.

Limitations also arise from the homogeneity of the study sample. These mothers had relatively privileged socioeconomic backgrounds compared to the populations often served by perinatal nurses. Most of these mothers had access to specialized PH care services. Income, education, availability of specialized care, and other resources could potentially influence mothers' decision to continue affected pregnancies as well as their

subsequent needs once that decision is made. Racial, ethnic, and cultural diversity were also under-represented in this sample. Future studies of PH mothers in more diverse populations could provide additional needed perspectives.

<div align="center">Conclusion</div>

Continuity and change in these mothers' personal stories highlighted the transformative, as well as the painful, aspects of their journeys through time after perinatal losses. In contrast to perspectives that emphasize grief recovery and resolution of symptoms, these mothers valued some aspects of their experiences, particularly personal changes and connection to their babies, and wanted to maintain them. Established nursing practices in perinatal bereavement care, such as birth planning, cultivating memories, memorial celebrations, and creating mementoes, were supported by the mothers' accounts. Mothers' expressions of personal meanings emphasized the need for nurses to facilitate self-discovery rather than offering nurses' own interpretations.

The mothers who participated in this study expressed gratitude for the opportunity to share their stories. As one participant said, "Every mother has a need to talk about her children." Listening to mothers, providing a receptive audience for their personal stories, and reflecting and validating their interpretations contribute to a sound basis from which nurses can approach PH care.

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Appendix A: Initial Recruitment Announcement

An Invitation

An invitation to mothers who continued a pregnancy after learning that their baby had a serious condition that would eventually cause the baby's death

My name is Anthony Lathrop. I am a nurse-midwife and PhD student at Marquette University. I have cared for many mothers who have decided to continue their pregnancies after learning of a serious problem diagnosed during pregnancy. I am doing research to learn more from mothers about what this experience is like. The title of the study is "A Narrative Analysis of Perinatal Hospice Stories." I hope to learn how nurses, doctors, and others professionals can give the best possible care to mothers and families in this situation.

Who can be in the study?

To be in the study, you must
- have been 18 years old at the time of the pregnancy in which the baby had a problem
- speak English
- have learned during pregnancy that your baby had a severe condition and would die during pregnancy, at birth, or shortly after birth
- have decided to continue your pregnancy
- be at least 1 year past the date you delivered your baby and not more than 12 years past that date

What are some examples of serious conditions that can cause babies to die?

You may have been told that your baby had one of these conditions or others.
- Problems with brain development, like anencephaly or holoprosencephaly
- Genetic or chromosome problems such as trisomy 13 or trisomy 18
- Problems with the kidneys such as renal agenesis or Potter's syndrome

If you aren't certain whether you can be in the study, you can fill out the contact consent form (attached) and I will contact you to answer your questions.

What will happen if you decide to be in the study?

Before the research project begins, you sign a consent form. I will keep a copy and you will keep a copy.

I will ask you to tell the story of your pregnancy, your baby, and the care you received. You can tell your story in your own words, any way you like. You can tell me anything you want to tell me or that you think might be helpful. You don't have to tell me anything you don't want to tell. I will audio tape what you tell me so that it can be typed out. You can get out of the study at any time.

What I learn from you in this research project is private. You will be identified by a number, not by name. When I talk or write about this study, I will not use your name or any details that identify who you are.

It's entirely up to you whether you become part of this study. You will receive the same care and services from the person or agency that told you about the study whether or not you decide to be in the study.

Thank you for considering whether you would like to be in my study. If you want to be in the study or learn more about it, please fill out the information on the contact consent (attached).

Anthony Lathrop (Principal Investigator) Email: <u>ALresearch@hotmail.com</u>
Dr. Leona VandeVusse (Faculty Sponsor) office phone: (414) 288-3844
Marquette University Office of Research Compliance: (414) 288-1479

Appendix B: Contact Consent

Consent to Be Contacted

Research Study: A Narrative Analysis of Perinatal Hospice Stories

By filling out and signing this form, you are indicating that you are interested in learning more about the study and you are agreeing to have Anthony Lathrop, the Principal Investigator, contact you. This is not a final agreement to actually participate in the study. It is only an agreement to be contacted so you can learn more about participating in the study. If you decide later that you are not interested in participating, you only have to say that you are not interested and you will not be contacted again.

Please indicate how you would like to be contacted:

Telephone Number (with area code): (_____)_____-_____

Email Address: _____

Mailing Address: _____

_____

City_____State_____ Zip_____

Please let me know any additional information about contacting you, for example, days

or times that are most convenient for me to call you:

Printed Name: _____

Signature:_____

Date:_____/_____/_____

Appendix C: Perinatal Bereavement Support Organizations

Compassionate Friends National Office
Website: www.compassionatefriends.org
Telephone: 877.969.0010

RTS Bereavement Services
Website: www.bereavementservices.org
e-mail: info@bereavementservices.org
Telephone: 800.362.9567 extension 54747

SHARE National Office
Website: www.nationalshareoffice.com
Telephone: 800.821.6891

UNITE Inc.
Website: www.unitegriefsupport.org
Telephone: 215.728.3777

Appendix D: Text of Informed Consent Document

MARQUETTE UNIVERSITY
AGREEMENT OF CONSENT FOR RESEARCH PARTICIPANTS

A Narrative Analysis of Perinatal Hospice Stories
Anthony Lathrop MSN CNM
College of Nursing

You have been invited to participate in this research study. Before you agree to participate, it is important that you read and understand the following information. Participation is completely voluntary. Please ask questions about anything you do not understand before deciding whether or not to participate.

PURPOSE: I understand that the purpose of this research study is to understand the experiences of mothers who continued a pregnancy after learning that their baby had a serious condition that would eventually cause the baby's death. An important aim of this study is to gain knowledge that could help nurses and other health professionals provide better care to mothers in this situation. I understand that I will be one of up to 15 participants in this research study.

PROCEDURES: I understand that if I agree to be in the study, I will be asked to tell the story of my pregnancy and my baby's birth, life, and death. I will be encouraged to tell my story in my own words, any way I want to tell it. I understand that I will be audio recorded while telling my story to ensure accuracy. My story will be typed out from the recording. The recordings will be destroyed three years after the completion of the study. To ensure my privacy, my name will not be included on the recording or write-up of my story. I will also be asked to fill out a form containing descriptive information, but I do not have to provide any information I do not want to provide. OPTIONAL: some mothers have photos, handprints, footprints, or other mementoes of their babies. I may give my permission for my mementoes to be photographed by the researcher. I may also decline to allow such photography.

DURATION: I understand that my participation will consist of one interview, when I will tell my story. This may last approximately 1 or 2 hours. OPTIONAL: I may give my permission to be re-contacted by the researcher to review the results of the research. I may also decline to be re-contacted.

RISKS: I understand that the risks associated with participation in this study include only minimal risks that I might encounter in everyday life. It is possible that I may become emotionally upset when telling my experiences of difficult life events. If I become very upset when telling my story, I will have a chance to take a break if I want to. I will be provided with a list of support agencies and services I can contact if I am too upset and need help. I understand that if I say things that suggest I am dangerous to myself or others, the researcher may be legally required to report this to health care, family service, or law enforcement authorities.

_____   _____
 Participant Initials   Date

BENEFITS: I understand that there may not be direct benefits to me from being in this study. Some people find that telling their stories about difficult life events can help them feel better. Some people find it rewarding to participate in research because they feel like they are helping others who have similar experiences in the future.

CONFIDENTIALITY: I understand that all information I reveal in this study will be kept confidential. My story will be identified by a participant number rather by my name or any other information that could identify me. When the results of the study are published, I will not be identified by name. I understand that the data will be destroyed by shredding paper documents and deleting electronic files 3 years after the completion of the study. The transcript of my interview will be kept indefinitely, but it will not contain any information that could identify me. The consent form I sign will be kept locked in a safe, and my participant number will be kept in a password-protected computer file. My research records may be inspected by the Marquette University Institutional Review Board or its designees, and (as allowable by law) state and federal agencies.

Voluntary Nature of Participation: I understand that participating in this study is completely voluntary and that I may withdraw from the study and stop participating at any time without penalty or loss of benefits to which I am otherwise entitled. If I want to withdraw during my interview, I only have to say so and my audio tape will be erased immediately. After my story is recorded and typed out it will not be possible to withdraw my story from the study.

COMPENSATION: I understand that I will not be paid for my participation. I will receive a $20 gasoline card, or mileage reimbursement at the rate of 50.5 cents/mile, whichever amount is greater, to compensate for my travel expenses to the interview location.

Contact Information: If I have any questions about this research project, I can contact Anthony Lathrop by email at ALResearch@hotmail.com. I can also contact the Faculty Sponsor for this study, Dr. Leona VandeVusse, at (414) 288-3844. If I have questions or concerns about my rights as a research participant, I can contact Marquette University's Office of Research Compliance at (414) 288-1479.

OPTIONAL: Permission to Photograph Mementoes
(please initial by your response)   _____ Accept   _____ Decline

OPTIONAL: Permission to be Re-Contacted
(please initial by your response)   _____ Accept   _____ Decline
(please indicate how you want to be contacted)_____

I HAVE HAD THE OPPORTUNITY TO READ THIS CONSENT FORM, ASK QUESTIONS ABOUT THE RESEARCH PROJECT AND AM PREPARED TO PARTICIPATE IN THIS PROJECT.

_____   _____
          Participant's Signature   Date

_____
          Participant's Name

_____   _____
          Researcher's Signature   Date

Appendix E: Descriptive Data Form

Sometimes it is helpful to have information that describes the group of participants in a research study in order to understand the results of that study. The information you provide will be reported only in aggregated form. For example, a report of this study might include the statement "participants ranged from 18 years to 32 years of age," but would never include the statement "Mrs. Smith is 26 years old."

Please fill in or check the answers to the questions below. If there is any question you do not want to respond to, you may skip that question.

Please do not write your name on this form.   Participant Number:_____

1. Age _____

2. Relationship status (at the time of the pregnancy discussed in this research interview)
   a. Single
   b. In a casual relationship
   c. In a committed relationship
   d. Married
   e. Divorced

3. Relationship status now
   a. Single
   b. With the same spouse/partner I was with at the time of my pregnancy
   c. With a different spouse/partner I was with at the time of my pregnancy

4. Race/ethnicity
   a. African-American/Black/African
   b. White/Caucasian/European
   c. Hispanic
   d. Asian/Pacific Island
   e. Native American
   f. Other:_____

5. Religious affiliation, if any:_____

6. Religious attendance: how often do you attend religious services?
   a. More than once per week
   b. Once per week
   c. Monthly
   d. Special events or holidays

    e. Never

    f. Other:_____

7. Education: which best describes your educational background?

    a. Less than 8th grade

    b. Some high school

    c. High school graduate or G.E.D.

    d. Some college

    e. Graduate of technical school

    f. Undergraduate college degree

    g. Graduate degree

8. Family income: which best describes your combined family income for one year?

    a. Less than $10,000

    b. $10-20,000

    c. $21-30,000

    d. $31-45,000

    e. $46-60,000

    f. $61-80,000

    g. Over $80,000

9. Pregnancy history (please fill in beginning with your first pregnancy)

Pregnancy Number	Month and year of Delivery	Type: miscarriage, vaginal, or cesarean	Infant's Gender M - F	Complications or problems
1	/			
2	/			
3	/			
4	/			
5	/			
6	/			

Please circle the number of the pregnancy that we discussed in your interview
Please continue on the back of this page if you have had more than six pregnancies

10. History of the pregnancy discussed in this research interview

    a. If you named your fetus/baby, what was his/her first name?

        _____

    b. What was the baby's diagnosis? _____

    c. How many weeks pregnant were you when you learned something was wrong? _____

    d. Did you have (please circle all the kinds of tests you had):

        i. Test of mother's blood to screen for birth defects

        ii. Ultrasound

        iii. Chorionic villus sampling (CVS)

        iv. Amniocentesis (amnio)

        v. Other:_____

    e. Did you receive care from a specialized person, team, or program specifically designated for the care of women who are continuing pregnancies after learning of a life-limiting fetal condition?   Yes   No

    f. Was the baby born alive?   Yes   No

    g. If the baby was stillborn, did you:

        i. Deliver by induced labor

        ii. Deliver by labor that started by itself

        iii. Deliver by cesarean section

        iv. Other:_____

    h. If the baby was born alive:

        i. How long did your baby live?

        ii. Did you take your baby home?

        iii. If the baby died, did this happen

            1. in the hospital

            2. at home

            3. other:_____

11. Other intimate bereavement or losses: have you experienced

    a. Death of one or both parents?

    b. Death of another child?

    c. Death of a spouse or partner?

    d. Other:_____

12. Please write in below or on the back of the page if there is anything else
important to you that we did not discuss in the interview or include on this form.