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"It's not fair!" Mothers' experiences with perinatal loss upon confirmation of a lethal prenatal diagnosis

Teske Renee Drake
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“It’s not fair!” Mothers’ experiences with perinatal loss upon confirmation of a lethal prenatal diagnosis

by

Teske Renee Drake

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of
MASTER OF SCIENCE

Major: Human Development and Family Studies

Program of Study Committee:
Mary Jane Brotherson, Major Professor
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Ames, Iowa

2008

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ABSTRACT

The loss of a child does not agree with most people's perceptions of the natural order of life and death. It marks an end to the hopes and dreams that parents have made for their children (Znoj & Keller, 2002). This feminist narrative inquiry explores mothers' experiences with decision-making and grief after receiving a lethal prenatal diagnosis for their unborn child. In such circumstances, mothers are often faced with two options: 1) expectant management/continue the pregnancy, or 2) termination of the pregnancy (Rapp, 1999; Hoeldtke & Calhoun, 2001). Through interviewing, participant observation, and personal narrative, I uncover the grief experiences of mothers as they reflect on their child's terminal diagnosis, decision-making pertaining to pregnancy management, and the unavoidable death of their child. These women's stories inform policy, practice, and future research by providing insight into the support services offered, or lack thereof, depending on the option chosen for pregnancy management.

CHAPTER 1. INTRODUCTION

“Maybe everything was a mistake and there was nothing wrong at all. Couldn’t this all be some sort of mix up?...We [my husband and I] cried together and we held each other. That night was a horrific night. I was outraged by the news. They had to be wrong. What they were saying could not be true! All I wanted was for you [Chloe] to live. I screamed out to no one, ‘Why? It’s not fair! I just want her to live, that’s all!’”

(Self, Mommy to Chloe)

Rationale

The process of grief is a continuous journey for the bereaved, particularly for parents who have lost a child. The loss of a child does not agree with most people’s perceptions of the natural order of life and death and also marks an end to the hopes and goals that parents have made for their children (Znoj & Keller, 2002). Arnold & Gemma (1994) acknowledge that the death of an infant is a loss of the future or what might have been. Rando and colleagues (1986) characterize parental grief as being a long lasting, severe, and complicated form of grief and the symptoms associated with it tend to fluctuate over time (cited in Lang, Goulet, & Amsel, 2004). When transitioning into parenthood, attachment to the child occurs antenatally, or during pregnancy. Issues of attachment will be discussed in further detail later in this paper, but it is significant to point out that because parents can become attached to their unborn child before the child is physically born, that a loss during pregnancy or shortly after birth can elicit very intense grief reactions (Rhigetti, Dell’Avanzo, Grigio, & Nicolini, 2005). It is important for others to acknowledge the life and death of that child so that parents do not feel isolated in their grief experience or as if their loss goes unrecognized (Kish & Holder, 1996).

Some argue that advancements in medical technology have encouraged antenatal attachment. Because of such advancements, many women in American society do not tend

to fathom the possibility of death for their infants and therefore, begin bonding with their unborn child early on in pregnancy. In addition, the use of ultrasound as a routine procedure in prenatal care has given parents the opportunity to see their unborn child, providing a means for them to visually bond with the baby (Robinson, Baker, & Nackerud, 1999). Though the procedure is conducted with the intent to screen for various anomalies and/or birth defects, many parents see the ultrasound appointment as an opportunity to meet their child, and they often look forward to taking home a video or still image of the baby as a keepsake. According to Detraux and colleagues (1998), the process of attachment is fostered through the use of ultrasound examination because parents are given the chance to visualize their future child (Detraux, Gillot-DeVries, Vanden Eynde, Courtois, & Desmet, 1998).

In addition, the technological advancements and routinization of prenatal testing is placing women in a position to then choose whether or not to continue their pregnancies when a serious diagnosis is confirmed (Rapp, 1999). Women who choose expectant management, or to continue their pregnancies, in the face of a lethal prenatal diagnosis have access to an emerging program across the United States: Perinatal Hospice. Perinatal Hospice aims to support families who have made the decision to continue pregnancies with a terminal diagnosis, focusing on both the medical and psychosocial aspects that surround this experience, as well as provide aftercare support services once the baby has been born and died (Hoeldtke & Calhoun, 2001). Most women, however, choose to terminate pregnancies when a lethal prenatal diagnosis has been confirmed (Rapp, 1999; Hoeldtke & Calhoun, 2001; Howard, 2006). In these instances, formal bereavement support may be overlooked. It is imperative to explore the experiences of mothers' facing lethal prenatal diagnoses for their unborn child, despite choice for pregnancy management. Disregarding mothers' choices for

pregnancy management and focusing on their medical and psychosocial needs will allow professionals and healthcare providers to determine whether they are adequately meeting these mothers' needs.

Purpose Statement and Research Question

The purpose of this feminist narrative inquiry is to understand the experiences, decision-making process, and accompanying grief of mothers who have experienced a confirmed lethal prenatal diagnosis for their child and have also endured the subsequent death of their child. My aim is to find out how mothers perceived their experience of receiving their child's lethal diagnosis and what the decision-making process was like for them when faced with the options of expectant management (continuing the pregnancy) or termination. In addition, this study uncovers the grief experiences of these mothers that accompanied the confirmation of a lethal prenatal diagnosis and death of their infant child.

The questions of this research are: 1) What is the decision-making process like for mothers faced with a lethal prenatal diagnosis for their unborn child? 2) What is the grief experience like for mothers who receive a confirmed lethal prenatal diagnosis? It is important to address these questions so that the professionals who work with mothers in such a unique circumstance can gain an understanding of the complexities involved with this specific type of perinatal loss, as well as the difficult choices that mothers in these circumstances must consider. Of equal importance, mothers in this study have been given the opportunity to express the significance of such loss, which often goes unacknowledged in much of our society.

Organization of the Study

This study is organized in multiple sections, encompassing a number of ideas related to the socio-political context surrounding reproduction, prenatal diagnosis, perinatal loss, and implications for policy, practice, and research. Chapter 2 provides an overview of the literature on the topic of perinatal loss as a result of a lethal prenatal diagnosis. It gives a summary of the socio-political context that surrounds the issue of female reproductive rights in the United States. From there, I highlight research on the topic of prenatal diagnosis of a lethal fetal anomaly and accompanying decision-making that is necessary with the discovery of such news. Further detail is given in regards to the options women face upon confirmation of a lethal prenatal diagnosis, as well as the social and professional supports available to them, depending on choice. Concluding the literature review, I will present information on formal Perinatal Hospice programming and its accessibility to mothers facing lethal prenatal diagnoses, leading into the Methodology section for the current study, Chapter 3, which will include ideas from feminist research and theory as it relates to prenatal diagnosis, testing, and choice.

In addition, Chapter 3 will incorporate information on narrative inquiry and its significance of story telling to this study. Also, I will give further explanation about the participants involved, the procedures for conducting the current study, and the data analysis procedures. From there, I will present the findings and discussion in Chapter 4, detailing each of the emergent themes and sub-themes identified through data analysis of interviews and observations with the participants. Each of these themes can be found in a model, which emerged from the findings in this research, illustrating the common course mothers in this study took in their experience of prenatal diagnosis and perinatal loss. This model

encompasses all emergent themes, identified through a feminist lens, and explains how mothers begin to make meaning from experiencing this phenomenon.

Chapter 5 of the study concludes with a summarization of the findings as they relate to literature in the field on the topic of lethal prenatal diagnosis and perinatal loss, as well as by revealing implications for policy, practice and future research. These implications were drawn from mothers' stories, insight from a healthcare provider to mothers facing prenatal diagnosis and perinatal loss, as well as identified gaps in services to mothers based on their choice for pregnancy management upon confirmation of a lethal prenatal diagnosis.

An important aspect of this study to take note of is my very personal connection to the topic at hand and the inclusion of myself as a full participant in the study. My personal experience with a lethal prenatal diagnosis for my daughter, Chloe, and her subsequent death, is what generated my research interest in this phenomenon. Thus, the entire study is filtered through my interpretation, both as a researcher and as a bereaved mother and informant to the study. Much of this research is written in first-person narrative, with inclusion of personal thoughts and feelings throughout.

CHAPTER 2. LITERATURE REVIEW

Socio-Political Context Surrounding Reproduction

The medicalization of the childbirth experience and the use of prenatal testing have become increasingly routine in the past few decades (Sandelowski & Barroso, 2005; Rapp, 1999; Ginsburg & Rapp, 1991). With the routinization of prenatal testing, thus providing increased knowledge, medical services and options, a woman has the opportunity to enhance the survival of her unborn child. At the same time, this increased knowledge and power brings about ethical eugenic issues, as women are faced with the option of abortion when prenatal testing reveals the diagnosis of disability or abnormality (Ginsburg & Rapp, 1991).

In a meta-analysis of qualitative findings on the topic of positive prenatal diagnosis, Sandelowski and Barroso (2005) conclude that the combination of choice and loss presents an experientially unique phenomenon as parents are faced with life-and-death choices for their unborn child. While this experience of receiving a positive prenatal diagnosis encompasses similarities to other types of perinatal loss, it remains distinct because of the emergence of chosen losses and lost choices (Sandelowski and Barroso, 2005). This increased knowledge and power go hand in hand with the political arena of reproductive rights, as women are making decisions about terminating pregnancies, while under the authority of what is legal or not, dependent upon where they live.

At the present time, the legal restrictions for termination of pregnancy vary by state. Individual states have the authority to restrict or ban termination of pregnancy after the fetus is considered viable, or the time in which the fetus is able to sustain life outside of the womb. Physicians play an active role in determining viability of the fetus. In some states, two physicians are required to make a viability determination. Other considerations by each state

include the life and health of the mother carrying the unborn child. To preserve the mother's life or health, including physical and mental health, 28 states allow later-term abortions. The state of Iowa, in which this study was conducted, falls under these guidelines, which are least restrictive with regard to termination. Later-term abortion, in Iowa, is allowed up until the third trimester of pregnancy, if it is being utilized to preserve the life and health of the mother, as previously stated (Alan Guttmacher Institute, 2008).

As demonstrated, advancements in medical technology, specifically with regard to prenatal care, as well as a basic understanding of the socio-political climate surrounding women's reproductive rights, provide a context for understanding the phenomenon under investigation in the current study; lethal prenatal diagnosis and perinatal loss, either by natural death or termination of pregnancy, dependent upon choice for pregnancy management.

Prenatal Diagnosis of Lethal Fetal Anomaly

According to Kemp and Page (1987), attachment occurs between mother and unborn child whether or not the pregnancy is considered high-risk or threatened. In some cases, ultrasound or other prenatal testing may provide a diagnosis of a lethal anomaly, or a diagnosis in which the unborn child is not expected to live. In these instances, parents are confronted with two options: 1) termination, or 2) expectant management, or continuation of the pregnancy (Hoeldtke & Calhoun, 2001; Rapp, 1999). This experience of diagnosis is an emotionally distressing occurrence. Parents are not only faced with the difficult decision of how to proceed with the remainder of the pregnancy, but are also faced with the inevitable loss of their child. Whatever they choose, intense grief and loss accompany this difficult experience (Howard, 2006).

According to Howard (2006), prenatal diagnosis of a lethal anomaly is an event that proves to be emotionally devastating to parents. Detraux and colleagues (1998) refer to this news as an “emotional traumatism,” eliciting feelings of depression, loneliness, and anxiety (pg. 210). When faced with such a diagnosis, parents often reflect a sense of loss over the hope and expectation of giving birth to a “normal” child (Howard, 2006). They may feel responsible for the founded abnormality in their child or as if they failed in producing a “normal” child (Detraux et al., 1998; Keefe-Cooperman, 2005; Howard, 2006). Therefore, parents tend to mourn the loss of the child they had imagined up to that point and are no longer able to picture their once imagined, healthy child, without first denying the diagnosis that has been given (Detraux et al., 1998). In addition, they are faced with the inevitable and unexpected loss of their infant, and difficult choices. As stated by Sandelowski and Barroso (2005), “A positive or suspicious prenatal diagnosis sets into motion a series of nested and time-sensitive decisions” (p. 310). Whether they choose to terminate the pregnancy upon confirmation of the diagnosis, or whether they continue, both experiences are marked by tremendous grief. Social support during this healthcare crisis is often compromised or limited because the options available to parents are not necessarily socially acceptable and involve a sense of stigmatization as a result of societal views on abortion and on disability (Howard, 2006).

In addition to the fact that parents must make time-sensitive choices regarding the management of the remainder of the pregnancy, either decision they make, they will have additional choices to make. For a mother who chooses to terminate her pregnancy, she may have to consider the specific procedure that she will undergo, which will be dependent upon how far along in her pregnancy she is and on the legal restrictions on abortion in the state she

resides. For those who choose to continue, choices must be made regarding the range of medical measures that may or may not be utilized to sustain the life of that child upon birth (Howard, 2006; Sandelowski and Barroso, 2005). As Sandelowski and Barroso (2005) state in their study on the topic of prenatal diagnosis and choice, “The irony of positive prenatal diagnosis was that couples were forced to contemplate choosing against a wanted pregnancy” (p. 314). In other words, all parents wanted their child, but with confirmation of a lethal prenatal diagnosis, they were now put in a position to decide whether or not to continue the pregnancy.

Termination for Fetal Abnormalities

As mentioned above, termination of a pregnancy is one of two options often given to mothers faced with the confirmation of a lethal prenatal diagnosis for their unborn child. Howard (2006) asserts that most women, when faced with a confirmed lethal prenatal diagnosis, will choose to terminate the pregnancy if they have access to this service. To further support this assertion, Evans and colleagues (1996) cite that “over 80% of patients with severe abnormalities have chosen to terminate regardless of “when” in gestation the diagnosis was made” (Evans, Sobiecky, Krivhenia, Duquette, Drugan, Hume, & Johnson, 1996, p. 354). The grief experiences accompanying the choice to terminate have been found to be similar to those experienced by mothers who have stillbirths or miscarriages (Howard, 2006).

According to Keefe-Cooperman (2005), women who elect to terminate their pregnancies when faced with a lethal diagnosis often experience a sense of guilt over ending the life of their child and that guilt is intrinsically woven throughout the mourning process. The literature suggest a distinction in the psychological aftermath experienced by mothers

who choose to terminate their planned and wanted pregnancy as a result of a diagnosed lethal fetal anomaly to those who terminate an unplanned pregnancy out of convenience, which has been found to have few long-term psychological effects, if any (Howard, 2006).

Furthermore, Howard (2006) asserts that the stigma associated with both abortion and disability impact mothers' comfort level with sharing their choice with family and friends, which can increase their risk of isolation and vulnerability.

White-Van Mourik and colleagues (1992) suggest that mothers who terminate their pregnancies due to a lethal prenatal diagnosis may not obtain adequate support, even though they mourn the death of their baby, due to society's lack of acknowledgement of such loss (White-Van Mourik, Connor, & Ferguson-Smith, 1992 as cited in Keefe-Cooperman, 2005). In a study by Geerinck-Vercammen and Kanhai (2003), mothers who terminated pregnancies reported experiencing empathic support from family and friends, but that the support lasted too short a time, thereby making coping with the loss more difficult (Geerinck-Vercammen & Kanhai, 2003). As previously mentioned, researchers assert that mothers who terminate a wanted pregnancy due to fetal anomalies experience similar grief reactions as those mothers who experience the loss of an unborn child to miscarriage or stillbirth (Howard, 2006 Geerinck-Vercammen & Kanhai, 2003). Thus, psychosocial care ought to administered in the same manner (Geerinck-Vercammen & Kanhai, 2003).

Expectant Management of Pregnancies with a Lethal Prenatal Diagnosis

There is a dearth of research on parents who choose to continue their pregnancies upon confirmation of a lethal prenatal diagnosis, because doing so is unique. Therefore, professionals must approach this situation, on the other end of the spectrum, in a way in which the exceptional needs of these parents will be met through various bereavement

support measures (Hoeldtke & Calhoun, 2001). From the evidence gathered on antenatal attachment and the bonding process of pregnant women with their unborn children, it is safe to assume that when struck by perinatal loss, the grief that accompanies such a loss is tremendous, regardless of whether the child was suspected to live long or not based on the ultrasound findings or other medical technology. The death of an unborn or newly born child would naturally elicit a grief reaction due to the antenatal attachment that takes place between parents and their unborn child (Worth, 1997).

Congenital anomalies, comprising .5-1% of all births, or between 30 and 50 thousand births, are the leading cause infant deaths each year in the U.S. (Calhoun, Reitman, & Hoeldtke, 1997; Hoeldtke & Calhoun, 2001). Given these statistics, it is evident that a significant number of parents experience the death of their infant each year. Therefore, it is imperative to take steps to gain a better understanding of parental grief/bereavement so that appropriate supportive programming can be tailored to meet the unique needs of families experiencing perinatal loss, particularly due to congenital anomalies, diagnosed prenatally. In cases such as these, parents receive a lethal diagnosis prenatally with a prognosis of early infant death, leaving them with the decision to continue or terminate the pregnancy. Those who choose to continue, otherwise known as expectant management, endure weeks, maybe months of preparing for and anticipating the inevitable loss of their child.

In regards to the grief process for mothers in such circumstances, research indicates that they experience an increase in the emotional pain they are feeling due to thoughts about their inability to make a healthy or “normal” child. The parents can no longer imagine their unborn child as they once had because the diagnosis of an abnormality has occurred and consumed their thoughts. Therefore, parents tend to mourn the child that they had once

imagined and prepare to cope with the physical loss of their child through death (Detraux et al., 1998). This is similar to the above-mentioned experience of mothers who choose to terminate their pregnancy as a result of a confirmed lethal prenatal diagnosis. The main difference in these scenarios is that of timing or when they would actually experience the loss. Callister (2006) notes that parents who choose expectant management have the opportunity to plan, maintain some control, and arrange for a memorable goodbye. To some, these opportunities may seem fortunate as opposed to the shock accompanied by a sudden perinatal loss. However, Howard (2006) describes some of the conflicts associated with choosing to continue pregnancies with a fetal abnormality. She states that some of these conflicts include the burden placed on the parents for choosing to bring a child to term who will likely experience an uncertain quality of life, possible pain that accompanies their medical needs, and the emotional suffering that the family will go through (Howard, 2006).

Perinatal Hospice/Palliative Care. Some families anticipating perinatal loss who have chosen expectant management of their pregnancies are fortunate enough to receive professional support through perinatal hospice or palliative care. Elisabeth Kubler-Ross, a pioneer in the hospice movement and end-of-life care, focused her efforts in caring for the terminally ill with a goal of providing them with compassionate care in their final stages of life (Kubler-Ross, 1973). There are thousands of hospice programs across the United States that provide palliative care for their dying patients. However, typical patients are elderly adults (DeSpelder & Strickland, 2005). Building off of these existing programs, perinatal hospice focuses on providing palliative care to the entire family of an unborn child who has been diagnosed with a terminal prognosis and emphasizes taking the limited time that families have with their child and living it to the fullest (Sumner, Kavanaugh, & Moro,

2006). The concept of perinatal hospice is relatively new, and therefore, programs may vary in the support services offered. Currently, there are approximately 55 perinatal hospice programs available in the United States. However, this does not mean that each state has a perinatal hospice program, as some states have several (<http://www.perinatalhospice.org>).

Byron Calhoun, obstetrician, has led the way in the implementation of formalized perinatal hospice programming, offered from its inception as an alternative to termination of pregnancies for fetal anomalies (Hoeldtke & Calhoun, 2001; Calhoun et al., 1997).

Calhoun's model of perinatal hospice is comprised of a hospice team, including the family, a perinatologist, nurses, social workers, counselors, and neonatologists. Depending on the individual needs of the family, certain professionals may or may not be included in the hospice team. The basic principles of perinatal palliative care or hospice include treatment decision-making, providing encouragement and support in preparation for the birth and loss of the child, bereavement support, and providing the family with whatever is necessary for them to enjoy the limited time they have with their baby (Hoeldtke & Calhoun, 2001; Calhoun et al., 1997, Romesberg, 2004; Sumner et al., 2006).

Social & Professional Support

The lack of social support for parents who have experienced perinatal loss can have an impact on the way they experience grief (Bennett, Lee, Litz, & Maguen, 2005). Since the 1970's social support has been linked to positive health outcomes as well as to the prevention of disease (Hutti, 2005). According to Ginsburg and Rapp (1991), social support is vital both during and after childbirth, regardless of the outcome. Logsdon (2000) asserts that the social support offered must meet the needs of the grieving parents in order to be effective. It should also be offered by a preferred provider, such as family members or close friends. If this is

not possible, the person in need of such support may decide to leave his or her needs unmet (Logsdon, 2000). Lang and colleagues (2004) suggest that a perceived lack of support can jeopardize the health of those needing support and affect the entire experience for them (Lang et. al, 2004).

Family and close friends unintentionally tend to minimize the grief experience of the couple in an effort to provide social support. Unless they too have experienced perinatal loss, they often do not understand the intensity of the parents' grief over a child they never had the chance to get to know (Kish & Holder, 1996; Wing, Clance, Burge-Callaway, & Armistad, 2001). Redlinger-Grosse and colleagues (2002), found that many parents they interviewed about their experience with perinatal loss due to a diagnosis of holoprosencephaly felt unsupported by family or friends. In some cases, family members questioned their decision of expectant management of their pregnancy (Redlinge-Grosse, Bernhardt, Berg, Muenke, & Biesecker, 2002). Although well-meaning, family and friends tend to offer hurtful clichés like, "You can always have another baby" or "At least you didn't bring the baby home," as support or encouragement, which subsequently minimizes the loss of the child that recently died and fails to acknowledge that child's life (Kish and Holder, 1996, pg. 76). The length of time that the parents spend with the child should not serve as an indicator for how significant the loss of their child is to them. Rather, all of the complex elements of attachment should be taken into account, thereby recognizing the death of their child, whatever the age, as a significant loss (Robinson, et al., 1999).

Distinguishing from social support, professional support includes support that comes from healthcare or mental health providers. This kind of support includes various counseling interventions, organized support groups, teaching, or encouragement (Hutti, 2005). Logsdon

(2000) suggests that, like social support, professional support can also result in improved health outcomes. Lack of support can increase the likelihood of adverse health effects and the physical symptoms associated with grief by more than 60% (Romesberg, 2004). Hutti (2005) suggests that support is most credible to bereaved parents when it comes from a person who has had a similar experience and has managed to deal with the situation effectively. A widely known program used as a means of professional support in many hospitals across the United States is Resolve Through Sharing (RTS). RTS is a program that provides nurses with training on perinatal and neonatal loss, offers support to families who experience such loss, and also provides families with mementos of their baby (Romesberg, 2004). Mementos of the baby are believed to be extremely helpful for parents throughout the grieving process and can include items such as photos, hand and foot prints, or a lock of hair (Hutti, 2005). Information on community resources should also be made available to families so that they have the opportunity to make connections with others who have experienced a similar loss, as local communities may offer a variety of support services (Hutti, 2005).

CHAPTER 3. METHODOLOGY

Researcher as an Instrument

In my efforts to explore the phenomenon of perinatal loss upon confirmation of a lethal prenatal diagnosis, it is imperative that I inform this audience of my personal biases and experiences that truly shape the interpretation and data analysis in the current study. As a self-proclaimed born-again Christian, as well as being pro-life with regard to the abortion debate, my initial idea for this study was to explore the experiences of mothers who chose to continue their pregnancies when faced with a lethal prenatal diagnosis. However, I came to the realization for the need to broaden the scope of this study as I embarked on the data collection and began to meet mothers who both chose to continue their pregnancies as well as those who chose to terminate upon confirmation of a lethal prenatal diagnosis. Additionally, I am a mother who has been in this situation myself, faced with whether or not to continue a pregnancy after finding out that my daughter had a rare chromosomal abnormality with a terminal prognosis. It is my hope that the audience will see how my personal beliefs, values, and opinions have shaped the interpretation of this data, while at the same time, have been transformed by my experience of engaging with and coming alongside these mothers as they travel along their grief journey of perinatal loss upon confirmation of a lethal prenatal diagnosis.

Feminist Framework Surrounding Reproduction, Rights, and Genetic Testing

In an effort to be completely transparent in my interpretation of this research, I must admit that I cringed when colleagues suggested I ought to frame this research in a feminist perspective. My initial, close-minded thoughts immediately shifted to the stereotypical pro-choice ideals. This left me to question how I, a mother who chose life in the face of a lethal

prenatal diagnosis, would even begin to understand the rationale and justification of women who chose to terminate a pregnancy, no matter the circumstances. As previously mentioned, my initial vision for this research was to interview mothers who had experienced a lethal prenatal diagnosis for their unborn child and had chosen to continue such pregnancies. I subconsciously deemed it unnecessary to explore the experiences of mothers who chose otherwise. In a personal journal entry about our choice to continue our pregnancy despite the lethal diagnosis, written just over two years ago, I wrote, "...I could not fathom making the choice to induce labor early. How could anybody do that? It is wrong, inhumane, and downright selfish!" Reading these thoughts, which once belonged to me, has been eye opening. The attitude possessed is one of self-righteousness, now humbly marred by self-indignation. In the same entry, however, I accounted for a change of heart that I had, which has proved to be a continuous process of change surrounding this issue of termination in the particular context of lethal prenatal diagnosis. It all began when I met a mother, Tara, who chose to, in her words, "say goodbye early" to her son, Christopher, who was diagnosed prenatally with a chromosomal abnormality, Trisomy 18. After my first interaction with her, I wrote,

When put in a face-to-face situation with a mother who made that choice [termination] for her son, however, my heart told me something different...I could see the love that she had for her precious son. I realized that she made the choice that was best for her family. She seemed at peace with it. Sure we made different choices, but the one thing that was the same was the way we love our babies.

(Self, Mommy to Chloe)

It was this very encounter that helped me first realize the importance of including mothers who chose to terminate after a confirmed lethal prenatal diagnosis, and each encounter I have had with a mother who chose to terminate, has reaffirmed my inclusion of them, as well as shaped my attitude about the complex issues surrounding this choice.

After exploring the research on feminism, particularly surrounding the issues of reproduction and abortion, it has become more apparent that my initial notions of this framework were false, embedded in stereotype and erroneous presumptions. Kennedy and Derr (1999) comment, “there is a widespread belief that to be feminist means to advocate abortion” (pg. 34). This was a belief that I too held. I have come to realize, however, that a feminist approach encompasses so much more than the complexities surrounding the issue of choice. Feminist scholars possess a range of beliefs on the issue of abortion and female reproductive rights. For example, Naomi Wolf (1995) has challenged pro-abortion feminists to embrace the reality that fetuses are unborn children, wanted or not (cited in Hartouni, 1999). This is a vastly different view than my former assumptions with regard to feminism and abortion.

Fine (1992) asserts that a feminist approach takes into consideration women’s experiences and that the researcher plays an active role in research (cited in Lichtman, 2006). Feminism also views social change as important (Lichtman, 2006). With these fundamental understandings about the feminist framework, it became increasingly important for me to position this research through a feminist lens, particularly as the women in this study told their stories and their experiences began to emerge.

Feminist researcher, Rayna Rapp, has spent her career delving into research on the topic of prenatal diagnosis and testing from a feminist standpoint and describes her use of

participant observation as a form of data collection by noting its benefit of being open-ended. She states, “I set out with one set of research questions, and was forced to enlarge and transform them as people educated me on the complexity of the issues as they perceived them” (Rapp, 1999). I found myself in this situation as I pursued this very study. The experts who educated me on this phenomenon, mothers who chose to terminate, helped me to understand the complexity of the issues at hand and unknowingly convinced me to realize the need to broaden my study to include all mothers, despite their choice for pregnancy management. These mothers have a voice, something I had initially refused to give them through my own inequity. Hartouni (1999) eloquently states, “From within a feminist frame, reproductive freedom requires not merely a set of invariably fragile legal settlements, but a fundamental refiguring of social life and relations” (p. 297). This statement is quite indicative of the shift in society that is necessary to fully accept women’s choice for termination in the context of lethal prenatal diagnosis. Just because termination is deemed “legal” does not necessarily mean that it is acceptable in society’s eyes. Making such a choice, regardless of the rationale, is still, unfortunately, surrounded by stigma and lack of support. It is these very ideas that deem it necessary to qualify this study as including elements of feminist research, as the notions of female reproductive rights are at the heart of feminist research.

It is my goal that the current study serves as a way for mothers’ voices to be heard; that their stories are communicated. Those who hear these stories and know the circumstances and context surrounding each situation cannot help but see things in a different light. It is not black and white; not either pro-life or pro-choice. Each of these mothers is for

life, the life of their very own child whom they so desperately wanted to live. For them, there was no choice between life and death, but of when the unavoidable would occur.

Narrative Inquiry

Narrative analysis aims to tell and make meaning of a story (Lichtman, 2006; Creswell, 2002). When thinking about the phenomenon of prenatal diagnosis, decision-making, and inevitable perinatal loss, it became apparent that the most effective way to begin to develop an understanding of this complex experience would be to hear women's stories, as well as tell my own. This autobiographical aspect of telling my own story through this research is not uncommon in narrative research (Clandinin & Connelly, 2000). In addition, the intersecting of hearing mothers' stories, while at the same time, sharing and interpreting through my own story, is characteristic of narrative inquiry. Clandinin & Connelly (2000) state,

As researchers, we come to each new inquiry field living our stories. Our participants also enter the inquiry field in the midst of living their stories. Their lives do not begin the day we arrive nor do they end as we leave. Their lives continue. (pp. 63-64).

In application to the current study, the women who have shared their stories have also become a part of my own story, and I a part of theirs. An example of this includes the support group I formed in collaboration with Jen, a mother in this study. Through our conversations specific to this study, we learned about each other's desire to form a support group, and we since have. This is a shared portion of each of our stories.

According to Clandinin & Connelly, narrative inquiry should always have purpose and focus, though it is possible for either to these to shift (2000). I found this especially true for the current study, as I had initially embarked on this research journey with the purpose of

interviewing mothers who chose expectant management when faced with a lethal prenatal diagnosis to realizing my need to include mothers who also chose termination as their choice for pregnancy management. This shift became necessary as the stories began to unfold, and as my own story was changing as a result of my interaction with mothers who made the choice to terminate, different from my own choice to continue a pregnancy in the face of a lethal prenatal diagnosis. Furthermore, my focus since conducting this study has become geared toward policy and practice implications for mothers who choose to terminate, a far cry from my initial focus of uncovering the decision-making process and grief experiences of mothers. This demonstrates the overall emergent nature of qualitative research (Lichtman, 2006).

According to Creswell (2002), seven major characteristics of narrative research include:

focusing on individual experiences, reporting a chronology of the experiences, collecting the individual stories told to the researcher or gathered through field texts, restorying the individual stories, coding the stories for themes, describing the context or setting of the individual stories, collaborating throughout the process of research with individuals whose stories are being reported. (Creswell, 2002, pg. 526).

I used these key characteristics as a guide to this conducting the current study.

A focus on individual experiences was achieved by using reflexive dyadic interviewing (Ellis & Berger, 2002) with mothers and a healthcare provider about mothers' experiences with perinatal loss after a receiving a confirmed lethal prenatal diagnosis. Reflexive dyadic interviewing flows as a conversation and allows for the researcher to disclose personal information and experiences related to the topic under investigation (Ellis

& Berger, 2002). This type of interviewing was essential for the current study, given the sensitive nature of the issues that I discussed with the informants.

In terms of chronology, I focused on the timeline of the pregnancy until the time in which our interviews took place. In gathering stories, I asked questions in a chronological sequence, starting with pregnancy, moving on to the time of diagnosis, the experience surrounding that phase, the time between the confirmed lethal diagnosis and the birth, and finally the subsequent death of the baby and their present experience pertaining to that loss. As suspected, the stories that were collected did not necessarily follow a chronological order, which was addressed through restorying, which will be discussed below.

The mothers told stories separately through individual interviews. In addition, I served as a participant observer in varying settings, including memorial services and events and through my facilitation of a support group, in which some of the mothers participated. The healthcare provider told her story more broadly, providing her perspective on mothers' experiences, given her expertise in providing care for women who fit the criteria for this study in her career. In narrative research, restorying involves gathering and analyzing stories so that the researcher can then rewrite the story chronologically (Creswell, 2002). To do this, I used field notes and my interview summary sheet as well as interview transcripts to examine the data for key elements of each individual informant's stories. I have included a brief chronological story for each participant in the current study by writing a brief "bio", which is included in the Participants section of this paper, later in this chapter. Other elements of each of these women's stories are included throughout the results section in Chapter 4.

I coded the transcripts of each interview by using the following process: 1) writing synthesis statements in the margins, 2) using synthesis statements to develop common categories/themes and/or sub-themes, 3) typing category/theme name in front of excerpts of the narratives and using the “Edit/Find” function in Microsoft Word to easily access those coded narratives.

Regarding the context of these women’s stories, I asked questions that addressed these issues by asking informants to describe the social supports, or lack thereof, that were and/or are in place throughout their experience. I gained an understanding of the setting of their stories just by hearing the stories and asking participants more about their experiences. I expected that my influence as a mother who has “been there” would impact the telling of the informants’ stories. I think that my closeness to the phenomenon under investigation did influence the telling of the stories, particularly with regard to one mother’s story, Elizabeth, as I came alongside her during her pregnancy and was involved with many aspects of the pregnancy, birth, and death of her son, Noah. I was a part of her story throughout, which is discussed in further detail in Chapter 4. The actual physical setting in which the interviews took place varied and were of the informants’ choosing, ranging from their home or office or a private room at the University to a restaurant or coffee shop.

Finally, regarding collaboration, I was deliberate in sharing my personal story of loss with the informants at the onset of the interview process. I felt it important to make my own story known so that they viewed me as an ally with them throughout their grief journey, and that through this research, I aimed to give the other mothers and myself a voice in the matter. As a researcher, I was subjective, including parts of my own story throughout the interpretation of data and presentation of results. I worked in collaboration with informants

through the use of member-checks, as a measure of rigor and trustworthiness. I summarized the identified themes and sub-themes, specific narratives of informants, and my interpretation of the narrative, and then discussed my interpretations with them, asking for feedback and checking for accuracy in the retelling of their stories.

Participants

Participants for this study included five mothers, all who have endured the death of their babies after receiving a confirmed lethal prenatal diagnosis with the prognosis of early infant death. Although it was not my original intent to seek out and interview Christian mothers, all mothers claimed to be of Christian faith. Three of the mothers chose to terminate the pregnancy upon confirmation of the diagnosis, and the other two mothers chose to continue the pregnancy, or expectant management, with the intent of carrying the baby to term. I am also included in this study as a full participant, and made the choice of expectant management. Finally, a healthcare provider participated in this study, offering her perspective on the phenomenon under investigation.

I contacted potential participants through snowball sampling and my affiliation with a local hospital's Perinatal Hospice and bereavement support programs. In addition, the perinatal hospice and bereavement coordinator agreed to disseminate a Participant Recruitment Letter (Appendix B) to previous patients regarding this study, indicating a need for participants and directions for contacting me to participate in the study.

The criteria for participating in this study included the following: 1) mothers whose unborn children were diagnosed prenatally with a lethal congenital anomaly, 2) mothers received the prognosis of early infant death due to the diagnosis, 3) mothers chose to either continue or terminate their pregnancies upon confirmation of the diagnosis, 4) mothers had

already given birth to and experienced the death of their child, 5) mothers were over the age of 18, and 6) one participant was a healthcare provider/caregiver to mothers who experience perinatal loss as a result of a confirmed lethal prenatal diagnosis. Below, you will find a brief “bio” for each of the participants to this study.

Diane, Healthcare Provider

As the Perinatal Bereavement Coordinator and Perinatal Hospice Coordinator for a Midwestern, Catholic hospital, Diane has frequent contact with mothers facing a lethal prenatal diagnosis for their unborn child, as well as mothers who subsequently experience loss. Diane, also a birthing center nurse, has been in the role of providing bereavement support to mothers for 20 years, and in the last 5 years has helped develop and implement a Perinatal Hospice program operated through the hospital for which she works. Her role in this program is to provide support and resources to mothers antenatally, who have made the decision to continue their pregnancies upon confirmation of a lethal prenatal diagnosis. She provides and oversees continued support for these mothers for a year after the birth and death of their infant. Diane worked closely with each of the participants in this study who chose to continue their pregnancies, myself included, though she is unaware of whom has agreed to be a part of this study, as that information has been kept confidential.

Self, Mommy to Chloe

I am a 25-year-old woman, married for nearly 4 years to my husband whom I met during my freshman year in college. We had our first child, Gabriel, now 6, a year after meeting and two years prior to our marriage. Our middle daughter, Chloe, died shortly after birth nearly two years ago. Currently, we are expecting our third child, due to be born in a

couple of months, whom we are happy to say is healthy in every way, according to ultrasound at this point in my pregnancy.

My husband works in banking and I am currently pursuing graduate studies in Human Development and Family Studies at a Midwestern state University. I decided to conduct this study as a part of my studies after my personal experience with lethal prenatal diagnosis and the subsequent birth and death of our daughter, Chloe. She is the inspiration for this study and the reason that I was able to hear the stories of all of the women who have chosen to participate.

In 2005, we became pregnant with our second child. In February of 2006, at around 20 weeks gestation, we found out that our unborn child was suspected to have chromosomal abnormality after routine ultrasound revealed that her brain structure appeared abnormal. After conducting an amniocentesis, results indicated that our daughter had an interstitial deletion of chromosome 2, or a small piece in the long arm of chromosome number 2 missing. Our daughter's brain, then, had failed to divide into the necessary lobes, diagnosed as holoprosencephaly, and also caused some craniofacial abnormalities. My husband and I decided to continue the pregnancy to term, strongly influenced by our then pro-life Catholic beliefs, but went into premature labor at 32 weeks along, due to the large amount of amniotic fluid I was carrying, a result of my daughter's inability to swallow the fluid in utero. Chloe lived for 45 minutes and was held by her father or me the entire time. We participated in a local Perinatal Hospice program, receiving a great deal of support pre- and post- nately.

Since our pregnancy with Chloe, we have found many ways to keep her legacy alive in our family and have seen the importance of being open and honest with our son, who was

4 ½ when she was born and died. She has taught us a number of valuable lessons and strengthened our faith in a life transforming way, as we have since left the Catholic Church and now consider ourselves born-again Christians and attend a non-denominational Christian Church.

Jen, Mommy to Andrew

Jen is a 25-year-old married woman, with no living children. This past year, Jen left a career working for the Midwestern City Government in which she lives, to pursue Communications work with her church. She works as an assistant to her Pastor for a non-denominational Christian Church, of which she is a member. Jen has been married for nearly two years and her husband works for a local Credit Union.

Jen gave birth to her son, Andrew Jen, in early August of 2005. She was 21 weeks along in her pregnancy, and electively chose to induce the pregnancy at this time due to a terminal prenatal diagnosis. It was clearly evident through the use of ultrasound that her baby had failed to develop kidneys, making it impossible for him to live. The name for this diagnosis is Potter's Syndrome, or Renal Agenesis. Because of this lack of kidney development, this also meant that she had virtually no amniotic fluid, making it impossible for her uterus to expand and grow with the growth of her son in utero, as well as for him to develop any lung capacity.

Andrew lived for 45 minutes after his birth. Immediately after his birth, medical personnel took him and cleaned him up, at Jen's request. After about 20 minutes and before handing him to his parents, the doctor came back into the room and told them that he was still alive. Jen and her husband were able to hold him for the last 25 minutes of his life, and then chose to keep him in the room with them and hold him for hours after his death. After

his death, they held a Celebration of Life service and buried him next to his paternal grandmother, who died just six months prior to his own birth and death.

Leah, Mommy to Neomyiah

Leah is a 37-year-old, married, mother of six, with children ranging in age from one year to 15-years-old. Her middle children are ages 14, 7, and 4. Her son, Neomyiah, was born and died at 33 weeks gestation after being born prematurely and would have been 2-years-old at the time of this study. Leah is a nurse at an urgent care clinic and has worked part-time for the past two years. At the time of our initial interview, she was preparing to return to work full time. She describes herself as a “Christian” and puts great emphasis on raising her children in a Christian home.

Leah went in for a routine ultrasound at 20 weeks gestation, which was when they discovered that Neomyiah had some developmental problems in the abdominal area. She describes this as the time when they found out he was “sick”. His stomach and esophagus were not properly connected. This type of problem can sometimes be treated, but further ultrasound examination revealed other serious problems, including a heart defect. With the combination of anomalies, it became clear that his prognosis was fatal.

Leah and her husband adamantly opposed terminating the pregnancy, which she attributes to her pro-life ideals and Christian views. She discussed dismay that one doctor suggested that they ought to induce once the prognosis was confirmed. She sought out second opinions and the expertise of specialists, and ultimately took part in the Perinatal Hospice program to prepare for the birth of her son. Neomyiah died after being born prematurely at 33 weeks gestation. He lived for 2 ½ hours, surrounded by his parents, siblings, and other family and friends.

Since his birth and death, Leah gave birth to a healthy baby girl whom they thought would be born with Down Syndrome, according to ultrasound and other screenings obtained prenatally. She reports feeling “blessed” by this healthy child. At the time of this study, Leah and her family were organizing a memorial event in honor of Neomyiah, as they approached what would have been his 2nd birthday.

Nancy, Mommy to Eli

Nancy is a thirty-five-year-old, married mother of 3. She lives in a small Midwestern town, is a self-proclaimed Christian, and works part-time decorating cakes. Her husband works in the area of computers for a reputable company in the area. Nancy used to work in Human Resources after receiving her college education from a state University. However, when her family began to grow, her husband encouraged her to stay with the children, which Nancy embraced and enjoys, sharing that she is fortunate to have the ability to do so.

Nancy spends most of her time at home, caring for her two living daughters, Natalie, age 4 and Claire, age 1. Her son, Eli, would have been 2-years-old this year. Nancy electively gave birth to Eli at 25 weeks along in her pregnancy with him, due to the confirmed diagnosis of anencephaly. In Eli’s case, this consisted of a total absence of the brain and skull, a 100% fatal prognosis. Eli did not survive his birth, but his parents spent several hours holding him after his birth. Nancy reported that she took several pictures of him, but the only person who has seen the photos besides her and her husband is her mother, Eli’s grandmother.

Since his birth and death, Nancy and her husband have given birth to a healthy baby girl and are expecting again. When Nancy reflects back on her experience with Eli, she often mentions that if she had not chosen to induce labor when she did, she would likely not have

become pregnant with her subsequent daughter and cannot imagine life without her. Though she clearly states her love and longing for Eli, she attributes his diagnosis and death to God's plan for their family.

Elizabeth, Mommy to Noah

Elizabeth is a 25-year-old married woman, with no living children. She is employed as a 7th grade math and science teacher in her town's public school district. Elizabeth has been married for three years to her high-school sweetheart. Elizabeth describes herself as being a born-again Christian, coming to the faith in March of 2006, after being raised Lutheran her entire life.

In August of 2007, Elizabeth gave birth to a full-term baby boy, Noah Michael. Noah was Elizabeth's first child, who lived for 2 ½ days. Elizabeth found out at 20 weeks gestation, through routine ultrasound, that Noah's brain was not developing correctly. After further ultrasound, Noah was diagnosed with anencephaly, the complete absence of the brain and skull, a 100% fatal diagnosis. Faced with whether or not to continue the pregnancy, Elizabeth and her husband took some time to consult with doctors, their pastor, as well as with friends who had been through a similar experience. These friends happened to be my husband and me. After several days, and a great deal of prayer, they had decided to continue their pregnancy to term, and participated in a local Perinatal Hospice Program, which they had learned about from their Perinatologist's office.

Noah was able to spend several hours at his home with his parents and got to meet his dog, between being discharged from the hospital and admitted into hospice. He spent his last 12 hours in a hospice facility, where Elizabeth and her husband had family, co-workers, and friends visit. Noah died peacefully 60 hours after his birth while in hospice care, being held

in his parents' arms. They kept him with them for several more hours, as grandparents said their final goodbyes and their pastors came to pray with them.

Since his birth and death, Amanda has returned to her work as a teacher and keeps his photo adorned proudly on her desk. She has attended two different support groups and attended various remembrance ceremonies to memorialize infants who have died, including Noah.

Tara, Mommy to Christopher

Tara is a 32-year-old married woman and a homemaker. Prior to choosing to stay home to care for her children, Tara worked for a state University in the Midwest. In her pregnancy with her second child, Tara found out at 20 weeks gestation that her son, Christopher, had been diagnosed with a chromosomal abnormality, Trisomy 18. Trisomy 18 is a chromosomal abnormality in which there is an extra chromosome 18 in the baby's genetic makeup. As a result, Christopher had a number of developmental anomalies, including fluid surrounding his brain and many of his internal organs had developed in a sac outside of his abdomen. Given the severity and combination of these developmental complications, doctors gave him a 100% fatal prognosis.

After consultation with a genetic counselor, perinatologists, and conducting an amniocentesis, Tara and her husband decided that they would terminate their pregnancy with Christopher At 22 weeks gestation. Christopher did not live through his birth. His parents were able to spend several hours with him, however.

At the time of our interviews, Tara had one living child, a 3-year-old daughter. In addition, Tara was expecting her third child, whom they were informed was a healthy, developing baby girl. Tara considers herself a Christian, and openly shared her reliance on

her faith community throughout her pregnancy with Christopher, as well as in her coping with his loss since.

Procedure

Before recruiting any potential participants and data collection procedures, I obtained approval from Iowa State University's Institutional Review Board. Upon approval to conduct the current study, I collected data from each of the six participants by conducting one to two individual interviews, which were audio taped and transcribed, as well as through participant observation of four of the six participants. Overall, 10 interviews and 12 participant observations comprise the data. Interviews lasted between 60-120 minutes long. Participant observation consisted of individual and/or small group interactions at memorial services, Perinatal Hospice events, and participation in Mommies with Hope Support Group. Observation field notes were recorded in a methodological log. All participants signed Informed Consent (Appendix C) prior to the implementation of any data collection procedures. Interviews were conducted in a natural setting of the interviewees' choice, which included their homes, a meeting room at a local coffee establishment, and my office, depending on the participants' preference and bearing in mind issues of confidentiality. Interviews were semi-structured in nature, aiming to tap into the mothers' experiences and caregiver's perceptions of mothers' experiences. I used an Interview Protocol as a guide (Appendix D). Upon completion of interviews, I subsequently transcribed all audiotapes of the interviews through the use of a transcription machine. In addition, I completed Interview Summary Sheets (Appendix E) after interactions with the participants, whether it was an interview or some other form of participant observation, described above. Furthermore, I collected my own thoughts and perceptions in a methodological log throughout the entire

research process, which gave further insight into these women's experiences and my own interpretation of their stories. Since this is a narrative design, it was essential to hear the stories of the individuals that I interviewed and observed, with the goal of reporting the informants' experiences and to make meaning of the experiences described in their telling of their stories (Creswell, 2002).

Interview questions for mothers participating in this study included: Tell me about how you found out about [child's name] diagnosis? What was the decision-making process like for managing the pregnancy upon confirmation of the diagnosis? Describe your pregnancy experience before and after the diagnosis? Describe the birth experience? Describe the experience of losing your child?

Interview questions for the healthcare provider included: Tell me about the work you do with perinatal hospice patients based upon where they are at in the program (initial diagnosis, waiting period, birth/loss)? What is your perception of these mothers' experiences during the diagnosis, pregnancy, birth, and loss phases? How are the experiences similar/different to mothers who experience other types of perinatal loss (sudden stillbirth or miscarriage)? Explain.

The questions posed above served as a general guide for the interviews. I anticipated that the sensitivity of the questions would evoke a great deal of emotionality from participants, which proved to be true throughout the interview and observation procedures. The signed informed consent obtained from each participant detailed this risk and made it clear that they were free to refrain from answering any question at any time, as well as free to withdraw from the study. Given my own personal account of perinatal loss after receiving a confirmed lethal prenatal diagnosis, I understood from the onset of this research that some of

the mothers' or healthcare provider's accounts would elicit emotions in me or may remind me of my own loss and the feelings that accompanied that loss. The participants were informed of my personal experience before we delved into the actual interview questions, and therefore, were not surprised in any sharing of emotionality throughout the interview and observation process. Since I approached this narrative study from a feminist framework, I took an active and collaborative role in the study and did not attempt in any way to position myself as an objective observer.

Analysis

Data analysis occurred throughout the data collection procedures in this study. During the interviews, I took field notes, which were kept on an Interview Protocol Form (Appendix D). On this form, I recorded initial reactions and observations during the actual interview pertaining to the research questions at hand. Immediately following each interview, I recorded additional thoughts on an Interview Summary Sheet (Appendix E). This form included reflections and impressions of the informant interviewed and provided a more structured way of organizing my initial field notes and interview impressions pertaining to the research questions. To further process, I kept an ongoing methodological log, recording and processing thoughts about interviews and observation experiences with informants. I used this methodological log to write about my personal experience with the topic of perinatal loss and how the informant's story did/did not elicit certain feelings and emotions in my own experience. Due to the sensitive nature of the topic of investigation and given my personal experience with this topic, I found it necessary to personally reflect and record these thoughts in writing, pertaining to the feelings that arose as a result of the intensity of the interviews and observations.

After completing the initial forms and field notes, I transcribed the interviews verbatim, with the use of a transcriber. I used narrative analysis to search the transcripts for common stories and themes that helped make meaning of the experiences of the informants. Upon reading through the transcripts, I wrote notes in the margin, forming synthesis statements pertaining to specific narratives. From there, I examined the synthesis statements and formed broader categories or themes, naming them with one word or a short phrase. I then typed these words and/or phrases in all capital letters at the beginning of the narrative that corresponded with that category or theme. Finally, I examined the narratives for sub-themes that fell under the more broad categories or themes and coded them in the same manner. For sub-themes, I typed the broader category/theme name in all caps, followed by a colon, and then the word or phrase identifying the sub-theme. To easily access the coded narratives, I utilized the “Edit: Find” function in the Microsoft Word word-processing program, which directed me to the specifically coded narratives.

Throughout data analysis and presentation of the findings to follow, I have included excerpts from my personal journal, pertaining to the topic of perinatal loss as a result of a lethal prenatal diagnosis. I include aspects of my own experience of loss and interpret the findings from this personal perspective.

To ensure rigor and trustworthiness of the data that was collected and analyzed, I conducted member-checks and made use of a peer reviewer, a fellow graduate student in my department. The peer reviewer, a 34-year-old female, was trained in qualitative research and was simultaneously working on a qualitative dissertation research study, which has since been successfully defended. I conducted member-checks by providing informants with a table-formatted handout that included the identified themes, their narratives, and my

interpretation of their narratives. Based on informant feedback, I adjusted the developing narratives accordingly, often adding to my initial interpretations. The peer reviewer examined the data analysis artifacts, including interpretation transcripts and field notes, and the emergent themes and sub-themes as they were arranged in a model, which is included in the Findings section of this paper. Triangulation of the data occurred through my personal experience with the phenomenon of perinatal loss as a result of a confirmed lethal prenatal diagnosis, the reported experiences of the mothers that I interviewed, and the perception of mothers' experiences from the healthcare provider who served as an informant to this study.

My continuous writing in a methodological log, which served as a record of my own personal biases and interpretations of the findings throughout the data collection and analysis procedures, also serves as a form of data used in the analysis of this study. Thus, the data was examined through my personal perspective, the perspectives of other mothers who participated in this study, and the perspective of a healthcare provider who provides medical care and bereavement support to mothers who experience a lethal prenatal diagnosis and perinatal loss. For samples of the data analysis and coding described above, please see the samples provided at the end of this paper (Appendix F).

CHAPTER 4. FINDINGS AND DISCUSSION

Emergent Overarching Themes and Sub-Themes

This Chapter will focus on the findings of the qualitative data that I collected over the past year, obtained through interviews, participant observation, personal insight and journal writing, as described in Chapter 3. It is organized and presented in a manner that will allow you to see the emergent themes and sub-themes visually, through the development of a model, describing how mothers make meaning of the phenomenon under investigation. In addition, you will find each overarching theme and sub-theme has been described in further detail and explanation, including narratives of the informants throughout to support the identified themes. They are organized by the overarching themes of Hopes and Dreams: Where it all Began; Diagnosis Denial: “This Can’t Be True”; and Making Meaning: Going Beyond “It’s not fair!” Sub-themes specific to mothers who chose expectant management include Continued Denial/Hope, Making Memories: Post-diagnosis/Pre-death, and Perinatal Hospice. Sub-themes specific to mothers who chose termination include Termination Euphemisms and Stigma. Shared sub-themes/experiences, despite choice for pregnancy management, include Spirituality, Mementos, and Legacy/Honor of Child’s Life. The results section concludes with an explanation of the overarching theme of Making Meaning: Going Beyond “It’s not fair!” Finally, the discussion will give further insight to the findings from the current study, and link these results to current research and practice.

How Mothers Make Meaning of Their Experience: The Paths They Choose

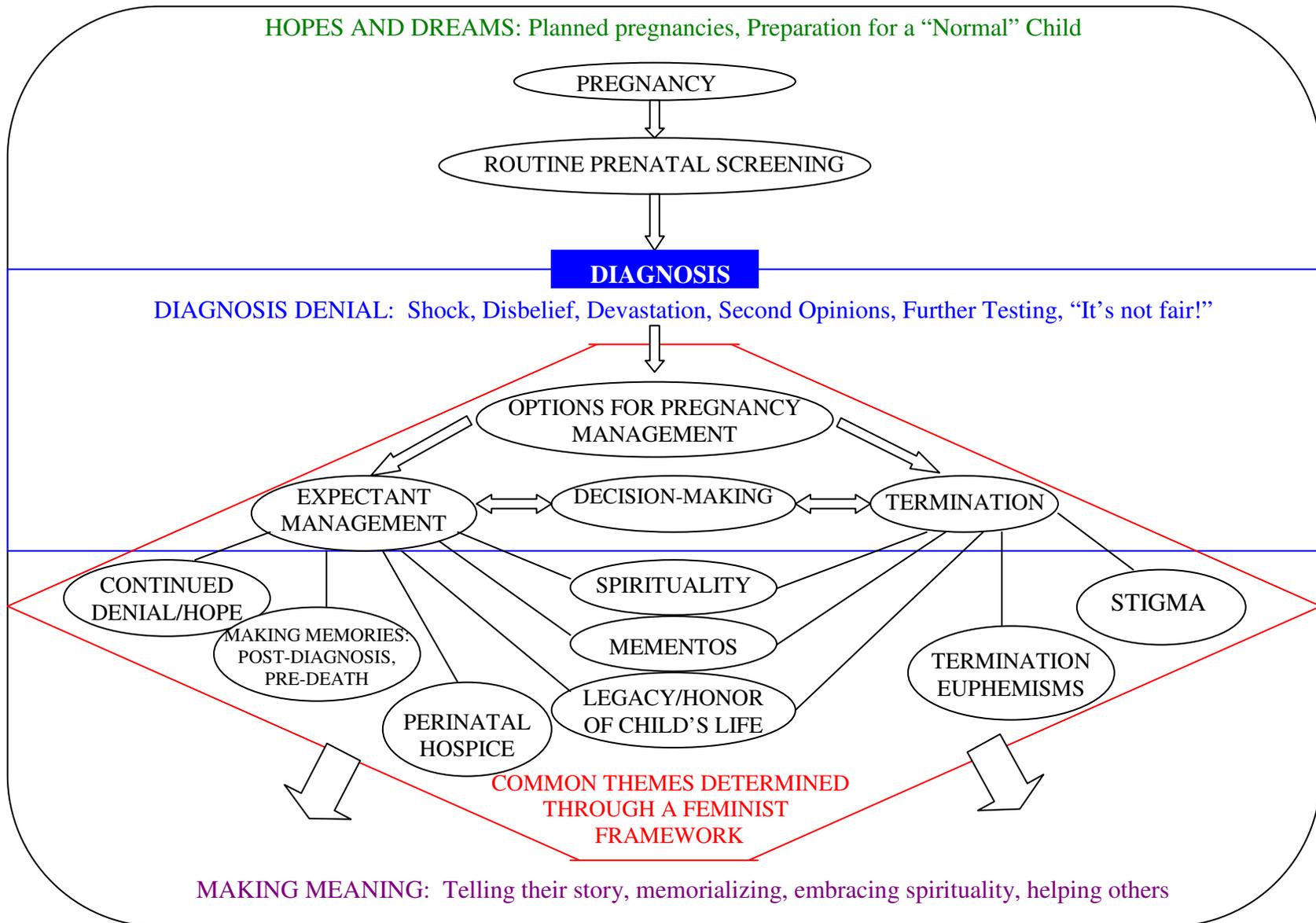
When graphically visualizing the themes that were beginning to emerge from the data in this study, I initially imagined that the themes would be overlapping everywhere, as the issues and experiences are all so intertwined. When thinking more about this phenomenon

faced by the mothers in this study, I discovered, however, that they all shared a common pathway through their experience, resulting in a model (Figure 1), with segments of their “path” framed in overarching themes or sections titled: a) Hopes and Dreams: Where it all Began, b) Diagnosis Denial: “This Can’t be True”, and c) Making Meaning: Going Beyond “It’s not fair!” These overarching themes encompass my analysis and interpretation of overlap, as they are then narrowed down into sub-themes.

All mothers had planned pregnancies and were expecting to deliver a healthy, “normal”, child, for whom they had so many “Hopes and Dreams”. All mothers found out about a problem with their baby’s development first through routine screenings conducted at between 18 and 20 weeks in their prenatal care, by either a non-invasive MSAFP (maternal serum alpha-fetoprotein) test and/or ultrasound, respectively. These initial screenings then led to more invasive prenatal tests, such as amniocentesis or chorionic villi sampling (CVS). Upon confirmation of a terminal diagnosis through subsequent prenatal testing, mothers were faced with two options: 1) Expectant Management, or 2) Termination. Mothers’ “paths” branched off depending on their choice for pregnancy management.

Within this time of weighing options and decision-making, it was characteristic for mothers in this study to experience “Diagnosis Denial”, one of the identified overarching themes in these results, evidenced by seeking out second opinions and following through with more invasive prenatal testing. In contrast to a medical model approach to examining this phenomenon of prenatal diagnosis, mothers often took these measures to obtain confirmation that their baby was in fact, “normal” or healthy, rather than to confirm a suspected diagnosis. This is consistent with findings of Rapp’s (1999) qualitative work in

FIGURE 1. HOW MOTHERS MAKE MEANING OF THEIR EXPERIENCE: THE PATHS THEY CHOOSE



the area of prenatal testing and diagnosis. A common reaction to the diagnosis was, “It’s not fair!,” an expression I constantly voiced throughout my own experience.

The next group of emergent sub-themes, identified through mothers’ narratives, personal experience, personal journals, a methodological log, member-checking, triangulation of data, and a healthcare provider’s perspective, were uncovered through the analysis of this qualitative data and are linked on the model to the options for pregnancy management chosen by the mothers in this study. Analysis procedures are described in Chapter 3 and a sample of data analysis is included in the appendices of this paper (Appendix F). Connecting lines in the model indicate shared sub-themes/experiences among mothers, despite choice for pregnancy management, as well as sub-themes unique to their choice for pregnancy management.

Finally, the third overarching theme, Making Meaning: Going Beyond “It’s not fair!” is the last section of the model and encompasses ways in which all mothers have begun to make meaning from their experience with prenatal diagnosis and perinatal loss. The activities carried out by mothers are all related to the theme of “Legacy/Honor of Child’s Life”. Mothers want to acknowledge their child’s brief life and want others to know their child and acknowledge that they existed.

An interesting finding when looking at these results as they are graphically organized in this model, is that all mothers started and ended their pregnancies with shared experiences. All mothers had hopes, dreams, and plans for their unborn children, all of which were shattered with the confirmation of a lethal prenatal diagnosis. According to their choice for pregnancy management, mothers were either provided or not provided with formal bereavement support. In other words, mothers who chose expectant management were offered and provided with perinatal hospice services, while mothers who chose termination were not offered or provided

with perinatal hospice services or any other formal bereavement support. Mothers' experiences continue on with the common shared goal of memorializing, honoring, and carrying on their child's legacy, despite whether they chose expectant management or termination upon confirmation of the diagnosis. Access to formal bereavement support resources differed for these mothers and they were not afforded the same opportunities for support in grieving the child that they so desired.

Hopes and Dreams: Where it all Began

All of the mothers in this study planned for and wanted their child. Two of the mothers in this study, Jen and Elizabeth, would give birth to their first child. The other mothers, including Nancy, Tara, Leah, and me, all had plans to welcome another healthy child into our family. All mothers had told family and friends about the newly expected addition to the family. All mothers completed the first trimester of pregnancy before any indication of a problem arose. As indicated in each of the participants' biographical paragraphs above, it was not until 18 weeks gestation at the earliest, that any mother in the current study knew of a potential problem with her unborn child's development. All mothers had received confirmation of a lethal prenatal diagnosis by 21 weeks gestation.

Upon confirmation of such a diagnosis, the hopes and dreams that all mothers once possessed for their child's life were shattered. There would be no first tooth, no first steps or words, or no first day of school. Mothers would not see their children off to their prom dance or stand by their side on their wedding day. All of the milestones and achievements that a parent has for their child, even before they are born, were wiped away when these mothers discovered the fate of their child's lives.

Six months to the day after Noah's birth, Elizabeth tells me, "I'm sure you remember this moment in the year after Chloe...thinking about what he'd [Noah] be like and what we'd be doing with him." (Elizabeth, Mommy to Noah) as she remembers him and imagines what life would be like with him here...alive.

She was right. I did think about those times, wondering what Chloe would have been like if she had lived. I thought ahead too, to the future and what she would have grown to be like. In a journal excerpt, written a few weeks after Chloe's death, I wrote:

We chaperoned a field trip for our son's class today. The children went to a farm out in the country and got to see a very beautiful garden and pond and also got to ride on a wagon pulled by a tractor. It was so neat to see the preschoolers enjoy themselves so much and explore, but at the same time, all I could think about was the fact that Chloe would never have that chance and would never get to explore or even have a childhood. Thinking of this broke my heart. (Self, Mommy to Chloe)

Jen (Mommy to Andrew), shared a song, titled "With Hope" with the Mommies with Hope Support group that she formed with me after her son's birth and death. Some of the lyrics include,

This is not at all how we thought it was supposed to be. We had so many plans for you, we had so many dreams. And now you've gone away, and left us with the memory of your touch. And nothing we can say, nothing we can do, can take away the pain of losing you. (Curtis-Chapman, 1999, track 11).

Being in attendance during this support group meeting and to hear the song, which I had heard before, reminded me that we (bereaved mothers) did lose all of those hopes and dreams that we had for our children on this earth. Another line in the song reads, "We can say goodbye with

hope, because we know our goodbye is not the end. There's a place where I'll see you're face again." This brings comfort in believing that we will be reunited one day, a belief held by each of the mothers in the current study, which will be discussed in further detail under the Spirituality theme.

Diagnosis Denial: "This Can't Be True"

As previously mentioned, all mothers in this study experienced a phase of denial of the diagnosis at some point after hearing the initial news of the suspected anomaly. Some mothers sought second opinions by going to specialists, while others opted for further prenatal testing for confirmation. They awaited the results of such testing, sure that they would confirm what they had hoped, that this was all a terrible mistake and their baby was perfectly healthy. It is a way of coping. Mothers denied that the suspected diagnosis existed and hoped that the genetic test results that were pending would come back establishing that the diagnosis was, in fact, "wrong." Healthcare provider, Diane, comments on the issue of diagnosis by saying,

They [mothers] are sure that it [the diagnosis] is wrong. It's that denial. That self-protection that all of us have, which is how we figure out how to live every day. So they're just sure that that initial diagnosis, that just can't be right. (Diane, Healthcare Provider)

As Diane mentioned, mothers facing a lethal prenatal diagnosis for their unborn child have a hard time believing the diagnosis. In the midst of the shock and horror of the news, mothers cling to a miraculous hope that they will somehow survive, evidenced by the following narrative by Nancy, mommy to Eli, on her diagnosis experience:

[The doctor] came back in and put that thing on my tummy [the doplar instrument] for probably five seconds, it was so quick, and I remember thinking, why isn't he looking

more? It was real quick and then he shut it off. And he says, “Well I don’t know exactly how to tell you this but I don’t have good news. Your baby doesn’t have a brain and doesn’t have a skull.”...I remember letting out like a scream or a cry that Gary describes to other people as the sound that only a mom will make when she finds out that she is going to lose a child. And I think I remember asking him (the doctor), and I knew it was a silly question, but I said, “He can still live, right? And he said “No. It is 100% fatal. Your baby will not live.” (Nancy, Mommy to Eli)

In my personal journal, I wrote an entry, which I titled “This Can’t Be True,” just days after the ultrasound that gave us the first glimpse of just how serious our daughter’s condition was. Here is an excerpt from that entry that so clearly denies the news we had been told:

Maybe everything was a mistake and there was nothing wrong at all. Couldn’t this all be some sort of mix up?...We [my husband and I] cried together and we held each other. That night was a horrific night. I was outraged by the news. They had to be wrong. What they were saying could not be true! All I wanted was for you [Chloe] to live. I screamed out to no one, ‘Why? It’s not fair! I just want her to live, that’s all!’ (Self, Mommy to Chloe)

A common reaction among mothers in this study included the seeking out of second opinions or the advice of specialists. They, in a way, were looking for confirmation that the initial suspicions of a positive prenatal diagnosis were, in fact, false. They were hoping that other doctors and professionals would inform them that everything was perfectly normal and healthy with their unborn child. This seeking of second opinions ranged from questioning their regular obstetrician, after already hearing from the perinatologist, to traveling long distances, in

one case to another state, to obtain medical care and consultation. Ultimately, all women had to come to grips with the fact the diagnoses existed and each found her own way of coping.

Decision-making.

For some women, the decision on whether to continue the pregnancy or terminate came easily. Here is a thought shared by Jen, Mommy to Andrew, on her decision to induce at 21 weeks gestation: “When we had found out the diagnosis, it was clear to us that this was God’s will for our son’s life.” Still, she and her husband took time to consult with their pastor and prayerfully consider their options. In less than a week from the initial diagnosis, they gave birth to Andrew. Born alive, Andrew lived for forty-five minutes.

Another mother, Leah, had her mind made up before leaving the office. She states, “We would not consider an abortion. We would continue at all costs.” (Leah, Mommy to Neomyiah). This was an attitude very similar to my own. I recall having made up my mind in the office the day that the doctor came in and told my husband and I “Your baby is going to die.” after he had spent only a few minutes looking at her ultrasound pictures. This was before an amniocentesis had even been conducted. Based on the pictures, he gave us this devastating and shocking news. Still, our attitude was one similar to Leah’s. We would continue no matter what. We were greatly influenced by our then Catholic beliefs and ideals. After all, we were pro-life. How could we abort? Looking at the situation now, I realize that being “pro-life” has nothing to do with it. Controversially, I assert that the termination of a healthy pregnancy out of choice is a far different experience than the termination of a pregnancy where a lethal prenatal diagnosis is confirmed and the child’s prognosis is death.

Other mothers took some time to talk to their pastors, family, friends, or other medical professionals before making a final decision. Elizabeth and her husband consulted with their

pastor regarding the situation and the options with which they faced. They also spoke to her mother, who is an obstetrics nurse at a hospital in her hometown. Finally, they spoke with my husband and me who were friends with them from church who had been in a similar situation just a year prior to the time of their son, Noah's diagnosis.

To an extent, mothers experienced some degree of weighing options, even if it consisted of hearing the options and ruling one or the other out almost instantaneously. All mothers in the current study reported feeling "at peace" with their decision and as if the decision they made was what was best for their families.

Sub-Themes Specific to Mothers who Chose Expectant Management

The following three sub-themes are specific to mothers who chose expectant management for their pregnancies upon confirmation of a lethal prenatal diagnosis. These sub-themes help us to better understand the experiences unique to the phenomenon of continuing a pregnancy with the prognosis of death.

Continued Denial, Clinging to Hope

In hearing mothers' stories of continuing their pregnancies in the face of a lethal prenatal diagnosis, it was interesting to see that these mothers clung to a hope that things would turn out in their favor. In other words, all mothers to a degree, had a suspicion that maybe the doctors would be wrong about the prognosis and that their baby would be born healthy or live longer than expected. This is evidenced by the seeking out of second opinions and expertise of specialists, also noted in the above-mentioned theme of Diagnosis Denial. Leah, Mommy to Neomyiah, was just certain that there was something that could be done to save her son. When describing the time when they found out about his diagnosis, Leah often referred to that diagnosis experience as "when we found out he was sick." This choice of words indicates that

there was some sort of cure for him. Though living in the Midwest, she sought out medical help from specialists as far away as Florida, only to find that the complications were too severe and, in reality, nothing could be done.

I recall during a time in my pregnancy watching a television show that highlighted a young family with a beautiful little girl who had been diagnosed with holoprosencephaly, the same condition that my daughter, Chloe, had been diagnosed with. They were telling their story about how doctors told them she would possibly be stillborn and surely would not live long after birth. She was now 3 years old. I recall going to the doctor that same week telling him all about the show and how this little girl was 3-years-old, and that maybe there was a chance that Chloe would live that long. He reluctantly reminded me that what I saw must have been a very rare case. He told me we would not know anything for certain about Chloe until she arrived. Still, I had hope.

Elizabeth, Mommy to Noah, told me during her pregnancy about how very active Noah was in utero. I recall her telling me that she was sure that he had more brain tissue than what the doctors were saying because when she would push on her stomach, he would kick back. She said, "It's like he was responding to us." To an outsider, this may seem absurd or like a stretch. To a mother clinging to hope, it becomes much more than that. It is a possibility.

Making Memories: Post-Diagnosis, Pre-Death

Another common theme identified through hearing the stories of mothers who chose expectant management, includes the deliberate and intentional memory making that took place between the time of the diagnosis and the actual birth and death of the child. The three women who chose to continue their pregnancies each had an interval between receiving the lethal prenatal diagnosis to the actual birth and death, ranging from twelve to twenty weeks.

This range existed because, although all mothers had received a diagnosis at around 20 weeks gestation, they went into labor at different times, depending on the medical conditions surrounding their unborn child's diagnosis. In my own pregnancy, I had a time period of 12 weeks of knowing about the diagnosis to when I gave birth, because I went into natural premature labor at 32 weeks gestation due to the increased amount of amniotic fluid present in my uterus. Elizabeth, however, experienced 20 weeks of pregnancy knowing the diagnosis before giving birth to Noah, as she was able to carry him full term and had a scheduled induction at 40 weeks gestation. Leah had a period of 13 weeks from the time of diagnosis to the actual birth of Neomyiah.

Mothers chose to use this time period of knowing as a time for making memories of their child's life, while they could. A good example of this is evident by Elizabeth's yearning to let Noah experience all he could, while he was in the womb. Her outlook was one that exhibited the attitude of "this is his life," referring to the time while she was pregnant with him. I can recall a conversation we had shortly after she had received his diagnosis. She and her husband were still weighing their options and they were in the decision-making phase regarding whether to continue the pregnancy or induce. One of the things that I had shared with her from my own experience was how I cherished the moments that I had with Chloe, while she was living inside of me, because for us, this was the only time we had. After they had made their decision to continue their pregnancy with Noah, she told me that it was this notion that helped her to decide that she too wanted to embrace each moment of Noah's life that she could, given the prognosis of his brain condition, anencephaly. Thus, she took each of those moments and made memories out of them.

While Elizabeth was pregnant with Noah, she and her husband made a point to do as many activities as they could with him, as they knew that his life after birth would be brief. They spent the summer before his birth taking trips to the zoo, baseball games, and went on a vacation, just to name a few. Elizabeth created a touching artifact to record these outings, which she and her husband shared at his visitation and funeral service. It was a scrapbook that she had made over the latter half of her pregnancy, which included photographs and captions detailing all the things that Elizabeth and her husband “did” with Noah.

Other mothers who continued did similar things to make memories while their child was in utero. On the night of our first interview, Leah brought a scrapbook that she had completed with her family, detailing the things that they had done together with Neomyiah while she was pregnant with him, including a family camping trip and picnics.

One thing that my family began to plan, while I was still pregnant, was a benefit in honor of Chloe. The idea was to raise money to help us with medical expenses and also to donate to the Perinatal Hospice program from which we were receiving so much support. Since I went into premature labor, the benefit actually occurred 3 weeks after Chloe was born and died. The thought behind it, however, was to have it while I was still pregnant, thus falling into this sub-theme of making memories post-diagnosis, pre-death.

Each of the mothers who chose expectant management pre-arranged funeral services for their unborn children. In the planning of services beforehand, mothers had the opportunity to make or plan for special mementos (described in more detail below) to be on display at the visitation and/or funeral service. It also gave families the opportunity to think of special ways to pay tribute to their children, evidenced by Leah’s two oldest daughters playing the guitar and singing a song at their baby brother’s funeral, as well as me recording a song in advance

for my daughter, Chloe, to be played at her service. All of these are ways that mothers were able to use the time between the diagnosis and the birth and death to create memories with and for their babies.

Perinatal Hospice

All mothers who chose expectant management when faced with a lethal prenatal diagnosis, myself included, were referred to and participated in a local Perinatal Hospice program to prepare for the birth and death of their child. As previously mentioned in the literature, Perinatal Hospice aims to provide encouragement and support in preparation for the birth and loss of a child, to provide bereavement support, and to provide the family with whatever is necessary for them to enjoy the limited time they have with their baby (Hoeldtke & Calhoun, 2001; Romesberg, 2004; Sumner et al., 2006).

Mothers who participated in the Perinatal Hospice program did not elaborate a great deal on the program specifically, but I feel it is important to include as a sub-theme because their inclusion in this program afforded them high standards of bereavement support that mothers who chose to terminate did not receive. These standards included the completion of a birth plan prior to labor and delivery, even for those who went into premature labor. The birth plan detailed desires and needs for the birth as meticulous as asking mothers about certain items that they want in photographs with their babies after the birth. In addition, mothers received professional support from the Perinatal Hospice/Bereavement Coordinator, the Maternal-Child Health Social Worker, a Family Therapist, and a Child Life Specialist, if so desired. All of these services were free of charge and at these mothers' disposal. Finally, the planning for and creation of lasting mementos, a significant part of this entire experience, was a major part of the services offered through Perinatal Hospice. This gap in services between

mothers who choose expectant management and those who did not is addressed in further detail in subsequent sub-themes, but even more specifically in the conclusions of this study, where I cite implications for policy, practice, and research.

Sub-Themes Specific to Mothers who Chose Termination

The following sub-themes are specific to mothers who chose to terminate their pregnancies upon confirmation of a lethal prenatal diagnosis. The two sub-themes, titled “termination euphemisms and confusion” and “stigma,” are directly related to their decision to terminate and emerged from their stories, the perspective of the healthcare provider informant, and personal reflection and insight.

Termination Euphemisms and Confusion

In my interviews with the healthcare provider and informant, Diane, I ask a variety of questions dealing with termination versus expectant management, interested in her knowledge on this phenomenon. She reports that she does not typically have sustained contact with mothers who choose to terminate their pregnancies upon confirmation of a lethal prenatal diagnosis. Reason being, she works for a Catholic hospital, and they do not conduct or support “early inductions,” unless the mother’s life is at stake. Therefore, mothers who choose to terminate are referred to one of the two other non-Catholic hospitals in the area that will conduct the procedure.

Diane does occasionally talk to and provide services to women who have chosen or are considering termination. When I asked Diane to describe a time when she helped guide a mother through the decision-making process, she mentioned two examples, in each example the mother chose to terminate their pregnancies. Through the stories that Diane told me about

these encounters, it became apparent that mothers are in a state of confusion when faced with such a choice.

Diane describes one of the examples about a mother she had phone contact with:

...they had had the amnio[centesis]. They didn't have results yet, but they were pretty confident what those test results would be, just because it was so classic. Catholic.

Didn't want to have an abortion; didn't want to carry the pregnancy. Struggling with 'what do I do, what do I do, what do I do'? Couldn't understand. [The mother] was

told by the physician that they could induce the pregnancy at any time. Therefore, thinking they could come here [to the Catholic hospital that Diane works for]. I'm

always the one saying we would like you to come here, but that is considered an

abortion by state law. And then that opens up all those cans of 'what do you mean,

well I'm not, I don't want to abort my baby. I just want this pregnancy to end [mom]'.

And not seeing that correlation that this is what state law is. So just struggling and going in that circle.... (Diane, Healthcare Provider).

When presenting the options to the mothers upon diagnosis confirmation, the physician tends to use words other than "abortion" or "termination." Typically, this procedure is referred to as "induction". We have all heard of or known someone who has had their labor induced. It is done routinely in pregnancies for a variety of reasons. However, as Diane described in the narrative above, induction before a certain gestational age, is legally considered an abortion. Some mothers, as the one mentioned above, may not fully understand that. Diane was forced to refer that patient elsewhere to receive medical care for such a procedure, since the Catholic hospital in which she works prohibits physicians from performing this service to mothers who choose to "induce" or terminate their pregnancies after a confirmed lethal prenatal diagnosis.

Diane describes the challenges posed in explaining these procedures by saying, "But trying to explain that to somebody, when they don't (pause) don't know. That's hard... This is not something everyone thinks about. This isn't something that you have a thought process to go through; and then you're slapped with it. It's so... it's when you try to soften the words by not saying 'abortion'. You try to soften the blow by saying 'induction', and, 'we can induce labor', 'we can get you delivered'. It softens all that to try to make it palatable. (Diane, Healthcare Provider)

She mentions the terminology used throughout and how it aims to "soften the blow". Hearing that you can be "induced" or "delivered" takes on a far different meaning for mothers than hearing that you can choose to have an "abortion". "Abortion" is a politically-charged word, associated with a great deal of stigma. So by using the other terminology mentioned (induction/delivery) mothers can feel free to make a decision that is right for them, without the bias involved by using the word "abortion", which may steer them away from making that choice, even if it is what they truly want to do and feel that it would be the best choice for their family. In the current study, none of the three mothers who chose termination ever stated that they had an "abortion" or "terminated" their pregnancy. Rather, they too used the euphemisms first used by their healthcare providers by saying they "induced early" (Jen, Mommy to Andrew; Nancy, Mommy to Eli) and even created their own by saying, "we chose to say goodbye early" (Tara, Mommy to Christopher). The use of such euphemisms, though understandably with the intent of "softening the blow" (Diane, Healthcare Provider), impacted the accessibility to support for one mother, Jen. During our conversations about this issue, I asked Jen if she sought support online through any kind of support groups or chat rooms and if so, what she types into the search engine. Jen responds, "I have googled some things online.

Really the only thing I type in is ‘induce early’ or ‘early induction,’ but I haven’t had much luck finding anything.” It is clearly evident to me, that because of her use of euphemisms, initiated by healthcare providers, Jen is unable to key in the appropriate search words that would provide her with some relevant results. Her use of the euphemisms of “induce early” or “early induction” do not turn up the same results as the terms “selective abortion,” “termination for fetal anomalies,” or “elective abortion.”

Admittedly, when I was faced with the choice, I was told that I could have an “induction”. I guess the difference was that I knew that it meant abortion, and I knew that the end result would be the untimely death of my daughter. As previously mentioned, I was opposed to even considering an early induction when I found out her diagnosis around 20 weeks along in my pregnancy. However, as my pregnancy progressed for the next 12 weeks, I became more and more uncomfortable due to the large increase in amniotic fluid that had built up in my uterus. It became more clear that my daughter’s abnormalities were as severe as suspected, crushing all inkling of hope that we had for her to live for a longer period of time, which in our minds, meant if even for a couple of months. We had hoped at least for that. But the reality of it was that it would likely be hours at best. At any rate, the idea of “inducing” became more appealing to me and had crossed my mind. I still wanted to wait as long as I could bear it. When I was 32 weeks along, barely able to walk up a flight of stairs, and unable to comfortably sit on my couch, Chloe made her arrival after I went into labor naturally. The choice was made for me. However, I did not realize until months after her birth that if I had chosen to induce, I would have been sent to another hospital in the area, despite the fact that I had been receiving all of my prenatal care through the Perinatal Hospice program and consistently seeing a core group of medical providers.

Diane describes a story involving a mother who had already chosen to terminate the pregnancy after receiving confirmation of a lethal prenatal diagnosis at 18 weeks gestation. The conversation, however, revolved around the type of procedure that this mother would elect, yet another decision to make in such a complex scenario. Diane explains,

It wasn't an issue of that [whether or not to terminate], but wanted to go ahead and have a delivery, but was going to do it a little earlier. I think she was 18 weeks. So considered not viable, it would be an abortion, but planning a suction D & C [dilation and curettage]; But wanted memorabilia. Wanted to have footprints and ...so not comprehending again, that when you're talking about that, then you're talking body parts, you're not talking [about the] delivery a fetus that's intact and, so explaining...trying to explain that to somebody without hurting their feelings...[begins to cry]. (Diane, Healthcare Provider)

In this situation, the mother wanted to have mementos of her child. She wanted footprints, handprints, all of those things to remember her baby by. She failed to realize that the procedure that she initially elected would not make this possible. The baby would not be delivered whole, as an induction of labor would allow. Diane was placed in a role in which she had to explain this to the mother. She had to tell her what the initially elected procedure involved and how it would not be possible to have memorabilia if that is what she chose. The mother's reaction to Diane's explanation was "unbelief". Diane was emotional during her telling of this story. It was apparent that this component of her role is very challenging, understandably so. These mothers love their babies. The mother that she mentioned in the example above wanted mementos of her child. When she found out that this would not be

possible given her decision for procedure election, Diane mentions that her reaction was “unbelief”.

Stigma

Termination of a pregnancy undoubtedly brings along a degree of stigma for those who have chosen such an option. Under the law, termination of a pregnancy, no matter the circumstances, is considered an abortion. As described previously, medical professionals do not ask women faced with a lethal prenatal diagnosis for their unborn child if they would like to have an “abortion”. They use other words to “soften the blow” as our healthcare provider informant described. Words like “induce” or “deliver”; words that de-stigmatize the act of abortion. After all, these mothers, who had plans and dreams for their wanted child, would not willingly choose to have an abortion. But this is the situation these mothers find themselves in. They are in a state of making decisions they never thought they would have to make, while dealing with the stigma associated with termination, even if they feel it would be the best decision for themselves and their babies.

Jen, who induced at 21 weeks along, openly shared that she often feels “compelled to explain myself to others” when talking about her and her husband’s decision to induce early with their son, Andrew. After further probing, she agrees that it is partly to do with the stigma that surrounds the decision she made, even though she “know(s) it was not an abortion”, despite how the law defines it and how society may view it. Later in our conversation, Jen describes an encounter with the doctor who delivered their son. After his birth, the medical staff took him from the room to clean him up before handing him to her, per her request. After approximately 20 minutes had passed, the doctor returns and says, “I’m very sorry to tell you this, but your son is still alive.” Jen immediately asks that he be brought in so that she and her

husband could hold him and spend what little time they had left with him. The doctor's statement seemingly assumed that Jen wanted her son to be dead, perhaps because she elected to terminate the pregnancy. This could not have been further from the truth. No mother who so desperately longs for a healthy child would desire to have to make that decision. This was true for Jen. She wanted Andrew to live more than anything. He lived for about 25 minutes longer, in his parents' arms. Though cut short, Jen still counts this time as a blessing.

My initial interaction with Tara, Mommy to Christopher, consisted of me approaching her at a coffee shop. I saw that she was working on a devotional that was eerily familiar, entitled *Grieving the Child I Never Knew*. Before I could realize what I was doing, I found myself standing right at her table, looking her in the eye. The only words I could utter, was something to the effect of "I'm sorry, but did you have a child that died? I have that same devotional." Immediately, she knew that I had "been there" and we began to talk more. That is when I learned that she "said goodbye early" to Christopher, which was her way of saying that she had chosen to terminate the pregnancy after finding out that her son was diagnosed with Trisomy 18, a chromosomal abnormality with a 100% lethal prognosis. In my naivete, I asked her if she had participated in the Perinatal Hospice program, not knowing at the time that it was specifically for mothers who chose expectant management. After all, it was evident that she wanted her little boy. Tara's response to my inquiry was that she "had [participated] to a degree, but not fully because we decided to induce the pregnancy early."

My personal reaction to this encounter, recorded in a methodological log later that day, gives insight to this encounter:

I could see the love in her eyes as she spoke about him. She was eager to tell me, a complete stranger, all about his condition. She wanted to tell her story. I was willing

to give a listening ear and I learned far more about this phenomenon than I thought could be possible in our short conversation. (Self, Mommy to Chloe)

This was the beginning of when I began to see that there was so much more to these mothers' experiences than I had initially thought, even as a mother who had "been there". I had began to broaden the scope of this study to include all mothers, despite choice for pregnancy management, and began to reconsider my own view toward mothers who chose to terminate when faced with a lethal prenatal diagnosis. I think this was the first step toward breaking down the stigma associated with such a choice in a very small way. In doing so, it is my hope that these women's stories reach countless others, further reducing stigma and providing insight into these women's lives and the brief, and wanted, lives of their children to whom they "said goodbye early".

Shared Sub-Themes/Experiences, Despite Choice for Pregnancy Management

The following three sub-themes emerged as shared experiences of all mothers, despite the choice they made for pregnancy management, upon confirmation of a lethal prenatal diagnosis.

Significance of Mementos

All mothers who participated in this study had mementos of their child. The mementos included, but were not limited to, items such as pictures, stuffed animals, statues/figurines, hand/foot prints and molds, funeral or memorial service programs, scrapbooks, flowers, cards, etc. All but one of the mothers who I interviewed, had brought along some sort of memento or showed me a memento in our initial contact. Leah, mother of Neomyiah, brought an entire scrapbook that she had made, detailing his life during her pregnancy with him, at his birth, and since his death. She seemed very proud to share this scrapbook with me. Jen brought along a

copy of Andrew's Celebration of Life service folder to share, and I had seen many of Elizabeth's mementos of Noah because of the closeness of our friendship and the role I played throughout her pregnancy with Noah.

Nancy and I initially met in her home, and I noticed a beautifully framed picture and poem, hung on the wall. Its title, "Ode to Eli", held a great deal of personal significance in their family and has a beautiful story behind it. Nancy describes that as she was growing up, she had a knack for poetry and was constantly writing "odes". This became an inside family joke over the years, which her husband found out early on in their dating relationship. In his proposal to her, he read an "ode" that he had written to ask her hand in marriage, to which she agreed. Then, when Eli was diagnosed with anencephaly, the two of them together wrote and "Ode to Eli". They had the poem written by a calligraphist and framed with a sketched drawing of a man resembling Jesus holding a smiling, beautiful baby, and the memento is displayed on their family room wall.

Though all mothers talked about the importance of these mementos of their children, they seemingly varied based on the choice for pregnancy management. All mothers who chose expectant management upon confirmation of a lethal prenatal diagnosis subsequently took part in a Perinatal Hospice program, operated out of a Catholic hospital in the area. As previously mentioned, Perinatal Hospice aims to help parents prepare for the anticipated death of their unborn child as well as support them through the birth and loss. Thus, mothers who participated in Perinatal Hospice worked with a bereavement coordinator who arranged, during pregnancy, for mementos to be created at the time of the birth. The standard included professional perinatal bereavement photography, complete with a compact disc of all professional quality photographs, as well as at least one framed print. In addition, mothers

were provided with hand and foot prints and molds, a personalized beaded bracelet for their child, spelling out his or her name, locks of hair, numerous digital pictures taken by the nursing staff and burned to a compact disc, a special baby book designed specifically for babies who receive a lethal prenatal diagnosis, several books and a devotional, among other things. As a participant in this program myself, I have to admit that the extensive thought and planning that went into creating such mementos was remarkable, and quite honestly, far too much for a grieving mother to attempt to tackle herself.

Mothers who chose to termination after receiving a confirmed lethal prenatal diagnosis were referred to other hospitals in the community, as the Catholic hospital which houses the Perinatal Hospice program would not conduct such a procedure prior to 38 weeks gestation, unless the mothers life were at risk. An elective termination, even for a lethal prenatal diagnosis is considered an abortion by law. Mothers who elected termination seemingly had fewer mementos, at least those of which were created at the time of the birth in the hospital or by hospital staff (hand and/or foot molds, prints, photographs, etc.). It can be assumed that this is because they did not have the assistance of medical staff helping plan for and creating mementos. Also, they did not have as much time as mothers who chose expectant management between the time of the diagnosis and the time of the birth. The hospitals they were referred to give birth at did not have the same bereavement coordinator who worked so diligently to create mementos for the mothers who delivered at the Catholic hospital, due to their participation in the Perinatal Hospice program.

Jen describes a story to me about the significance of mementos. She says:

I am so thankful that I took my digital camera with me to the hospital. When I was packing my stuff for the hospital, my mom questioned whether I really wanted to take

it or not. I am glad I did because my brother was able to take pictures of us with Andrew. (Jen, Mommy to Andrew)

I asked Jen if there was a bereavement coordinator present or any other hospital staff that arranged for any other mementos. She said that a nurse took pictures with a disposable camera, which held about 26 pictures. She noted that there were a few exposures left on the camera and the nurse used them to take close up pictures of Andrew's "perfect little hands and feet". The day after Jen was discharged from the hospital, she took the camera into a local drug store to be developed. Upon her return to the store, with her mother, the clerk informed her that while her camera was in the machine, the machine broke down and ruined the film on the camera, making it impossible to retrieve any of the photos. Jen describes her reaction by saying,

I know he had to think I was crazy. I just lost it. I was on the floor wailing. My mom had to pick me up and practically carry me out of the store. I was devastated. But when that's all you have...those pictures of his perfect little hands and feet...it's like you want every single thing you can get because you don't have anything else. (Jen, Mommy to Andrew)

Spirituality

All mothers in the current study considered themselves Christian. As previously mentioned, I came into contact with these mothers through snowball sampling and my connection to the Perinatal Hospice program, of which I was a former patient. Of the five other mothers who participated in this study, two of the mothers contacted me after receiving the Participant Recruitment Letter (Appendix B). The other mothers came to be participants in this study via a snowball effect. I introduced myself to Tara after I recognized her devotional

from across the coffee shop. Jen contacted me as a person of support, after hearing about my experience through a mutual friend. Elizabeth and I attend the same Christian church, which is how I came to know of her experience and later led to her participation in this study. It is important to note how these sampling techniques impacted the participant demographics when it came to the aspect of spirituality. Interestingly, however, there were no Catholic participants, despite the Perinatal Hospice program being operated out of a Catholic hospital. One mother, Jen, stated that she had “left the Catholic Church” about a year prior to her son’s prenatal diagnosis. I was Catholic during the diagnosis, birth, and death of my daughter, Chloe, but left the Church two months after her death. Both Jen and I now attend non-denominational Christian churches.

Each of the mothers in this study, regardless of choice made for pregnancy management, cited spirituality as important to them throughout their experience of receiving a lethal prenatal diagnosis, decision-making for pregnancy management, and the subsequent loss of their children. Five of the mothers consulted with their pastor during the decision-making process when faced with the options of expectant management or termination, while all mothers sought pastoral support after their decision for pregnancy management was made. This included officiating funeral or celebration of life services, counseling, and organized prayer.

Dated for February 23, 2006, just one week after the initial ultrasound that indicated that there was a problem, I wrote the following in my personal journal:

We knew that you would not be with us long, but we also knew that we loved you and it was not up to us to decide when you would go. I remember saying a prayer, as daddy and I waited in the waiting area to be called in for our consultation. I told God that I

knew He had a plan for us, and that we were handing the situation over to Him. He would do what was right for us and for our family, even if it was difficult for us to accept and to understand. We handed the situation over to God and knew that there was a plan for you. (Self, mommy to Chloe)

It was evident in this entry, very early on in my pregnancy with Chloe that I relied on my faith to get me through. It was my source of comfort and the only thing I could trust and it helps me to cope now. Elizabeth, Mommy to Noah, says the following to me when thinking about Noah on the 6-month anniversary of his birth:

I'm sure you remember this moment in the year after Chloe. Thinking about what he'd [Noah] be like and what we'd be doing with him. Surprisingly I'm okay with it though. It must be the Holy Spirit working in me, I've noticed it a lot lately. (Elizabeth, Mommy to Noah)

She attributes her being “okay with it” to the Holy Spirit working in her, clearly giving the credit to her faith.

Diane, healthcare provider informant, talked about the significance of spirituality and its influence in patient decision-making when faced with a lethal prenatal diagnosis by saying, When we have someone making the decision, 9 times out of 10, they're very rooted in their religion and it is because of their religion that they're making those decisions. I would say probably $\frac{3}{4}$ are Catholic and various assortments of other religions, but majority have been Catholic. (Diane, Healthcare Provider)

Several of the mothers felt that, when looking back, God had prepared them for the experience they had with the prenatal diagnosis and loss of their child. The mothers talked about how they could see, in retrospect, certain circumstances and or people who came into

their lives that helped them to cope with the experience once they encountered it. Jen, bereaved mother of Andrew, decided to induce at 21 weeks gestation, shortly after receiving confirmation that her unborn son had not developed any kidneys. Due to this fact, there was no amniotic fluid present in the womb, which is necessary for lung development. Thus, she and her husband were told that their child would die shortly after birth, most likely by gasping for air. Just six months prior, Jen experienced the death of her mother-in-law, who died from a respiratory problem, gasping for air. Having had this experience, they knew that they could not endure seeing their son, Andrew, die from the same fate. Thus, they decided they would induce early and spare him this suffering, after prayer and consultation with the pastor of their non-denominational Christian church. Reflecting on the overall experience, Jen says, “I am so thankful that we had a church family when this all happened.”

Since Andrew’s birth and death, Jen has found a number of ways to make meaning of his brief life. She has relied heavily on her faith in Jesus Christ, and sees her conversion from her Catholic upbringing not even a year prior to Andrew’s birth, as a blessing that prepared her to handle this situation. A significant way in which Jen has used her experience to be of comfort to others is through a ministry, Mommies with Hope, which is a biblically-based support group for mothers who have experienced the death of a child. This group was formed after my initial interview with Jen, just a month after Andrew’s birth and death. The two of us, since, have become good friends and formed the group together, as a way of honoring our children and living out God’s purpose for our experiences.

Another example from the stories of these mothers, is that of Elizabeth. Elizabeth also relied heavily on her church family throughout her pregnancy, birth, and death of her son, Noah, who lived for 2 ½ days after being born full-term and anencephalic (absence of the brain

and skull). Elizabeth is a self-proclaimed born again Christian, who came to the faith in March of 2006. It was almost exactly a year later that she and her husband received confirmation that their son's brain was not developing, a condition referred to as anencephaly and considered 100% fatal. Upon the news, they immediately contacted their pastor for counsel, as the options of expectant management and termination had been presented to them. Interestingly, there was a couple in their small church, which averaged between 75-100 people in attendance on a given Sunday service, that had "been there" in a similar situation with their unborn daughter the year before. That couple happened to be my husband and me. We met with Elizabeth and her husband just days after they received the diagnosis to share our story of Chloe and to be of comfort, support, and encouragement to them. Elizabeth has said many times that she believes that God orchestrated these circumstances to help get them through. She was thankful to have a personal relationship with Jesus Christ prior to the diagnosis of Noah, and believes that God brought us to the church to be able to come alongside them. As a part of my own story, I too believe that God prepared me to minister to others and provide comfort and encouragement because of Chloe's life and death. This is a part of her legacy.

Honor and Legacy of the Child

In a conversation with Nancy, bereaved mother and informant to this study, regarding her willingness to share her story for this study, she told me that she is "happy to be included because it gives me a chance to tell my story and honor Eli". This attitude was consistent among all mothers who participated as informants to this study, as they eagerly shared their stories of their children. After all, not everyone is comfortable with talking about a child who has died. It can be a difficult topic to discuss, even with close family and friends, because they may feel awkward about bringing the topic up and sometimes mistakenly think that things are

better left unsaid. In fact, all mothers agreed that talking about the child is a way for them to remember and honor them and to acknowledge that they lived, if only briefly.

Aside from the simple act of talking about their babies, all mothers had tangible artifacts that they had created in honor of their child, including scrapbooks, photo albums, framed pictures, or other mementos that they kept on display in their homes for visitors to see. One mother, Elizabeth, Mommy to Noah, created a birth/death announcement that she sent out to close friends and family. The announcement included a photo of Noah, along with a bible verse and the dates of his birth and death. This served as a keepsake for family and friends, while at the same time acknowledged Noah's life, though brief.

Mothers reported doing special activities or rituals for their babies, particularly on special days such as anniversary, birth, or death dates and holidays. For what would have been Chloe's first birthday, we held an actual birthday party in her honor. We recruited the assistance of our son and centered the entire party around a children's theme, complete with a piñata and water games. We welcomed over 50 guests to the butterfly-themed barbecue and concluded the event with a balloon release, all in remembrance of Chloe's birth and death. Other mothers talked about how they took flowers or a special stuffed animal to their child's grave for holidays.

As I have mentioned in previous sections of this study, Jen and I decided to form a support group after our first time meeting. We both felt led to do so, and by combining each of our resources, we were able to develop a support group, Mommies with Hope, and have each seen this as a legacy to our children, Andrew and Chloe.

In journaling about my experience with Chloe, I wrote:

I see it as a great opportunity to teach others something. It amazes me how someone

so small and who lived for a short amount of time is able to teach others. Chloe has taught me and her father a lot about life (and death), but more importantly she has taught us about love. This love that we have for her inspires and motivates us to do all that we can to help others in so many ways. (Self, Mommy to Chloe)

All mothers are keeping the legacy of their child alive and honoring them in a very special way by telling their story to be included in this research. They are providing insight to a complex phenomenon that impacts far too many women. What they have shared, because of their children's lives, can be used to further develop programming and support for others, which is quite remarkable.

Making Meaning: Going Beyond "It's not fair!"

Each of these mothers tries to make sense of it all; they attempt to understand the experience of losing a child to a lethal prenatal diagnosis. They cry out, "It's not fair!" None of them truly understands it all the time. They run through it in their minds time and again, questioning how something like this could happen. After all, they were young, they were healthy, and some of them have had had healthy children prior. What did they do wrong? It could have been that glass of wine they had before I knew I was pregnant, or maybe it was the cleaning solutions they used early on in their pregnancy? These questions seem absurd to an outsider looking in, but are real concerns mothers possess when something has gone wrong with their unborn child.

They question God. How could He, supposedly all-powerful and all loving, allow such suffering? After all, God could have stopped this, and when they prayed for a miracle for Him to save their babies, He did not answer. They see other women in their midst, deemed unfit to be mothers, by their own judgment. After all, they had drunk alcohol or done drugs throughout

their entire pregnancies and their babies turned out fine, and if not fine, at least they were alive. Now, they cannot even stay sober enough to care for them. Why are they allowed to have healthy children? These thoughts and questions permeate these mothers' minds as they struggle to make sense of such a senseless loss. Sure these thoughts seem judgmental and disapproving, and they are. Mothers who experience the loss of a wanted child cannot help but notice the unfairness in the questions posed above. These mothers had hopes and dreams for their children. They planned for them and had plans for their future and their futures as a families. All of this was shattered that day they found out the news.

Somewhere along this journey, they find some of the answers to these questions and the anger that once engulfed their thoughts begins to diminish. They meet someone who has "been there". They see the legacy of their child living on in the hearts of those who surround them, though he or she was physically here for only a glimpse in time. They see themselves change because of the immense love they have for their child. They seek to tell others their story of their child and they remember and honor them in ways they never knew possible. Time goes by and they begin to see the treasures left behind by their child; whether it is in their newfound strength and ability to be there for others experiencing something similar, or it is in the way this tiny baby's siblings, still only children themselves, exhibit an understanding of life and death that they wish the many adults who surround them could possess. They embrace God and cling to Him to provide comfort, even in the midst of sorrow and anger, and they seek His plan and purpose for their babies' brief lives, in an effort to find meaning. They touch the lives of others, all because these babies existed. This becomes a part of their new selves, forever changed by the precious lives of those who grew inside of them, and whom they held in their arms, only briefly.

Looking back to a personal journal entry from April 22, 2006, just weeks before the birth and death of my daughter, Chloe, it is clear that I was beginning to make meaning from the circumstances I found myself in. I waited in anticipation for what was to come, though I did not seem to understand or grasp why it was happening, but expressed to my daughter the following thought:

Daddy or I do not understand it. But what we do know is that you [Chloe] have really taught us all [our family] a valuable lesson. You've taught us to love and to give and to hope. Most important of all, you have taught us how precious and beautiful life is, in all of its capacities. (Self, Mommy to Chloe)

Discussion

Evidenced by the findings from the current study, there is a great deal to be learned from these mothers' experiences with perinatal loss upon confirmation of a lethal prenatal diagnosis. The emergent themes and sub-themes identified resonate with the findings in the literature in the field of perinatal loss and prenatal diagnosis, as it exists. In the current study, mothers were given two options once a diagnosis for their unborn child was made. These options included 1) expectant management, or 2) termination, also referred to as selective abortion or selective termination in the literature. This is consistent with other findings in the literature on the topic of positive prenatal diagnosis (Rapp, 1999; Calhoun, et al., 1997; Hoeldtke & Calhoun, 2001).

For all mothers, independent of choice for pregnancy management, the following themes were identified: 1) Hopes and Dreams, 2) Diagnosis Denial, 3) Making Meaning, 4) Spirituality, 5) Mementos, and 6) Legacy/Honor of Child's Life. Regarding Hopes and Dreams, mothers in the current study reported feeling like the plans they had made for their

family were shattered with the confirmation of a lethal prenatal diagnosis. This is consistent with the work of Znoj & Keller (2002), who assert that the death of a child marks an end to the hopes and goals that parents have made for their children. Arnold & Gemma (1994) recognize the death of an infant as a loss of the future or what might have been.

The themes of Making Meaning, Spirituality, and Legacy/Honor of Child's Life tend to intertwine with one another. Many of the stories that mothers shared overlapped into each of these themes. For example, all mothers' spirituality tended to impact how they chose to memorialize and honor their child as well as make meaning or find purpose for their lives through their experience with prenatal diagnosis and perinatal loss. In a study conducted by Redlinger-Grosse and colleagues (2002), parents faced with a prenatal diagnosis of holoprosencephaly for their unborn child discussed decision-making in terms of their belief in God or religious beliefs. Many of the women in this study felt that it was "God's plan" or that it "happened for a reason" (Redlinger-Grosse et al., 2002, p. 372). These notions are similar to mothers' stories in the current study, with regard to finding meaning in their child's life, clinging to their spirituality and faith communities for support, and possessing the ability to see a purpose in the experience as a whole.

Sub-themes specific to mothers who chose expectant management included:

1) Continued Denial/Hope, 2) Making Memories in Life, Post-diagnosis, Pre-death, and 3) Perinatal Hospice. Much of the existing literature related to expectant management tends to focus on decision-making and/or grief experiences. With the development of Perinatal Hospice in recent years and the literature available on this type of programming, one can see the positive outcomes from such programming both in the literature (Hoeldtke & Calhoun, 2001; Calhoun et al., 1997, Romesberg, 2004; Sumner et al., 2006) and those of the mothers in

the current study who participated in Perinatal Hospice. With regard to the themes of Continued Denial/Hope and Making Memories in Life, Post-diagnosis, Pre-death, the current study offers insight to these aspects of mothers' experiences who chose expectant management when faced with a lethal prenatal diagnosis.

Sub-themes specific to mothers who chose termination included: 1) Termination Euphemisms/Confusion, and 2) Stigma. As previously cited, Keefe-Cooperman (2005) asserts that women who choose to terminate a pregnancy due to fetal abnormality experience guilt for this choice, which permeates their grief. However, mothers in the current study did not report any such feelings, but rather indicated that they felt they made the right choice for their families, after fervent prayer and consultation with their pastors, medical personnel, family, and friends. All mothers seemed to report a sense of guilt over their child's diagnosis, regardless of the choice they made for pregnancy management. This guilt, however, was linked more directly to the actions they may or may not have committed to "cause" the abnormality being detected, despite doctors' reassurance that all of the diagnoses could not have been caused by anything the mother did or did not do.

With regard to the theme of Termination Euphemisms/Confusion, it is interesting to take note of the fact that the literature describes the phenomenon of termination by using words such as "termination for fetal anomalies", "selective termination", "genetic termination", "elective termination of pregnancies" or "selective abortion" (Keefe-Cooperman, 2005; Zlotogora, 2002; Evans et al., 1996; Korenromp et al., 2005; Roberts, Stough, & Parrish, 2002). Yet, mothers in the current study report that they were faced with the options of "continue the pregnancy" or "induce" or "deliver early". None were told that they could "terminate" or have an "abortion". As discussed in the findings, these euphemisms were used to "soften the blow"

and make the options seem acceptable. This difference in language, however, can cause confusion. One mother in the current study, Jen, mentioned that she sought out support online by use key search words such as, “induce early”, as she did not realize the technical terminology in the field used to describe her experience. It would be worthwhile to further explore the genetic consultations women receive with doctors and/or genetic counselors when a fetal abnormality/diagnosis is confirmed, which would provide insight into the consultation experience and shed light on how to best convey the options in a factual, yet caring manner.

An important point of discussion, which will be addressed in further detail in Chapter 5 of this paper, is the lack of support services available to mothers who chose to terminate their pregnancies. Based on findings of professional bereavement support services offered to mothers who chose termination, it is apparent that these mothers were not offered or provided with the same standards of care as mothers who took part in the Perinatal Hospice program as a result of choosing expectant management.

Limitations of the Study

While findings from the current study offered some valuable insights and implications, which will be further discussed in the Conclusions section of this paper, it is necessary to address the limitations of the study. An important limitation to note is the sample size and demographic make up. All participants in this study were Caucasian and married. In addition, all mothers reported being Christians, which assumingly contributed to the emergent theme of Spirituality. It would be important for future research on this phenomenon to include a broader representation of mothers to explore the range of experiences from their varying perspectives.

Another limitation is the number of observations and interviews conducted, 12 and 10, respectively. Though several themes emerged from the data, I believe that prolonged

engagement with the participants would have revealed further support for these themes. Each of the themes identified in the current study could be further explored individually, offering additional insight and understanding on the ideas cited in this study.

Finally, further exploration of this phenomenon could include experiences of fathers and/or siblings, thereby obtaining valuable information about how the experience of lethal prenatal diagnosis and perinatal loss impacts the family unit as a whole, or how family dynamics impact coping with the experience. In the current study, though all mothers were married and some had living at the time of this research, I did not focus any interview questions on the couple and/or parent/child relationship, nor did I include any additional family members as participants.

CHAPTER 5. CONCLUSIONS

Summary

Mothers and the healthcare provider who told their stories in this research have exposed some interesting findings, highlighted above, with regard to the phenomenon of positive prenatal diagnosis and perinatal loss. The initial purpose of this research, to understand the experiences, decision-making process, and accompanying grief of mothers who have experienced a confirmed lethal prenatal diagnosis for their child and have also endured the subsequent death of their child, has been achieved by sharing of these stories. This study provides a better understanding of this phenomenon and emphasizes the significance of the loss experienced.

Interestingly, these mothers' stories have offered information that goes far beyond the initial scope of this study. Their accounts have offered insight into the disparity of support services available to women, based upon their choice for pregnancy management when faced with a lethal prenatal diagnosis. Feminist approaches view social change as important (Lichtman, 2006). The disparity of services offered is just one indication of where change must take place to adequately and equitably meet the support needs of all mothers who experience lethal prenatal diagnosis and perinatal loss. Mothers in this study possessed the freedom to verbalize their stories, speak openly about their wanted child, and offer up their own stories to inform professionals and healthcare providers about this phenomenon.

I believe that my personal change and growth throughout the course of this study has helped me to acknowledge this unexpected finding. This transformation in my own views only occurred because of the participants who shared their stories, in particular, mothers who chose to terminate their pregnancies when faced with a lethal prenatal diagnosis. Their willingness to

share their experience of loss, openly talk about the choices they made, and most importantly, the love they had for their babies, impacted me in ways I never anticipated. I am now able to see the gap in bereavement support services offered to mothers based on choice. As previously mentioned, since the Perinatal Hospice Program is operated out of a Catholic hospital, and its aim is to support families who have chosen to continue pregnancy in the face of a lethal prenatal diagnosis. Women who choose termination do not have access to the same kind of bereavement support during the diagnosis experience or after the pregnancy termination. In the meantime, all mothers, despite choice, are grieving the loss of a wanted and loved child. Before hearing these mothers' stories, particularly those who have chosen termination, I embarrassingly admit that I very likely may not have given the issue a second thought, nor would I have had any desire to advocate for their needs. In my eyes, I did not realize the need existed. Yet, now I see that they are grieving the loss of their wanted child, just like I and any other mother who chose expectant management. This transformation supports feminist researcher, Rayna Rapp's experience with participant observation within the phenomenon of positive prenatal diagnosis. She found that after delving into the experiences of women, her initial research questions and ideas broadened to include the intricacies of the issues as the participants perceived them (Rapp, 1999). Similarly, this describes my personal conversion with regard to the study. This study brings about several significant implications for policy, practice, and future research, discussed below.

Implications

Policy. In my exploration of the phenomena of prenatal diagnosis and perinatal loss, I have identified a policy implication with regard to the definition of abortion. Based on the findings from this study, particularly those emergent sub-themes specific to mothers who chose

termination, it is apparent that the legal definition of abortion possesses a great deal of stigma. Mothers who selectively choose to “say goodbye early”, “induce”, or “get delivered”, prior to 38 weeks gestation are, by law, choosing to abort. These euphemisms used by perinatologists, genetic counselors, or any other medical providers that mothers come into contact with upon confirmation of a lethal prenatal diagnosis, tends to “soften the blow” (Diane, Healthcare Provider) in an effort to make the option seem more acceptable.

Mothers themselves use these euphemisms. I never came into contact with a mother who openly said, “we chose to abort”. After all, we tend to associate abortion with unwanted, and in each of these scenarios, the mothers desperately wanted their children. They wanted them to live. Thus, mothers who chose termination do not see themselves as “aborters” as society categorizes them. They made the choice that was right for their family. In their eyes, it was not a matter of choice, but of timing. It is important to address this issue as a policy implication, because the choice mothers elected dictated the hospital they could utilize and subsequently impacted the extent of bereavement support services offered and provided, which leads to implications for practice, explained below.

Practice. From the findings of the current study, it is apparent that mothers experience confusion over the euphemisms used by medical professionals to describe the option of termination. While it is understood that such language is used to “soften the blow”, it would be important to provide clear explanations of options to mothers facing a lethal prenatal diagnosis for their unborn children, so not to increase confusion.

Once a choice has been made, regardless of whether it is termination or expectant management, professionals ought to have a standard of bereavement support care in place to offer mothers. Currently, Perinatal Hospice programming continues to emerge across the

United States, but is only offered to mothers who choose expectant management. However, these same hospice principles could be expanded to reach mothers who choose termination, as they too grieve their wanted child, and have a similar birth/loss experience as mothers who carry to term. The main difference is the timing at which they give birth. This is an issue I have become intimately familiar with as I have explored this phenomenon through this study and have grown to know and become friends with mothers who chose termination. The mother with whom I co-lead the Mommies with Hope support group has taught me a great deal about her personal experience with choosing to “induce early” (Jen, Mommy to Andrew). As a result, I foresee great possibilities for this group to serve as a source of support for mothers who have chosen to terminate their pregnancy when faced with a lethal prenatal diagnosis.

Finally, professionals should educate doctors and medical professionals on the phenomenon of prenatal diagnosis resulting in perinatal loss, as it is only expected to grow in prevalence as medical technology continues to advance and prenatal testing becomes more routinized. More specifically, education should be provided on the context surrounding a woman’s choice for termination upon confirmation of a lethal prenatal diagnosis. It should not be assumed that because a mother chooses termination that she did not want her child or does not grieve that loss.

Future Research. With regard to future research on the topic of prenatal diagnosis and perinatal loss, there are many areas needing further exploration. It is imperative to explore the existing bereavement support services available to mothers who choose termination upon confirmation of a lethal prenatal diagnosis. By understanding the supports available, professionals in the field would be better able to design, implement, or expand upon services for this population of mothers.

Evident from the findings in this study, several themes and sub-themes emerged. It would be interesting to delve into the spirituality aspects surrounding prenatal diagnosis and perinatal loss, specifically with regard to the option of termination. Most religious groups oppose abortion, yet many women consulted with pastors for spiritual guidance in their decision-making process, with varying responses. It is clear that women in the current study relied heavily on their faith community and faith as a way of coping. Examining the phenomenon of prenatal diagnosis and perinatal loss specifically through a spiritual lens would provide insight for pastors, priests, and other clergy in their counsel with these families, as well as inform hospital pastoral care departments on best practice.

Other areas needing further research include studying fathers' grief experiences in the face of prenatal diagnosis and perinatal loss. Due to gender differences, it can be assumed that obvious differences would emerge from fathers' experiences when compared to mothers. Thus, a better understanding of fathers' experiences would assist in bereavement support program development specific to fathers or for couples together. In addition, couples' experiences as a whole could be explored, as well as siblings' experiences. Each of these family members' relation to the baby will offer insight to various dynamics in family relationships, thereby providing information that will assist in supporting families through this experience.

Concluding Self-Reflection

Through my endeavors in completing this research, I have begun and continue to make meaning of Chloe's brief life and death. I have seen countless ways in which she has impacted others and has changed who I am. The list of treasures that Chloe has left behind is endless, ranging from the spiritual growth and transformation in me and my husband's lives to the ministry formed with Jen, a mother who terminated her pregnancy when faced with a lethal

prenatal diagnosis, resulting in the development of a support group for mothers who have experienced the death of a child, Mommies with Hope.

This study itself is a testament of the lives represented and serves as a legacy to each of these precious babies. It does not start and end here. These children will continue to impact the world around them when their stories are told. Each time we say the name of the child who was here, and lived only briefly, we are honoring them. They are remembered.

APPENDIX A. INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

IOWA STATE UNIVERSITY
 OF SCIENCE AND TECHNOLOGY

DATE: 9 January 2007

TO: Teske Drake
c/o M. Brotherson, 51A LeBaron

CC: Dr. Mary Jane Brotherson
51A LeBaron

FROM: Jan Canny, IRB Administrator
Office of Research Assurances

SUBJECT: IRB ID 06-612

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FAX 515 294-4267

Approval Date: 8 January 2007
Date for Continuing Review: 7 January 2008

The Chair of the Institutional Review Board of Iowa State University has reviewed and approved the protocol entitled: "'It's Not Fair!' Mother's Experience with Perinatal Loss after a Confirmed Lethal Prenatal Diagnosis." The protocol has been assigned the following ID Number: 06-612. Please refer to this number in all correspondence regarding the protocol.

Your study has been approved from 8 January 2007 to 7 January 2008. The **continuing review date** for this study is no later than **7 January 2008**. Federal regulations require continuing review of ongoing projects. Please submit the form with sufficient time (i.e. three to four weeks) for the IRB to review and approve continuation of the study, prior to the continuing review date.

Failure to complete and submit the continuing review form will result in expiration of IRB approval on the continuing review date and the file will be administratively closed. All research related activities involving the participants **must stop** on the continuing review date, until approval can be re-established, except when necessary to eliminate immediate hazard to research participants. As a courtesy to you, we will send a reminder of the approaching review prior to this date.

Please remember that any **changes in the protocol or consent form** may not be implemented without prior IRB review and approval, using the "Continuing Review and/or Modification" form. Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office of Research Assurances website or available by calling (515) 294-4566, www.compliance.iastate.edu.

You must promptly report any of the following to the IRB: (1) **all serious and/or unexpected adverse experiences** involving risks to subjects or others; and (2) **any other unanticipated problems involving risks** to subjects or others.

Upon completion of the project, please submit a Project Closure Form to the Office of Research Assurances, 1138 Pearson Hall, to officially close the project.

APPENDIX B. PARTICIPANT RECRUITMENT LETTER

Teske R. Drake
Iowa State University
Human Development and Family Studies

Hello, my name is Teske Drake. First and foremost, I would like to extend my sincerest condolences for the loss of your baby. A quote that I've found quite acknowledging that recognizes the significance of such a loss states: "*The loss of an adult is the loss of the past; the loss of a baby is the loss of the future*".

~ Arnold & Gemma

I am writing to request your participation in a qualitative study that I am conducting for my Master's thesis at Iowa State University. I am interested in studying the experiences of mothers who have experienced perinatal loss as a result of a confirmed prenatal diagnosis with the prognosis of early infant death. To explain my interest in this topic, I find it necessary to share some information about my personal experience with such loss and my motivation to understand it more fully.

I am the mother of two children, Gabriel who is 4 ½ years old, and Chloe, who was born on May 11, 2006 and subsequently passed away 45 minutes later that day. I was 32 weeks along in my pregnancy with Chloe when I gave birth, but had known since 20 weeks that she would likely not survive long after birth. She had been diagnosed with a rare chromosomal abnormality and severe brain condition (holoprosencephaly), detected by routine ultrasound. Having an educational background in family services and social work, I have always had the motivation to help others. I came to Iowa State University last year to work on my Masters degree in Human Development and Family Studies. Once faced with the situation I found myself in during my pregnancy, I became inspired to help other families who have endured or will endure the loss of a child. Therefore, I decided to do my thesis research on the topic of perinatal loss and to devote my career to research and program development in this area.

To gather a picture of what mothers, including myself, have experienced in their grief journey, I would like to interview you two to three times for approximately 60-90 minutes. Topics that I hope to cover include: your experience of finding out the diagnosis of your child and your decision-making process regarding management of your pregnancy as well as the grief experiences associated with the loss of your child. The interviews will be conversational in style, allowing for you to express your emotions freely to someone who has experienced perinatal loss under similar circumstances. As a mother who has lost a child, I recognize that all losses are unique in their own way. I can not assume to know "exactly how you feel", but can offer empathy and a sense of understanding, serving as a supportive person for you to talk to.

By conducting these interviews, it is my goal to gain a better understanding of the experiences of mothers who have experienced the loss of their baby after being faced with a

positive prenatal diagnosis of infant death. Ultimately, this information may be used to provide a basis and rationale for the improvement of existing programs and the development of new ones for families who have endured or expect to endure perinatal loss.

If you are interested in being a participant in this study or have any questions regarding the study, please feel free to contact me by phone (515)232-2789 or (319)404-0272 or email: tdrake@iastate.edu. Your participation is completely voluntary. Please note that this research is being conducted independent of Mercy Medical Center and has absolutely no bearing on the support services that you may receive related to your experience with perinatal loss. I am conducting this research because of my own personal and academic experiences that have led me to this area of interest.

Sincerely Thinking of You as You Travel Your Grief Journey,

Teske R. Drake

APPENDIX C. SAMPLE INFORMED CONSENT DOCUMENT

INFORMED CONSENT DOCUMENT

Healthcare Provider

Title of Study: “It’s Not Fair!” Mothers’ Experiences With Perinatal Loss After a Confirmed Lethal Prenatal Diagnosis

Investigators: Teske Drake
Mary Jane Brotherson

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to understand the decision-making process and accompanying grief experiences of mothers who received confirmation of lethal prenatal diagnosis for their child. You are being invited to participate in this study because you are a healthcare provider for mothers facing a lethal prenatal diagnosis and can offer your perspective on mothers’ experiences.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last for two months and will involve two to three interviews, lasting approximately 60-90 minutes each, regarding your perspective of mothers’ experiences with receiving confirmation of a lethal prenatal diagnosis and pregnancy management decision-making. All interviews will be audio recorded and transcribed for data analysis. Recordings will be kept for five years and then erased. You may refrain from answering any interview questions that you do not feel comfortable with and can withdraw from the study at any time. Upon completion of all individual interviews, you will be invited to attend a focus group, involving all other informants, aiming to understand how bereavement support services can be improved upon, as well as to offer information for program development. Implications for policy may also be addressed.

RISKS

While participating in this study, you will not be exposed to any foreseeable risks.

BENEFITS

If you decide to participate in this study there may be no direct benefit to you. It is hoped that the information gained in this study will benefit society by providing a greater awareness of perinatal loss and the significance of such loss. Furthermore, the findings from this study will help professionals to understand the experiences of mothers who have endured anticipated perinatal loss, thereby establishing implications for bereavement support program improvement and development as well as further research in the area of perinatal loss.

COSTS AND COMPENSATION

You will not incur any costs from participating in this study. There will be no compensation for your participation in this study.

PARTICIPANT RIGHTS

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

CONFIDENTIALITY

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken. Participants will be assigned a pseudonym, which will be used on all documents and data. The principal investigator will have sole access to all records from this study, which will be kept in password protected computer files. All hard copies of documents will be stored in a locked filing cabinet. The audiotapes of the interviews will be kept on file for five years and will then be erased. If the results are published, your identity will remain confidential.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

- For further information about the study contact Teske Drake: (515)294-9578 or Mary Jane Brotherson: (515)294-3667.
- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, jcs1959@iastate.edu, or Diane Ament, Director, Office of Research Assurances (515) 294-3115, dament@iastate.edu.

PARTICIPANT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant's Name (printed) _____

(Participant's Signature)

(Date)

INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

(Signature of Person Obtaining
Informed Consent)

(Date)

INFORMED CONSENT DOCUMENT

Bereaved Mother

Title of Study: “It’s Not Fair!” Mothers’ Experiences with Perinatal Loss After a Confirmed Lethal Prenatal Diagnosis

Investigators: Teske Drake
Mary Jane Brotherson

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to understand the decision-making process and accompanying grief experiences of mothers who received confirmation of lethal prenatal diagnosis for their unborn child. You are being invited to participate in this study because you received a prenatal diagnosis of a fetal abnormality with the prognosis of early infant death and have experienced the loss of your child.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last for two months and will involve two to three interviews, lasting approximately 60-90 minutes each, regarding your experience with receiving your child’s diagnosis, the decision-making regarding pregnancy management, and your birth and loss experience and accompanying grief. All interviews will be audio recorded and transcribed for data analysis. Recordings will be kept for five years and then erased. You may refrain from answering any interview questions that you do not feel comfortable with and can withdraw from the study at any time. In addition, it is expected that you may or may not have other forms of casual contact with the researcher, and those interactions and conversations may be included in the data collection for this study as a form of participant observation. Upon completion of all interviews, you will then be asked to participate in a focus group discussion with the other participants in this study, aiming to gather information that will be instrumental in improving upon current bereavement support services as well as develop new programming.

RISKS

While participating in this study you may experience the following risks: Emotional Risk. Due to the sensitive nature of the topics that will be discussed throughout the interview process, you may be at an emotional risk.

BENEFITS

If you decide to participate in this study there may be no direct benefit to you, although talking about your child and your experience may prove to be therapeutic. It is hoped that the information gained in this study will benefit society by providing a greater awareness of perinatal loss and the significance of such loss. Furthermore, the findings from this study will help professionals to understand the experiences of mothers who have endured perinatal loss as a result of a lethal prenatal diagnosis, thereby establishing implications for bereavement support program improvement and development as well as further research.

COSTS AND COMPENSATION

You will not have any costs from participating in this study. You will not be compensated for your participation in this study.

PARTICIPANT RIGHTS

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled. Participating in this study may be terminated if I feel that you are at an emotional risk in which I am unable to adequately and effectively address your emotional needs. At this point, participation will be terminated and you will be referred to a trained mental health professional for assistance.

CONFIDENTIALITY

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken. Participants will be assigned a pseudonym, which will be used on all documents and data. The principal investigator will have sole access to all records from this study, which will be kept in password protected computer files. All hard copies of documents will be stored in a locked filing cabinet. The audiotapes of the interviews will be kept on file for five years and will then be erased. If the results are published, your identity will remain confidential.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

- For further information about the study contact Teske Drake: (515)294-9578 or Mary Jane Brotherson: (515)294-3667
- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, jcs1959@iastate.edu, or Diane Ament, Director, Office of Research Assurances (515) 294-3115, dament@iastate.edu.

PARTICIPANT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that

your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant's Name (printed) _____

(Participant's Signature)

(Date)

INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

(Signature of Person Obtaining
Informed Consent)

(Date)

APPENDIX E. INTERVIEW SUMMARY SHEET

Interview Summary Sheet
“It’s Not Fair!” Mothers’ Experiences with Perinatal Loss
After a Confirmed Lethal Prenatal Diagnosis

Interviewer: Teske Drake

Interview Date/Location: _____

Informant: _____

1. Briefly describe/reflect on the person involved.

2. What were the main impressions or issues that struck you in this contact?

3. Summarize the information/ideas you got (or did not get) on target research question:

Research Question	Information
What is the grief experience like for mothers who receive a confirmed lethal prenatal diagnosis?	
What is the decision-making process like for mothers faced with a lethal prenatal diagnosis for their unborn child?	

4. Describe anything else that struck you as salient, interesting, or important in this contact?

Are there any areas needing clarification/further exploration in subsequent interviews?

APPENDIX F. SAMPLE DATA ANALYSIS

Interview Summary Sheet
“It’s Not Fair!” Mothers’ Experiences with Perinatal Loss
After a Confirmed Lethal Prenatal Diagnosis

Interviewer: Teske Drake
 Interview Date/Location: February 7, 2007 – University
 Informant: Leah

1. Briefly describe/reflect on the person involved.
Kept her coat on (cold outside), talked openly, Christian
When I told “my story” she cried; showed a great deal of emotion by crying at times
2. What were the main impressions or issues that struck you in this contact?
Very strong Christian faith, very emotional, loved her son so much
3. Summarize the information/ideas you got (or did not get) on target research question:

Research Question	Information
What is the grief experience like for mothers who receive a confirmed lethal prenatal diagnosis?	Mentioned that the diagnosis was more difficult than the actual passing of her son; angry toward God; hopeful for a cure—sought out doctors/specialists for the diagnosis, got a second opinion; reported that she screamed when he died
What is the decision-making process like for mothers faced with a lethal prenatal diagnosis for their unborn child?	Would not consider an abortion—was told that she should by the doctor, but got a second opinion; faith/spirituality and religious beliefs seemed to play a role in this decision; was questioned by family members about her decision to continue, which made it difficult for her

4. Describe anything else that struck you as salient, interesting, or important in this contact?
Many issues were brought up/touched on—spirituality was a key issue; also talked about: abortion, seeking resources, how her grief differs from her husband’s; her living children’s reactions to the death of their brother (oldest daughter was angry at her for not trying to save him), she brought along a scrapbook and shared it with me which made me feel honored
- Are there any areas needing clarification/further exploration in subsequent interviews?
Decision making—was there even a question about it?? What dictated your decision?
Children—how did they find out/what did you tell them
Subsequent pregnancy—how was that impacted by the death of your son

Title of Study: “It’s not fair!” Mothers’ Experiences With Perinatal Loss After a Confirmed Lethal Prenatal Diagnosis

Interviewer: Teske Drake

Date: April 2, 2007

Informant: Tara

Interview Protocol: Bereaved Mother

- Tell me about your baby (use child’s name)

Christopher – diagnosed with Trisomy 18, induced at 22 weeks (“chose to say goodbye early”)

Numerous anomalies – fluid around brain, internal organs outside of his abdomen in a sac

- Can you tell me what it was like when you found out about his/her diagnosis?

Found out there was a problem by ultrasound, then did an amnio which confirmed it

Doctors told us our options (induce now or continue)

- What kinds of feelings did you have at that time?

“Devastating” Shocked. Heartbreaking. Wondered what we did wrong

- What was the decision-making process like for you (induce or continue)?

Knew there was no chance for survival – too severe

Struggled with telling family and Catholic friends (after they decided to induce)

Felt like inducing was the best decision for their family

“Chose to say goodbye early”

- What has the grief process been like for you? Supports? What/who has been most/least helpful?

Up and down with grief – some days better than others; realizing grief is different b/w husband and wife; faith community/church support is helpful, some family and friends say insensitive things, though well-intentioned

Coded Transcript Sample

Interviewer: So how often are you present or there when they (mothers) have the confirmation from their tests?

Diane: Never. That's usually done before. Because they want to make their decision on whether they're going to carry the pregnancy or not.

Interviewer: Okay.

Diane: At Mercy, we don't do inductions or abortions. We are not to be involved in that. There have been patients where someone told them about me, then they'd call. And then 9 times out of 10, religious beliefs are, determine their decision.

Interviewer: Can you tell me a story about or a time, if you can recall guiding someone through that decision-making process?

SPIRITUALITY--

Diane: Um, (sighs) one example was a gal that called me, uh, my number was given to her step-mother. They called me on the unit, it was a weekend, I wasn't here. Of course they wouldn't give my home phone so I called her back and we were on the phone for 2 ½ hours, going around with all the ifs ands or buts, uh, new what the ultrasound was in their doctor's office, knew what the ultrasound results were and wanted ..(inaudible). Waiting for, they had had the amnio, they didn't have results yet, but they were pretty confident what those test results would be just because it was so classic. Um, Catholic, didn't want to have an abortion, didn't want to carry the pregnancy...struggling with 'what do I do, what do I do, what do I do'? Um, couldn't understand, was told by the physician that they could induce the pregnancy at any time. Therefore, thinking they could come here. And I'm always the one saying we would like you to come here, but...

Interviewer: mmm hmmm

“SOFTEN THE BLOW”/TERMINATION EUPHEMISMS--

Diane: That is considered an abortion by state law. And then that opens up all those cans of 'what do you mean, well I'm not, I don't want to abort my baby. I just want this pregnancy to end [mom]'. And not seeing that correlation that this is what state law is. Um,

Catholicism – dictated decision

Different words are used to describe “termination”

phone. Talk through that again. ‘Oh well we didn’t think that that was an abortion, he called it an induction. I wouldn’t dream of it [grandma]’. It’s an induction but it’s still considered an abortion by state law. ‘Well we gotta, should we call the bishop?’ [grandma talking]

SPIRITUALITY--

You can call the bishop, but the bishop is going to tell you the same thing I’m telling you...that it’s not allowed. So, you know, that’s that’s one example of another situation....

CONFUSION--A mom..I got a call and the mom and I were on the phone for over an hour, wanting to be induced...it wasn’t an issue of that, but wanted to go ahead and have a delivery, but was going to do it a little earlier. I think she was 18 weeks. So um, considered not viable, it would be an abortion, but planning a suction D and C. But wanted memorabilia. Wanted to have footprints and ...so not comprehending again, that when you’re talking about that, then you’re talking body parts, you’re not talking delivery a fetus that’s in tact and, so expla..., trying to explain that to somebody without hurting their feelings that, ya know...(becomes emotional)

Interviewer: But you had to, because of your role. (Diane nods in agreement). And then what was, what was her reaction?

Diane: Unbelief. (begins to cry...motions to turn off the recorder)

Interviewer: It’s okay.... (I turn off recorder for a moment, Diane gathers herself and motions to turn the recorder back on)

“SOFTEN THE BLOW”/TERMINATION EUPHEMISMS--

Diane: But trying to explain that to somebody, when they don’t (pause) don’t know. That’s hard. Cuz I don’t, this is not something everyone thinks about. This isn’t something that, ya know, when you have a thought process to go through and then you’re slapped with it. It’s so..it’s all like it’s, ya know it’s when you try to soften the words by not saying abortion. You try to soften the blow by saying induction, and, we can induce labor, we can get you delivered. Um, it softens all that, to try to make it palatable. The other side of it is there are some people that are in horrific situations. They’re in abuse, they’ve got things going on. Or maybe they just think mostly they can’t handle it. Um, so it’s trying to figure out a way for them to come out of this whole thing as in tact as they can with the most positive experience that we can provide them in a safe environment...it’s really a tough piece. To try to explain to somebody, ya know, this isn’t this isn’t something you can do...if you choose this route, you won’t

Catholic, Pro-life – don’t believe in abortion, but making the decision to “abort” given the circumstances.

Causes confusion; misunderstand the terminology used because they don’t say “abortion” or “termination” – causes confusion over procedures

They use other words (euphemisms) because they want mothers to have options without feeling bad about “aborting”

have no memorabilia. Um, if they do an induction of labor, that would be different in that (inaudible). So I think that ended up being her choice and that was somebody that I know and continue to have conversations with. Um, most of the time, in fact, you spend time like that talking to somebody, they usually check back with me, ya know, and I get to invite them to all of our support groups and remembrance services.

STIGMA

Interviewer: So you mentioned how, um, kinda softening the words and the language that is used, and I'll admit, I didn't know until recently when we spoke that they didn't induce the pregnancies here. I guess I always was under the assumption, too, with my own pregnancy that if I chose that, it would be done here. And so, um, I can see obviously why you would want to soften the language, you know...

STIGMA

Diane: (interrupting) Abortion sounds...

Interviewer: You don't wanna bias...

Diane: Right, you don't wanna bias what their decision is either. He's (talking about the perinatologist) in a very difficult situation, but does a very good job with how he says it, but he doesn't...

Interviewer: But you have to...

Diane: I'm the one that says it.

Interviewer: Mmm hmm. That's probably really hard.

Diane: It is. So I cry a little...(both laughing)

Women who terminate maintain contact with Diane if it is of their choosing

Women who terminate are sent elsewhere to deliver their babies

Member-Check
Diane, Healthcare Provider
Emerging Theme: “Soften the Blow”/Termination Euphemisms

Interview Transcript Excerpt	Narrative Interpretation
<p>In this excerpt, I asked Diane to tell me about a time or an example of helping a patient through the decision-making process, after receiving the diagnosis.</p> <p>Diane:A mom..I got a call and the mom and I were on the phone for over an hour, wanting to be induced...it wasn't an issue of that, but wanted to go ahead and have a delivery, but was going to do it a little earlier. I think she was 18 weeks. So um, considered not viable, it would be an abortion, but planning a suction D & C [dilation and cuttlige]. But wanted memorabilia. Wanted to have footprints and ...so not comprehending again, that when you're talking about that, then you're talking body parts, you're not talking delivery of a fetus that's in tact and, so explai..., trying to explain that to somebody without hurting their feelings that, ya know.</p> <p>Interviewer: But you had to, because of your role. (Diane nods in agreement). And then what was, what was her reaction?</p> <p>Diane: Unbelief. (begins to cry...motions to turn off the recorder)</p> <p>Interviewer: It's okay.... (I turn off recorder for a moment, Diane gathers herself and motions to turn the recorder back on)</p> <p>Diane: But trying to explain that to somebody, when they don't (pause) don't know. That's hard. 'Cause I don't, this is not something everyone thinks about. This isn't something that, ya know, when you</p>	<p>The other example that Diane described to me involved a mother who had already chosen to terminate the pregnancy. The conversation, however, revolved around the type of procedure that this mother would elect, yet another decision to make in such a complex scenario.</p> <p>Diane explains, “it wasn't an issue of that [whether or not to terminate], but wanted to go ahead and have a delivery, but was going to do it a little earlier. I think she was 18 weeks. So um, considered not viable, it would be an abortion, but planning a suction D & C. But wanted memorabilia. Wanted to have footprints and ...so not comprehending again, that when you're talking about that, then you're talking body parts, you're not talking delivery of a fetus that's in tact and, so explai..., trying to explain that to somebody without hurting their feelings that, ya know.”</p> <p>In this situation, the mother wanted to have mementos of her child. She wanted footprints, handprints, all of those things to remember her baby by. She failed to realize that the procedure that she initially elected would not make this possible. The baby would not be delivered whole, as an induction of labor would allow. Diane was placed in a role in which she had to explain this to the mother. She had to tell her what the initially elected procedure involved and how it would not be possible to have memorabilia if that is what she chose. The mother's reaction to Diane's explanation was “unbelief”. Diane was emotional during her telling of this story. It was apparent that this component of her role is</p>

have a thought process to go through and then you're slapped with it. It's so...it's all like it's, ya know it's when you try to soften the words by not saying abortion. You try to soften the blow by saying induction, and, we can induce labor, we can get you delivered. Um, it softens all that, to try to make it palatable.

Interviewer: So you mentioned how, um, kinda softening the words and the language that is used, and I'll admit, I didn't know until recently when we spoke that they didn't induce the pregnancies here. I guess I always was under the assumption, too, with my own pregnancy that if I chose that, it would be done here. And so, um, I can see obviously why you would want to soften the language, you know...

Diane: (interrupting) Abortion sounds...

Interviewer: You don't wanna bias...

Diane: Right, you don't wanna bias what their decision is either. He's (talking about the perinatologist) in a very difficult situation, but does a very good job with how he says it, but he doesn't...

Interviewer: But you have to...

Diane: I'm the one that says it.

Interviewer: Mmm hmm. That's probably really hard.

Diane: It is. So I cry a little...(both laughing)

very challenging, understandably so. These mothers love their babies. The mother that she mentioned in the example above wanted mementos of her child. When she found out that this would not be possible given her decision for procedure election, Diane mentions that her reaction was "unbelief".

Diane describes the challenges posed in explaining these procedures:

"But trying to explain that to somebody, when they don't (pause) don't know. That's hard. 'Cause I don't, this is not something everyone thinks about. This isn't something that, ya know, when you have a thought process to go through and then you're slapped with it. It's so...it's all like it's, ya know it's when you try to soften the words by not saying abortion. You try to soften the blow by saying induction, and, we can induce labor, we can get you delivered. Um, it softens all that, to try to make it palatable."

She mentions the terminology used throughout and how it aims to "soften the blow". Hearing that you can be "induced" or "delivered" takes on a far different meaning than hearing that you can choose to have an "abortion". "Abortion" is a politically-charged word, associated with a great deal of stigma. So by using the other terminology mentioned (induction/delivery) mothers can feel free to make a decision that is right for them, without the bias involved by using the word "abortion", which may steer them away from making that choice, even if it is what they truly want to do and feel that it would be the best choice for their family.

Coded Methodological Log Samples

Excerpt about expanding the study to include all mothers, regardless of choice for pregnancy management

...To further explain my reasoning for choosing to possibly include mothers who choose to terminate after confirmation of a lethal prenatal diagnosis, I will mention a recent encounter I had with one such mother. I was at a local coffee shop working on some things as I do regularly. I was cleaning up my table, taking my cup to the dish bin that they have available when I noticed a woman sitting nearby. She was by herself, reading a devotional that was far too familiar.

SPIRITUALITY

The devotional, titled “Grieving the Child I Never Knew”, is one that I have myself. The book’s teal green cover, with a bright yellow rubber ducky on the front are quite conspicuous. I immediately felt the urge to talk to this woman and before I knew it, I was standing at her table. Once I realized I was there, I knew I had to say something, and was able to mutter something to the effect that I too had that same devotional, asked about her loss, and told her how sorry I was that she had lost a child. We began to talk and I found out more about her story.

STIGMA

Because I had received the devotional from the hospice program, I asked if she had been involved in that program as well. She indicated that she had to a degree, but not fully because she and her husband had decided to induce the pregnancy early due to the lethal prognosis surrounding her unborn child’s diagnosis. She described to me some of the details surrounding his “abnormality” (which I tend to put in quotes because the term “abnormality” is quite bothersome to me). I then asked if she would be joining us (other hospice families) for a remembrance ceremony/service project that I was helping to coordinate, which would take place in a few weeks. She mentioned that she would. I found myself reiterating to her that I wanted her to feel that she could come and be supported and encouraged during this difficult time, even though she may have made a choice different from the other families involved in the hospice program. I extended my support to her, we exchanged phone numbers/email addresses, and I was on my way.

CHANGE IN MY OWN ATTITUDE/EXPANSION OF THE STUDY

In retrospect, I am surprised by my own reaction to her story. As someone who has been in a similar situation where my own daughter had a lethal prenatal diagnosis, I could not fathom making the choice to induce labor early. How could anybody do that? It is

Spirituality – she was doing a scriptural based devotional

Could not “fully” participate in the Perinatal Hospice program because of their choice for pregnancy management

Begin to see a change in my own attitude – use this as a pull quote

wrong, inhumane, and downright selfish! When put in a face-to-face situation with a mother who made that choice for her son, however, my heart told me something different. As the tears welled up in her eyes as we spoke, I could see the love that she had for her precious son. Chris was his name. I won't forget that. He was born July 6th, just two days before my daughter, Chloe's, due date. I realized that she made the choice that was best for her family. She seemed at peace with it. At peace as much as one could be in such a circumstance. Sure we made different choices, but the one thing that was the same was the way we love our babies. I could see the love in her eyes as she spoke about him. She was eager to tell me, a complete stranger, all about his condition. She wanted to tell her story. I was willing to give a listening ear and I learned far more about this phenomenon than I thought could be possible in our short conversation. Although I know that I made the right choice in my own pregnancy by continuing, I realize that it is not my place to say what would be best for them.

By incorporating a story like the mother I have described above, the reader will be able to gain a broader perspective of the issue at hand: mothers experiences surrounding the confirmation of a lethal prenatal diagnosis. I anticipate finding differences between mothers regarding decision-making, particularly in terms of management of the pregnancy upon confirmation of the diagnosis. However, I suspect for the grief experiences to be similar in nature because it is obvious that these mothers wanted their children, they loved them, and they are grieving this tremendous loss.

Begin to see a change in my own attitude – use this as a pull quote

Excerpt about termination and associated stigma – observation notes

Last night I went out for dinner with Amanda and Lindsay. The three of us had a great time of socializing and in our conversation after dinner, talked more about our experiences with loss and the decisions we were faced with.

STIGMA

It was interesting because Lindsay openly shared that she often feels compelled, in a way, to provide further explanation to people when talking about her and her husband's decision to induce early with Andrew Lindsay. I probed her a bit more and she agreed that it was partly to do with the stigma that surrounds the decision she made, even though they do not feel like it was an "abortion". By law, she realizes, the decision she made was considered abortion. I've been thinking about this topic a lot as I've mulled over the information gathered from the moms in this study who decided to induce, and

Lindsay often has to explain her decision to terminate to outsiders

have come to my own realization that abortion, as we know it and as society defines this word, would not include the choice that these women made. All of these women so badly wanted their children to live and be a part of their families. However, circumstances beyond their control prohibited this from happening. They were then faced with a highly politicized and stigmatized choice, but still it was their choice. They each had their own reasons – ranging from experiencing similar loss (respiratory failure of a loved one) to it being the “right” choice for their family. In each conversation I’ve had with Shannon, a mother who chose to induce, she never fails to mention that if they wouldn’t have made that choice, they would not have had their subsequent child, Claire, and she can’t imagine living without her.

DECISION-MAKING

Amanda admitted that she too went back and forth in deciding and weighed options. It wasn’t an immediate choice to continue the pregnancy. They consulted with doctors, family, friends, and their pastor before making the decision. She showed a great deal of empathy to Lindsay in this tender interaction.

STIGMA, DISPARITY IN SUPPORT/CARE

I was feeling very frustrated about the context as a whole; the fact that women are being stigmatized by this choice made out of love for their children, and are subsequently not receiving the same standard of bereavement support and care as mothers who choose to continue their pregnancies and have the Perinatal Hospice Program serving as a buffer. I verbalized my frustrations to the both of them and they both agreed with me. How, then, do we make this case known so that all women, regardless of choice, receive the same supports and resources? Can we truly change a policy of a Catholic hospital regarding this topic? Probably not. What about the other hospitals? Do they understand the choice that the women are making to induce when faced with a lethal prenatal diagnosis is not out of selfishness or convenience? Some medical professionals most certainly do, while others haven’t got a clue! An account of this is evidenced by Lindsay sharing her experience after Andrew’s birth. She induced at 21 weeks and gave birth to him. After his birth, the doctor/nurses took him out of the room to clean him up before giving him to her to hold, per Lindsay’s request.

STIGMA/TERMINATION

After about 20 minutes, the doctor came in and said, “I’m really sorry to tell you this, but your baby is still alive.” Think about this. What a sad situation that the doctor was “sorry” to tell her this, as if she wanted him to be dead. She was happy he was alive and she requested that he be brought in right away. She and her husband held him for the remainder of his life, another 25 minutes. She is thankful that they had that time.

Amanda went back and forth with how to manage the pregnancy after the diagnosis

Varying standards of care/support are offered based on choice for pregnancy management

Assumptions made regarding Lindsay’s choice to terminate – insensitivity and stigma associated with this choice

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