

GRIEF PATHWAYS AFTER PERINATAL LOSS ON THE METAPHORICAL
JOURNEY OF LOSS

by

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ABSTRACT

A study using qualitative descriptive methodology was done to learn of the decision pathways that mothers experiencing six types of perinatal loss recall making during their experiences of loss. Five participants describe their experience as they recall decisions within their journeys of miscarriage, stillbirth, fetal malformation; one carrying to term by choice (perinatal palliative care), the other terminating, a neonatal death, and a SIDS death. Effort was made to understand specific available choices these mothers remember making along with their recollected experience of what was helpful and what was not helpful as they were navigating those choices. Exploring the experiences of mothers along their grief journeys exposed decisions that were intuitive and alternately decisions that were facilitated with guidance and help. Participants revealed that nurses and physicians were important in their initial collective journeys; however, sometimes these providers show discomfort beside parents experiencing perinatal loss who deserve to make their own meaning of the hopes and dreams dismantled after the loss of their children. This was coupled with continued ‘awkward’ and ‘uncomfortable’ moments provided by society as a whole during the experiences of these mothers as they navigated both concrete and abstract decisions after loss. This study explored the voices of those who need to be heard most clearly in perinatal loss; those who experienced this type of grief and are still navigating their way on their own unique journeys.

Key words: perinatal loss, perinatal grief, grief journey, grief pathway, perinatal bereavement, perinatal palliative care, emotional ambulation, grief trajectory, abstract decisions in grief, concrete decisions in grief, sharing perinatal grief, interdisciplinary education in end of life care

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LIST OF ABBREVIATIONS

DPM	Dual Process Model
SIDS	Sudden Infant Death Syndrome
WIN	Western Institute of Nursing

CHAPTER I: INTRODUCTION

Pregnancy is a life altering event for all parents and can begin with a momentous celebration and hope-filled journey. However, for some in our society, this hope-filled journey takes an unexpected turn and ends in heartbreak. The death of a child before birth or shortly after birth is an unanticipated, profound, and life altering event for the parents. Individual reactions to this event, when it occurs in our society, can vary greatly. Initial feelings of numbness, denial, anger, fear, or countless other reactions can occur.

Conceptualizing grief as thoughts and feelings, actions, and words with its diversity from person to person and loss to loss is very complex and ambiguous (Rosenblatt & Bowman, 2013). Rosenblatt and Bowman (2013) discuss how commonly metaphors are used when searching for ways to describe grief. A common metaphor used for grief is a grief journey. The journey begins at the time of loss and can take many different pathways (Wilson, 2011). One example of differing pathways in perinatal loss may be whether parents choose to continue a bond with their child after death or whether they decide to detach from the whole experience of the pregnancy or any memory of it or the child (Klass, Silverman, & Nickman, 1996).

The Metaphorical Journey after Loss

As with any journey that begins and ends, the grief journey does not have just one route, it has many different routes, which are referred to here as pathways. Just as the journey from one destination to another, say a trip from Boise, Idaho to Los Angeles,

California, has many alternative routes, each person experiencing grief starts a journey from the moment the loss is realized and also has optional pathways. When considering the trip from Boise to Los Angeles, one could go by way of the quickest route, through Fallon, Nevada along a barren desert trail. In the middle of summer, that might be a miserable path but it can still serve for arrival to the destination; however, it may not be a pleasant experience and can be viewed as but a means to an end. Another choice might be to consider a scenic route, stopping to make memories along the way in Lake Tahoe; or still another might be to go all the way to the coast to meander down Highway 1. The latter choice involves a longer pathway perhaps, but one that is filled with more than the destination as the objective.

Parents experiencing new grief may begin this part of their journey with uncertainty and questions that require guidance, nurturing, and information. Frequently in perinatal loss, the parents have not even considered loss when they embark upon their experience of a pregnancy. When loss stops the journey of parenthood and places the parents on the grief journey instead, they must quickly consider pathways ahead of them to a perhaps unknown destination in grief. Another complication of the grief experience when it occurs before birth is that parents have gathered very few memories of the child. In the darkness of their early grief days, it may feel impossible to find their way. What are the available pathways? How do parents of loss decide upon the best route to take in their grief journey? Once decided, how do they make it to their destination? A nurse who has walked with other parents on their grief journeys can be a guide to the different pathways available for each sojourner, and if allowed, may describe for the parents of loss what the expectations along each path might become. Should the parent choose

burial or cremation? Should the parent interact with their baby to know who he or she was, even after death? This may be a seemingly unnatural pathway at first, but one that many parents ultimately were glad that they chose.

Problem Statement

When a parent is informed of a perinatal loss, they are suddenly in unknown territory with decisions to make for a grief journey. Gold (2007) summarizes, after reviewing the experiences of 6,200 bereft individuals, “parents have demonstrated that health care providers can make families feel either supported or helpless after their infant dies” (p. 230). Due to the stressful nature of the death of a child, Gold (2007) related that “seemingly benign mis-steps by a health care provider may be engrained in a bereaved parents’ memory replayed over and over in years to come” (p. 230).

There are many pathways a parent could choose during that moment that are influenced by many factors; some of the factors might have a negative influence while others might have a positive influence and all of them with varying degrees of each. With this much variability and confusion, it is extremely complicated to determine which pathways parents are currently on or going toward. How do parents get from point A to point B when there are so many ways to get there and so many points where mis-steps can occur? What different paths might they take to the ultimate destination and why might they choose one path over another? How do care providers help? Do parents look back in gratitude or regret for the pathways they chose?

Translation of Terms and Concepts

Grief, as defined by Rosenblatt and Bowman (2013), is not a distinct object; however, making it an ‘ontological metaphor’ or taking a nonconcrete concept such as grief and defining it in physical terms helps to aid thought and discussion surrounding it. Rosenblatt recommends that we stop thinking about grief as the same from person to person and try to understand a person’s grieving as a single person’s grieving defined by their thoughts and feelings that have been influenced over time with other thoughts and feelings they, and they alone, experience.

Perinatal loss is the demise of a desired unborn child or a child who dies shortly after birth, and is a heartbreaking experience for millions of women throughout the world. Statistics show that over a million fetal deaths occur in the United States each year, 25,972 occur after the 20th week of gestation meeting criteria to be defined as stillbirths (MacDorman, Kimeyer, & Wilson, 2012). Still, because of a lack of consistency in reporting miscarriages, this is a conservative figure and does not include many of those who remain uncounted. Estimates determine 20% of all pregnancies end in loss and the literature asserts that upwards of 50% of all women suffer pregnancy loss in their lifetime (Price, 2008). Infant mortality data for the United States also reports 19,094 babies per year die within the neonatal period (Matthews & MacDorman, 2011).

The metaphorical concept of ‘grief journey’ reported by Rosenblatt and Bowman (2013) is a common way to describe grief on a time continuum from the moment of realization of loss to wherever the person experiencing the loss finds themselves at that particular moment in regard to their emotions and thought processes. The journey

continues to describe their changing emotions and thoughts as they look back upon their experiences in summary.

Pathways therefore are choices or decisions that are laid out as different ways for people to navigate their ultimate grief journeys. These choices may be decisions about continuing bonds or detachment. They may be decisions that will create meaning of the loss or will assist the parent to avoid triggers that remind them of their loss. Should the parents have an autopsy; do they get stuck on their journey if etiology for loss is indeterminate? The pathways could be countless to the destination since the journey has been determined to be complex, ambiguous, and individually chosen. The nurse or a guide to the parent could illuminate the different pathways and allow the griever to choose their own pathways. At the very least, informed decision making regarding the nature of those pathways is essential.

For many, the concept of death in any form is foreign and unwelcome. The loss of a child in pregnancy or shortly after birth may be the first exposure to death that a couple experiences in their lifetime. Egan, City, and Labyak (2010) discuss how culturally in the United States today the process of accepting death can be offensive and difficult due to the life-prolonging technological advances and perceived miracles of modern medicine. These advances are applied even to the elderly and as a result the idea of losing a preborn baby to death is almost unthinkable in a death-defying society, such as ours. For those living in a society that denies death, there is not a common, known, or single pathway that exists to guide parents in a concrete way through the experience of perinatal death (St John, Cooke, & Goopy, 2006; Renner, Verdekal, Brier, & Fallucca, 2000; Uren & Wastell, 2002). Clearly, some people do better during the journey than

others, exhibiting what some might assess as a healthy grieving process but even different points of time during the journey have their complexity, diversity, variability, and ambiguity (Rosenblatt & Bowman, 2013). It may be that each individual chooses their pathway as they journey in grief based on previous experience, comfort level with death, guidance from those around them, or just whatever feels “right” or meaningful to them at the time.

Hilliker (2006) summarizes a societal need to reclaim the experience of death in our culture in a way likened to the reclaiming of the birth experience typical of the 1970's when fathers were allowed to enter the birth experience as partners. She states that survivors of the dead often cherish a token of memorabilia but frequently need to do so secretly because of the societal norms we have regarding the taboo subject of death. Her work offers a historical perspective on post-mortem photography but also discusses the societal changes and roots of discomfort with death in our country. She goes on to discuss how a healthy society needs to have a healthy grieving process, which would include being able to openly grieve and even share, display, and relish post-mortem photography instead of death being a subject as unacceptable as pornography.

Phenomenon of Study – Grief Pathways

When parents are informed of perinatal death, they are expected to make many decisions quickly and may be permanently impacted by these same decisions, made in a very stressful time period as they pertain to their overall grief journey and healing. Many parents struggle with these experiences one moment at a time. These include decisions about their own bodies and their baby's bodies as they navigate choices toward their unique trajectory.

Their care provider may make some decisions for them; however, parents may not know what to ask or may even be presented with incomplete or missing pertinent information concerning choices like “How will I deliver my child and when?” “Will I be asleep in the Operating Room or experience a full blown labor experience?” “Do I have a choice?” Different options do exist for how and when delivery will occur (Dalton et al., 2010). Some parents are still not being allowed a voice nor do they have an invitation to partner in decisions that affect their own bodies or meaningful options. One example of this dilemma exists in the choices of delivery mode for parents carrying babies to term with known fatal conditions who desire to be delivered via Caesarian Section route. Frequently, this is a decision based on belief system of the parent for the desire to meet their child alive and not have an already weakened child withstand the forces of labor to be exerted on their survival ability. Even though this seems to be a legitimate reason for the parents, not all physicians can agree and will deny the wishes of the parents thinking that their broader scope of knowledge regarding future risks to the parent trump the parental voice (Balderrama, 2014). Policies and laws also influence when a parent can be delivered after a fatal diagnosis of their child is known. Some states force a quickened decision from parents regarding the “big” decision of carrying to term after fatal diagnosis or terminating the pregnancy at time of diagnosis because of their statutes that delineate when termination can occur. This can also determine when a child can be delivered, forcing some to go to 39 weeks when a delivery at 35-36 weeks would have prevented stillbirth and allowed moments of live interaction with parents (Miller, 2014).

More decisions surround parents for disposition of the body of their child. “Should I decide for burial or cremation?” “What funeral home should I call?” Should I

have an autopsy performed? These types of questions are active in the decision process and required within a short timetable.

Other decisions are more subtle requiring guidance and processing of emotions such as “What relationship will I keep with this deceased child and where do I place the meaning of this experience in my life?” Milstein (2003) related the thoughts of a father after his infant daughter, Rose, died after only 19 days:

...it became clear that they had learned some very profound lessons, and that learning had not been just a cognitive exercise. I have heard the expression ‘having a good death,’ but when I think of how Rose interacted with her family, she did not have a good death, she had a good life; a life that was meaningful for her and her family.

Parents sort out these decisions from the moment they know of the loss along their grief trajectory and they have moments where they question and worry about the pathways they may have chosen. In my nursing role, I have received phone calls from parents fixated on questions regarding their baby’s body. “Where is it right now? I can’t sleep and I need to know.” Mothers of early gestational losses wonder “Was my baby’s body apparent and if it was, how was it treated?” “Did my baby feel pain or suffer?” The decisions made at time of loss are just as influenced by who is guiding the couple through the process, comfort or bias toward death by both caregivers and family members surrounding the parents and a personal state of mind during this tumultuous initial grief reaction. These are the experiences that influence the couple while they navigate the health care system or as they are introduced to their options. Different experiences emerge and form the basis for a healing journey or they may form a traumatic one that is frightening and filled with regret and played over and over again in their minds.

For newly bereaved parents in a short window of time, decisions and choices that influence the ultimate grief journey may be taking form. Unlike the death of an older child, parents do not have a lifetime of memories they can draw upon for comfort during bereavement when they experience the loss of their child before birth. This may also be why the moments surrounding the birth become so searing to the parents. They are all the parents have in memory of their child. Continuing a bond with a loved, but memory-inhibited, life is a challenge. During a very chaotic and short time, with little to no experience with death, parents of loss may receive conflicting messages regarding these pathways of grief. Should they disengage and put this behind them immediately, including rejection of memory-making opportunities as a pathway choice? Should they decide to try and pretend like this pregnancy never happened? Should they actually try to deny a relationship with this child so that the pain of loss does not even occur? They may choose not to name this child but instead save the name for another child who lives in the future dreams of the parent. Depending on the knowledge of their caregivers, or a personal bias, often influenced by this society of death denial, different caregivers can introduce opposing options. When parents make decisions during this stressful time about their pathways, as they look back, they may regret decisions made at this point. This is evident oftentimes when parents adamantly refuse to see their baby or have them photographed, only later to call and ask if photographs were actually taken. A personal experience of newborn child loss captures this ambivalence when author Sherokee Ilse (2002) writes from her and her husband, David's, personal experience:

David and I felt uncomfortable when we were asked if we wanted a picture taken. In my heart I knew I wanted one, but I couldn't agree to it at the time. Now, I wish I had a photo, in fact many photos, but especially one of us holding Brennan.

I have only my memory which is fading over time. I have nothing tangible. I also feel bad that my family and friends didn't see Brennan and can't even see him in a picture. Often his brothers ask about him and I wish I could make him real for them, at least through a picture. (p. 22)

When parents are first informed of loss and are brought into the hospital, they are bombarded with decisions to be made like David and Sherokee's. They may be in physical pain during this time, not to mention the emotional strain and chaos they are experiencing. The goal is to deliver the mother's body of the dead child through induction of labor or the surgical procedure of dilation and curettage as quickly as possible. Parents may be encouraged to put this experience behind them, or may feel as though this is what they want to do, learning what they can from a failed pregnancy and moving on to a successful pregnancy as soon as possible in the future.

Following the trusted advice of a physician for detachment in this way sounds hopeful and enticing and to be able to shed the pain of this experience quickly and completely is inviting. Yet, Davies (2004) relates how parents can later derive consolation and solace from holding on to possessions and carrying out rituals associated with their child. If it were possible to completely rid oneself of the pain and grief from the death of a child that would be ideal, however when parents realize that they had formed a deep relationship with their child who died, this becomes impossible. If the first inclination is to dissolve bonds or let go and later the response becomes to find a link toward the lost child for resolution, the opportunity for gathering this link through possessions or memory making may have passed.

Aim of the Study

The aim of this study is to explore the experiences that mothers of loss have had in their creation of grief pathways in the larger scope of their grief journeys. Considering differing and sometimes conflicting choices for pathways, the overarching question guiding this study was: What decisions do mothers of loss remember making at time of loss until now and what became helpful or unhelpful in the process of deciding among those paths?

Evolution of the Study

I never find it painless to watch as a parent is informed of the death of their child. I have watched the process occur many times in my thirty seven years as a nurse at the bedside. I have watched it done with compassion and grace and alternately with complete ineptness and uneasiness. This research aim was chosen hoping that the knowledge produced could benefit and possibly prepare all care providers who meet this population with some empirical evidence that could develop their skills in becoming a therapeutic agent to these parents. I began to critically think about the parental experience of grief and the different trajectories parents of loss could choose and what might be influencing choices.

Rationale for Doing the Study

I have observed physicians informing parents of loss and also observed physicians and nurses discussing next steps for the care of their patients. They have shown differing comfort levels with death and I have heard different advice given to parents of loss. The concept of moving on and putting the experience of this pregnancy loss behind them is

common advice and even pushed for as quickly as possible by some. I conducted an earlier unpublished study and I discovered a lack of permission to grieve a pregnancy or child loss in our community as a theme while talking to my sample of mothers months after their losses (Jonely, Munroe, & Brudenell, 2009).

Historical Context

Due to the differing opinions and decisions that women face regarding detaching from the baby and pregnancy, they may be guided to put the experience behind them not only by physicians but by family and friends who do not give permission for long-term perinatal grief. This is in direct conflict with a need to continue a bond with a memory-inhibited life. According to Klass et al. (1996), continuing bonds have only been denied as part of a normal bereavement for the past 100 years. Prior to that, during the Romanticist era, Stroebe, Gergen, Gergen, and Stroebe (1996) relate that the concept of grief signaled the significance of a relationship and the depth of one's own spirit. To dissolve the bond would have defined the relationship as superficial and would have denied one's own self-worth.

From my experience, offering continuing bonds with the deceased child is not always chosen as an option by parents and some families have regretted this decision later. Parents who originally do not want to even see the baby or have any mementos or keepsakes, later call and ask if personnel may have actually obtained them against their will in hopes that they had. For this reason, keepsakes and mementos were often gathered and saved "in case" a parent changed their mind later. This was a common practice during the 1990's.

Fast forward to May, 2011. An Ohio woman who had a premature baby survive for 16 days before he died received photos of her child, which were taken against her will. They were sent to her in the mail by a bereavement team with good intentions. There is now a lawsuit for *desecration of a corpse* in progress. She truly wanted her memories to only include the 16 live days she spent with her child and her request should have been honored. The reporter who published this story states:

While researching this practice, I saw several stories of mothers who lost children who stated that while they insisted they didn't want pictures of their child at the time, they had nurses and grief counselors insist ... and now they cherish these photos as invaluable physical mementos of their child. (Murphy-Raines, 2011)

Since grief is an individual experience, it is not possible to have a routine practice that meets the needs of each patient at all times (Hart, 2012). It is no longer acceptable to go against parental wishes and obtain mementos of a dead child without permission; even if later it would be regrettable. Yet the decisions of the parent are perhaps under-guided and based upon biases either for or against that are frequently unchartered and influenced by fear of death in our society. These decisions become unchangeable later.

Researcher's Expertise with the Phenomenon

As principal investigator of this research project, my expertise beyond my thirty seven years of clinical nursing with this population includes Certification in Perinatal Loss Care from the National Board for Certification of Hospice and Palliative Nurses. Currently, I am one of forty three individuals with this certification in the nation. Assisting families to form relationship with a deceased baby has become a skill of mine and when I practice and teach this appropriately, it appears to be very beneficial to

members of this population. I have been able to initiate a role at my facility as a perinatal palliative care and loss specialist and I follow up with these bereaved parents for the weeks and months after loss usually by telephone to assess and evaluate their needs post-loss.

I have noticed that another common reaction of parents experiencing a stillbirth is to initially decide against the need for these mementos. Along the experience of delivery and as processing of the event occurs, parents become more accepting of the desire to see or hold their infant when at first the thought was disturbing. With my support, parents often become courageous and decide to pursue a peek, a memory, and then spend time with their child and request the mementos of photography, footprints, and castings. My follow up phone calls with these patients often reveal that when asked what helped them the most during the experience, spending time with the child post-delivery was cherished and frequently very beneficial. My thoughts began to focus on parents who experienced a fear of connection to the decaying remains of their child after death. In our society, many consider it unnatural to display, touch, or involve themselves with the body of another after they have died. This can create a desire to turn away from an initial relationship with their child with decisions not to explore and not to get to know their children after death. What does this choice on their pathway bring into their ultimate grief trajectory? I suspect that fear, society's influence, or bereavement support that is suboptimal or nonexistent can contribute to the decision that ultimately belongs with each parent of loss. Permission to have a continued bond with the child for some parents who find this practice intolerable may be difficult. It is through my desire to improve parental

options after loss occurs and to practice evidence-based nursing that this study has evolved.

Relevance to the Discipline of Nursing

This study is relevant to the discipline of nursing because nurses meet this population at the time of their loss in labor and delivery or in the surgical and emergency areas. Nurses are part of our culture of death-denying in the United States. Just because they are nurses does not mean they give up their overall cultural identity. Many nurses are still very uncomfortable with death and dying concepts, especially those who choose to work in labor and delivery where end of life is not part of everyday occurrence and care. It is common practice to deliver failed pregnancies as soon as possible after knowledge of the loss. If patients are being encouraged to cut ties at the time of their care in the health system or feel strongly in that direction on their own at the time, but later find that they would have preferred to have gathered memories, possessions, or even the idea of continuing a bond with their child, this opportunity could be lost and parents could experience regret lasting a lifetime. The findings from this study may help further the understanding that the option of a continuing bond would be positive. Nurses could practice appropriately facilitating continuing bond options for parents while increasing awareness for patient, family, and all health care providers that offering continuing bond options is appropriate.

CHAPTER II: GENERAL METHODOLOGY OF STUDY

Qualitative descriptive research provides a rich understanding of a phenomenon needing further study. Besides the rich descriptive opportunity that presents itself in qualitative inquiry, I find that knowing the truth as having differing perspectives in the lived experiences of individuals is just as valid a truth as understanding perspectives based on quantitative data and volumes. Truth in meaning, even if experienced by one individual from my perspective, is still a truth. The lumping of experiences into truth because it is true for most, does not in my experience leave room for relationship to this patient, this time and in this experience. Jean Watson and her theory of Human Caring (1979) require a first step of establishing a relationship with each patient, and treating the patient in a caring holistic way often called relationship-based care. In order to do this, it is required that the basis of care is done individually. Rosenblatt (Rosenblatt and Bowman, 2013) states that in his career of studying grief, he fell in love with qualitative research for the study of grief because as time went on, he learned after many inquiries that he was less apt to say what grief was, less willing to measure it or even define it because of its complexity and ambiguity. I used the qualitative descriptive method of inquiry to explore the metaphorical grief journey of individuals who had experienced perinatal loss. I found it necessary and important to investigate and examine these recollections of parents of loss to determine if decisions made at time of loss influenced the grief pathway experienced as their grief journeys unfolded.

Research Assumptions

I assumed that qualitative inquiry was the best possible way to seek the answer to a question of how individuals perceived their decisions at time of loss to influence the pathway they traveled in grief. I assumed that research participants would answer semi-structured research questions truthfully. I also assumed that I could not fully know nor could participants fully articulate what was inside of them as a complete picture of what their grief journey comprised.

Although it may be common for a literature review to occur after data collection in qualitative inquiry, I have been exposed to and have maintained a literature review over the past 6 years through scholarly activity and personal interest in my subject; therefore, it is not feasible to proceed without acknowledgement of investigator bias from this source. This bias in preconceived ideas prior to my contact with the research participants for this study was already present. I made effort to bracket these biases as data analysis occurred with input from my committee chair and reflection from me during the process. I used memos for consideration as a method while analysis proceeded.

General Steps, Procedures, and Outcomes

Since grief pathways as a phenomenon had not been studied, a qualitative descriptive study aimed at providing an in-depth exploration of the research question occurred. Recruitment of participants who had experienced perinatal loss in their lifetime and were willing to discuss their grief journey ensued. Study participation was explained to each participant and informed consent was carried out. Interviews were audiotaped and transcribed verbatim. A description of the response to questions in everyday language was then available. According to Sandelowski (2000), a qualitative

descriptive study would gather an accurate accounting of events that both researcher and participant agree are accurate and an accurate accounting of the meaning participants attributed to the events that participants agree is accurate, in this case, recollections of decisions or pathways chosen affecting a personal grief journey after perinatal loss.

Qualitative descriptive studies include diverse methods that gather data to describe in everyday language the events according to the participants that the researcher and participant can agree are accurate, keeping the data as naturalistic as possible (Sandelowski, 2000). Constant comparative analysis (Corbin & Strauss, 2008) became the method of analysis for data obtained in this form of inquiry, which produced a summary of the descriptive data after the analysis had occurred. The analysis was ongoing during data collection and had the ability to be modified during the process for adjusting to the data as it was collected. According to Armour, Rivaux, and Bell (2009), “No single or commonly accepted guideline exists to assist researchers in the creation of quality research within qualitative methods” (p. 105). Sandelowski (2010) asserts that all methods of qualitative research become what they are in the hands of the users. For these reasons, exact method was determined during data collection as the “tones, hues and textures” (Sandelowski, 2000, p. 337) of the qualitative approach were discovered.

CHAPTER III: APPLIED METHOD OF INQUIRY

Researcher's Credentials for Conducting Qualitative Inquiry

In order to explore and understand how decisions made at time of loss affect grief pathways for parents, it was necessary to interview research participants who were willing to share their experiences and thoughts and feelings with this investigator. Although there were concerns regarding the vulnerability of bereaved parents, Breeze, Statham, Hackett, Jessop, and Lees (2011) found through empirical evidence that it is possible to undertake research with newly bereaved parents, and it may even be well received. They acknowledge the responsibility of the IRB to “ensure that research does not add to distress, but this must be balanced by ensuring that those who wish to be able to speak about difficult experiences are not prohibited from doing so” (p. 367). In fact, they cite Burnhall and O’Keefe’s (2004) conclusions that “most parents who have lost a child want to tell their story; we have a responsibility to listen” (p. 738). I am fully involved with this population of parents, am comfortable in relationship with them, and in hearing their whole stories of perinatal loss. I have completed all CITI training as necessary.

Site and Population

A sample of bereaved perinatal loss mothers in the community of the greater Boise area were sought as research participants who were willing to share their stories through audiotaped interviews. The site involved was any place the participants were

comfortable in sharing these stories with me. I achieved my recruitment of participants assisted by physicians, midwives, and nurse practitioners in the Treasure Valley.

Plan for Researcher's Role

Physicians, midwives, and nurse practitioners in the community were engaged to help actively recruit participants from their patient populations who had experienced perinatal loss and wanted to participate in the research opportunity. A cover letter was sent to these providers to ask if they would like to assist me in my research efforts by helping in the recruiting process (Appendix A). If they wanted to assist and after IRB approval, flyers were made available to potential participants who would be able to contact me if they were interested in participation (Appendix B). These flyers were available on campus through Boise State University's health clinic where the appropriate patient population who might have been interested in participation could receive them. SHARE of Idaho, a perinatal grief parental support group, was also notified of the study and participant recruitment available to this group through flyers as well.

As per accepted qualitative methodology, no definite sample size had been set. Although some repetition of themes did occur after four interviews, following the concepts of Rosenblatt and Bowman (2013) revealing that grief is individual, complex, and ambiguous, it is my belief that within this study aim, saturation would never be possible. A fifth interview was included as a way to check themes garnered from participants and repetition in the themes was present. The sample included mothers who had experienced a perinatal loss of any gestational age in their lifetime and who were willing to share their experience and recollections. Participants were invited to include a support person in presence for comfort, however none of the participants chose to have a

support person present. Participants were all at least 18 years of age and were able to speak English.

Ethical Considerations

While there is no physical risk to the sample population, participation in the study might have triggered painful memories and a relapse of grief for the participants. It has been my experience in talking to parents of loss that it is normal for them to express emotional pain, feelings of emptiness, tears, and anxieties. Parents may also experience feelings of anger and self-blame over their loss. In order to mitigate the risk of harm, I fully explained that expressions of these feelings would be validated and allowed and complete permission to opt out of the study at any time they desired was assured. While no money was available for counseling, employed participants may have had access to employee EAP counseling services and it was suggested that each of them look into that option should they decide they might benefit from it. Mothers were also given a card with the names and contact information for other resources (spiritual care or a clinical nurse specialist with experience in postpartum depression) that had agreed to help them at no cost should they desire further help (Appendix C).

I offered unconditional listening, which Tsartsara and Johnson (2002) had found to decrease the anguish of those who had experienced a miscarriage. The sample population in that study said that participating by the telling of their stories was beneficial since it allowed them an opportunity to discuss their feelings and concerns about their perinatal loss (Tsartsara & Johnson, 2002). I have extensive experience caring for parents of perinatal loss and I am certified in perinatal loss care by the national board for certification of hospice and palliative nurses. Participants who had received the flyer and

were interested in contributing their voice to the study initiated first contact between investigator and participant. A brief interview was done to make sure they met inclusion criteria and to determine where they wanted to meet (Appendix D). Additionally, care was taken not to assign any certain meaning to a parent's loss. The significance attached to a perinatal loss is individual and should not be belittled or exaggerated by others. While some view the beginning stages of pregnancy as a cluster of cells, others perceive it to be a pregnancy, and still others think of it as a baby or child. By asking the meaning of the loss to each participant on the written demographic questionnaire, this pitfall was avoided.

Data Collection

I explained the study in detail to each participant and answered all questions she had about the process. Due to the sensitivity of the study, care was taken to ensure the participants' comfort during the interview process. The possibility of tears and grief was acknowledged to the participant by the interviewer and the mother was given the option to end the interview at any time she chose. Also, participants were reassured that unconditional listening would be extended and that the interviewer was completely comfortable with the sharing of tears. Tissues were provided during the interview to allow for comfort during tears. The interviews occurred at various locations chosen by each participant to facilitate their comfort. Interviews were audio-recorded on a digital recording device (Complete Interview, Appendix E). Each participant desired to continue after the initial explanation of the study and they were given the consent form to read and sign (Appendix F). Prior to signing the consent, the participants were informed of the study's lack of funding for psychological counseling and if they felt the need for

therapy after the interview, it would be at their own expense. A suggestion for the employed participants was to seek out their EAP benefits at work if needed and if provided. A resource card was also provided that they could refer to for other alternative places to obtain support in their grief experience. Prior to beginning the interview, the participants were given a written questionnaire with regard to their demographic information (Appendix G). The questionnaire asked the participant's age, ethnicity, and marital status. The participants were also asked questions regarding previous pregnancies and perinatal losses or how many, gestational age, and how long ago the losses had occurred. The participants were asked if they considered their perinatal loss to be (a) the loss of a pregnancy, (b) the loss of a baby/child, or (c) other. After discussing the study, signing the consent, and filling out the demographic questionnaire, the interview began. The interviews lasted between 37 minutes and 1 hour 7 minutes and I had anticipated the interviews to last approximately one hour. Ending time occurred when the mother felt she was done. Extreme care was taken to ensure the participant's privacy. Each mother admitted to the study was given an alias name and given the opportunity to choose the alias themselves. Every participant declined the alias choice and so they were chosen for each parent by this investigator in the genre of bird names. The demographic questionnaire, typed transcripts, and tapes of the interviews were labeled only with the participant's alias. The consents with the participants' identities were stored separately from the interview tapes, transcripts, and questionnaires. I ultimately chose to transcribe the interviews myself in partial account of interviewee's privacy. I also felt as though the subject matter could be construed as heavy or

burdensome to a transcriber. One further argument for transcribing myself was to become very familiar with the content of the interview data.

Data Analysis

While analyzing the data, only my faculty chair and I had access to the data. Qualitative content analysis includes the identification of themes and patterns among themes and the breaking down of data into smaller units, coding, and naming of the content and analyzing of shared content among the data units (Polit & Beck, 2008). Willing participants who had experienced perinatal loss provided data through semi-structured interviews. I chose to transcribe the interviews myself in the process so that I would immerse into the data as closely as possible. I transcribed audiotaped narratives word for word, analyzed the data after each interview, and then compared each interview to each interview. This facilitated accurate constant comparative data analysis and produced themes and patterns of themes and reduction to manageable segments of data. Analysis involved constructing by inductive process meaningful segments that when placed together produced patterns and concepts that were useful for understanding. This helped to explore the grief pathways of parents of loss and decisions they made at time of loss that may have influenced their ultimate grief journey up to this point in time. The consent included a provision for a second interview for clarification and accuracy purposes after the initial interview had been transcribed and analyzed. Qualitative inquiry, by nature, is nonlinear and can require additional contact to validate accurate meaning as data is analyzed. This is known as member checking, a form of verification of the information. The data collection took approximately three months for recruitment to be realized and interviews to occur. Recruitment began as soon as IRB approval was

obtained on November 20, 2013. First cycle coding included the process coding appropriate for all qualitative studies but particularly for those that Corbin and Strauss (2008) say search for “ongoing action/interaction/emotion taken in response to situations or problems, often with the purpose of reaching a goal or handling a problem” (p. 96-97).

The order of steps taken in my analysis process were as follows:

- I wrote a memo directly after each interview had occurred with general impressions of each participant, as seen in Table 1.
- I transcribed the interview.
- I separated the transcript into line by line segments.
- I coded line by line segments with gerunds, as seen in Table 2.
- I wrote memos of divisions and subdivisions of data as I saw them as a whole in comparison of one transcript with another, as seen in Table 3.
- I continued this process after each interview.

Table 1. Portion of interview impression memo written directly after interview

1/31/14 Finch Interview:
Finch was very willing and excited to talk with me, to share and her excitement lasted throughout the entire interview as she really had a fast pace in her speech patterns which lasted throughout. She shared a lot of information. She didn't believe she would feel emotional during the interview and when she cried, it surprised her but she was okay with it. She had the longest gap so far with how long ago her loss was (14 years) but she was able to recall with fine details, her loss experience.
Interview: 1 hour 7 minutes Place: In my home Memo regarding thoughts about self-bias bracketing after interview: I am

amazed at Finch having the strength to walk the journey of perinatal palliative care alone long before any programs existed for this type of support through pregnancy. She is a very strong person who had a core self-knowledge of her own needs, wants and wishes connected to a strong belief system.

Table 2. Portion of Initial Line by Line Coding

Eagle, Transcript p. 5	Line by Line Gerund Coding by JJ
<p>Eagle: some people you want to talk with and some people you don't and I don't really know why. I think that some people from church, they come over and their intentions are great, they're sweet, but I just don't want to tell em anything [<i>giggle</i>], I don't know why, but um, but I think that mostly for me, is that I, I think I've just been blessed with knowing that people's intentions are good even though they start rambling on about like weird stories about losing babies and, it's just uncomfortable, so they start rambling about like awful things, I'm like you should probably not talk, like you probably shouldn't share that with me [<i>giggle</i>]</p>	<p>Deciding to share</p> <p>Deciding not to share</p> <p>Questioning how she makes that decision</p> <p>Seeing good in others intentions</p> <p>Questioning how she makes 'sharing' decisions</p> <p>Realizing choice of thought</p> <p>Choosing optimism</p> <p>Identifying emotional discomfort</p> <p>Recognizing awkward behavior of others</p> <p>Feeling uneasy from others' words</p> <p>Wishing for different behaviors in others</p>

Table 3. Coding Memo: Comparison of Abstract Decisions

Coding Memo: Abstract decisions	Researcher's thoughts about abstract decisions:
<p>Sparrow 1/29/14</p> <p>Decisions to hope, Decisions to dream were scary to her. Decided to be honest with sharing, Decided to feel joy and peace</p>	<p>Sparrow had decided to “not end on death” for her family’s journey- an abstract decision versus concrete decision to have another child</p>
<p>Eagle 1/29/14</p> <p>Conscious decision to feel, to allow feelings of anger, Decision to celebrate, Decision to not cry for 9 months, Decided to not be a ‘Drama Queen’ , Allowing the questioning of her faith</p>	<p>Eagle is in anticipatory grief as yet; still she is able to make abstract decisions about her grief journey. Abstract decisions can therefore be made at any point in the grief journey as opposed to “down the road, once healed”</p>
<p>Blue Jay 1/29/14</p> <p>Decision to share providing surprise Deciding to be honest, Deciding to feel together in grief with another mother of loss, connecting , healing Deciding to not regret</p>	<p>Decisions to participate in healing activity or sharing became a healing activity that allowed her to feel healed enough to conceive again. Wants to help others make decision to not regret.</p>

When the set of categories, themes, and common elements began to emerge, I met with my faculty chair who had reviewed the data herself to compare our analysis of the data and make sure that she could also concur with the inclusion of these themes and categories in the data. After this step took place, I typed out each line of gerund coding and cut them into little slips of paper that I could group onto theme pages and categorize further in a very tactile and visual process. This allowed me to clarify fit and extract a

more abstract view of the data as bits of data, by way of coded gerunds, came together into the categories and themes that made sense and had focus.

The last part of the process for me was to take these themes and categories now understood from the more abstract view after coding and go back to the verbatim data to connect these themes to actual participant quotes. Once I did this and had organized my findings, I was able to member check for accuracy. Instead of member checking with further interviews, in the interest of time, I contacted my participants by email to show my findings with them in this venue. The member checking was responded to by three of the five participants and in a way was also a debriefing of the interview process, at least for one participant who was able to share with me that it had been difficult to talk about the loss experience again but that it had been helpful and that she was glad she had done it. Of those who responded, none had suggestions for changes in the findings and feedback obtained was that it had been an accurate accounting of findings that they could agree with.

CHAPTER IV: FINDINGS

Description of the Participants

Recruitment for data collection opened on November 20th 2013 after IRB approval and closed on February 6th 2014 for this thesis. Five participants were recruited into the study. All participants described themselves as white and all were currently married. One of the participants was currently married to a different spouse than she had at the time of her loss. Participant ages ranged from 24 years of age to 42 years of age. It is interesting to note that despite the small number of participants, they represented all types of perinatal loss in the forms of early loss, stillbirth, neonatal death, SIDS, perinatal palliative care carrying to term, and perinatal palliative care choosing not to carry to term. As shown in Table 1, all participants were given an alias of the name of a bird to protect their anonymity after the interviews were complete.

The five participants had a combined history of nine losses between them as shown in Table 4, with some participants experiencing multiple losses in their own reproductive histories. Gestational age for those occurring pre-delivery, ranged from 6 weeks to 26 weeks at time of loss. Losses occurring after birth included a three day old neonatal death and a five week old SIDS death. Time elapsed since the loss, ranged from 11 months to 14 years with one exception. One parent was still pregnant during the interview process with a live child diagnosed with a definite fatal concern. Despite the length since the loss, participants were able to remember with fine detail, their

experience. One parent with a loss that had occurred nine years previously stated, “I’m surprised at how I can go back to that moment so easily. It never leaves you.” One of the participants returned to a house void of other children while the other four participants returned to families already consisting of children in the household.

Table 4. Demographic information for participants

Assigned Pseudonym Name	Age of Participant	Type of Loss	Age of Child at Time of Death	Elapsed Time since Loss	Other Children in Household	Descriptor of Loss According to Participant
Blue Jay	35	Perinatal Palliative Care with Chosen Termination + Early Losses	19.5 weeks, 6,7 and 8 weeks	11 months	Yes	Pregnancy and Baby
Sparrow	42	SIDS	5 weeks after birth	9 years	Yes	Pregnancy and Baby
Eagle	33	Perinatal Palliative Care-Carrying to Term	34 weeks so far	N/A	Yes	My 1 st Daughter
Finch	38	Neonatal Death + Early loss	Full Term Pregnancy, 3 days after birth 8 weeks	14 years	Yes	Baby
Flamingo	24	Stillbirth	26 weeks	3 years	No	Baby

Participants were given the opportunity to describe what they considered their loss to be, the loss of a pregnancy, the loss of a baby, or terms of their own choosing.

The loss of a baby was the sole descriptor of two participants while two other participants

chose both the loss of a baby and the loss of a pregnancy simultaneously. One participant described her loss in the words of gender with “my 1st daughter.” I created this opportunity to extract the meaning of the loss from the participant before assigning or assuming the meaning, which allowed me to partially understand the relationship before the interview started.

Findings in a Sacred Space

The research question for this study defined in Chapter I was:

- What decisions do mothers of loss remember making at time of loss until now and what became helpful or unhelpful in the process of deciding among those paths?

Due to the sensitive nature of the discussion, I needed to establish a trust relationship with the participants of loss and thus protect their best interests by providing an environment of therapeutic listening. I hoped that in asking a more general question to start the interview, creation of this safe and sharing relationship could begin and data distinctly related to the research question would emerge spontaneously. Following the general question, I asked more focused questions related to decision making recollections. This allowed me to extract themes from the data that contained the elements pertaining to the study aim. By following these steps, I gathered more information than required by my study aim but I needed to enter this sacred space of memory and invite the participant to share difficult memories in a way that was comfortable for them. Allowing for this less focused exchange created this safe and sacred space of sharing. After analysis and as themes revealed the broad area of data produced from this general question, I focused on ideas prompted by the analysis. The

analysis was allowing a higher level of abstraction to occur and new ideas were flowing from the data repeatedly that I could concentrate on in the scope of this descriptive study. I needed to deliberate on some of the results that I saw as providing a truer and richer meaning of the experience than my previous understandings allowed. Member checking occurred after themes were well established to focus even further into the themes extracted from the data. The last interview was used as a method of checking themes again since themes had already been established prior to the last interview. I hoped that the themes would re-emerge naturally during the last interview as a way to confirm the analysis thus far and they did. Despite the fact that only five interviews took place, the amount of data obtained while following this plan was amazingly rich and prolific.

Major Findings

Making Decisions for an Eventual Path

The recollections of mothers of loss regarding decision making along the trajectory of the grief journey represented much of my data and included thoughts and feelings related to those decisions. The interviews showed the complex and ambiguous pathways available to each of the mothers upon their review of their journeys. Participants assigned magnitude to decisions, described some decisions as difficult, big, permanent and having created struggles. The women remembered how they made decisions, with whom and what helped them to make these decisions. Unprompted review and judgment of decisions usually followed as seen in this exemplar from Finch.

I, I don't think I would have done anything different. I loved the decisions we made about bringing him home, I loved that he passed away at home, I loved that all my family came and I let, ya know, everybody got to hold him.

Participants disclosed that when a decision was difficult, sometimes they actually chose to avoid the decision all together knowing that they were making a decision with avoidance, which had consequences of its own. The women used avoiding and postponing decisions when they expressed their coping ability as minimal. They knew that avoiding was a decision easier to make, still a definite choice as seen in these exemplars from Blue Jay, Sparrow, and Eagle.

“So that you know I couldn’t, it would be like not making a decision, but sort, but making a decision by avoiding it.”

“I couldn’t handle it so the big decision I made was I wasn’t going to address it.”

“I can’t, I’ve kind of avoided that one.”

Two different kinds of decisions came into view, concrete and abstract. Concrete decisions included the decision to have another child or try again after the loss; relationship decisions post-loss and decisions related to time spent with the child’s body, final disposition, and funeral practices. Sometimes, the magnitude and eventual path of the decisions cascaded into decisions that became important in a healing journey for that particular mother ultimately. This was apparent in this remark from Flamingo when she described,

And I’m glad we didn’t cremate her in the end...We buried her and we have a place for her. We could have just had her and move, like just get out of the hospital and just pretend it never happened and I think that guilt would have overtaken us eventually if we would have done that. Um, ya know. What did our child look like? What um, what would we have done? Why didn’t we bury her?, um, Why didn’t I touch her and hold her and know who she was even after death?, and um, I definitely think that those, there are so many different paths that

you are looking at and in a situation like that and sometimes you don't even realize that you're choosing a path until you're already on it.

One parent of loss repeated the idea of not knowing the lasting effects of decisions made at time of loss and attributed it to how quick the decisions came flying at her. From Finch:

You don't even realize you are making the decisions, ya know but you don't have time, it's, I mean, anybody would love, oh well let's do this in a year or [*giggle*] you don't, they come and go so quickly and I think mostly for us it was just, it was just about healing and being okay with it and remembering him and loving him and being okay with that and having those memories and and with the whole situation, being okay with it.

The women cited opportunities to make abstract decisions along the journey such as allowing oneself to feel joy again, celebrating their dead child's life, allowing themselves to enjoy life, to accept it, to feel peace, to hope again and to dream again along with allowing themselves to do what felt good. Abstract decisions like these followed a repeated pattern of the intuitive knowledge that in order to survive this experience of loss, the women would need to get out of bed each day and move even though that wouldn't have been their choice at the time. Finch recalls it as a conscious decision in this example:

And I kept telling myself, I need to choose now, what I'm gonna do, ya know whether or not I'm gonna let this affect me for the rest of my life or if I'm gonna get up off the couch and take care of the child I already have.

The Concept of Emotional Ambulation

We all know that movement after a surgery, despite the pain it causes promotes healing. Inertia, on the other hand, can be the source of complications and even death post-operatively. These parents of loss compared their loss to a deep cut or injury but situated on their emotional being for which they expressed the innate need to move as a way of healing. They seemed to know this intuitively and not as something they had to learn along the way. There was an absolute line expressed by these participants, between the choice of insanity and healing from this experience by making themselves move. The participants expressed it in various ways including:

“I could just be a crazy person that sits around and does nothing and falls apart, or I can just make the decision to get up and move, ya know.”

“Sitting and hoping for healing didn’t feel right.”

“Choosing not to just sit with it.”

“Devoting all of my energy to just getting out of bed every day.”

“weighing the choice of shutting down or getting up and moving on.”

“maybe that was helpful actually, to keep going.”

“I can just shut myself off completely or I can get up and move on.”

“I could sit around and cry only, but NO, I don’t do that.”

“It was all I could do to get out of bed, get myself dressed, and take care of my girls well, and which I did and that was my priority without a doubt at that point.”

“It would have been easier than to step out of bed every day and try to heal, not necessarily move on, I don’t like that that phrasing, move on, um but move forward with everything and with those scars”

Every participant voiced this knowledge regarding the need to move in some way in their early and fresh process after grief. One of the participants referred to the beginning of the process as a “huge open wound” initially and comments on her healing journey by saying “there is definitely a scar there but it has healed very nicely.”

Contrasting these choices is the alternate choice:

“I was very unhappy and even getting out of bed every day was hard.”

“I know I wouldn’t have gone to the gym if my sister didn’t drag me there, so I would have just hunkered down in bed”

“Even getting out of bed every day because after a loss, your mind and your heart are in a very dark place and a very unhappy place and to be able to let light in and move forward is a lot of work and sometimes it would have just been easier to stay in bed.”

The choice for healing seemed clear to them all. The repetitive movement over time seemed to give way to the healing process. For most of my participants, more abstract decisions in their grief journey like celebrating the lives of their deceased children as an experience that produced growth or progress along their path and ultimate journey followed as witnessed in this quote from Finch:

I think the biggest thing is just to remember that you can get through it, that at some point in time, it won’t hurt as much, that you get up every day and just make that step and it truly is at the beginning just a day at a time, ya know and that it is okay to still have emotion about it, it is okay to still feel it and grieve for that person or that loss um, especially early on...um I think the biggest thing is just remembering that you’ll get through it, you will get through it, ya know and it will get better every day, so and you’ll move on and other miraculous things will happen, I mean I don’t think there will ever be a day that I don’t think about him

or, it just doesn't ever go away, I mean he was one of my children...I don't know, you just keep celebrating him and moving on.

Emotional ambulation is not a term I have ever heard of before, nor could I find it upon searching the literature. It seemed to be the most succinct way to label what the women were referring to and describing to me.

To Share or Not to Share

One of the more fascinating findings in this study turned out to be a theme related to the parent's decision of sharing the knowledge of the deceased child with others. There evolved in the data a description of the realization that they had a choice about showing the invisible child versus not sharing that information with others as shown here by Sparrow. As I listened, I could almost hear the frustration that her son was not obvious to all around her.

I was a woman with three girls and I didn't have any visible sons and I often got comments about, "don't ya want a son?", or when I was pregnant with G-----"Are ya goin for your boy?" NO, I already have a son, ya know, he died in infancy but I have a beautiful son named L--- and and most people "oh, I'm so sorry" are really appropriate and receptive, but there were those people that were really uncomfortable with it and then I felt bad at that, it wasn't so much that I had problems with the placement of him in my life, sometimes I felt awkward that I'd made somebody else feel uncomfortable because, I have a son, No, I'm not trying for my boy!

The women would relate how oft times a hurtful comment follows or an awkward moment or an uncomfortable reaction occurs for parents of deceased children when they choose to share them or make them visible. Eagle, Blue Jay, and Sparrow all provided

descriptions of spur of the moment decisions to share or not to share the presence of their children with strangers in conversation. They identified both positive and negative reactions from sharing in their combined stories with elements that told of self-preservation, honesty, and honoring contrasted by discomfort, “weirdness”, and awkward moments. Sparrow said it was just as likely to have a healing positive experience that bonded them to a complete stranger when sharing as it was to receive an awkward, uncomfortable reaction from a dear friend. Eagle confessed that she did not know what made her decide to share or not to share with certain people but it was definitely awkward at times. Flamingo shared:

If I could change one thing in people’s minds and in our communities, it would be to tell them that it’s okay to talk about it and share and just, because it’s unknown to them, it would make a huge difference if people could just not feel so uncomfortable with it but let that person who has faced the loss just talk about it.

One parent discussed the solution to this barrier for her by putting it out there into a visible place for others to see in the form of a tattoo. She discussed how it was part of her need in healing:

That was the way I was going to heal, talking about it to friends and family and I could watch them kind of almost squirm after a while when I would talk about it but that was what I had to do to kind of get through things... I decided to make it a part of my life that I wasn’t going to hide and a part that, even though it was so hard, it was building a lot of strength in me and my husband and it did so much for our relationship as a whole... whether it’s a miscarriage or a stillborn or a baby that’s three years old, it tends to be this socially awkward thing that people don’t talk about and it’s hard for women like me to move on if you can’t talk about it and to heal...both of us got tattoos...doing that, we also knew that we would be asked about um, about our tattoos, what they meant and why we got

them and who's *H-----*, so that was also a decision, we were gonna have to decide to tell people when they asked and sometimes you can just watch their faces completely change as soon as you say, well it was my daughter that passed, but for us, it's a moment I can talk about it.

The Broad Spectrum

Various findings not related to the study aim and yet of interest but not within the scope of this thesis were uncovered and discussed by the participants. Many sections of data dealt with faith, crisis and questioning of faith, relationship with God, relationship issues both positive and negative, ongoing grief of other children in their households, and pregnancy fears following loss. I needed to put aside this data, although captured and coded and focus on a reasonable size of data for this project and study. These data have not been discussed as findings.

CHAPTER V: DISCUSSION

Increasing the empirical knowledge in the body of nursing and for those who routinely interact with this population was certainly the reason behind doing this study. I would like to help those who face this population in a practicing role know, empirically, what would help this population. Translating research into improved practice through education is what eventually changed my journey from one that was awkward and uncomfortable to one now that understands more about the options for helping to start a healing journey for the bereft parents I meet. As a new labor and delivery nurse, I did not anticipate working in end of life care. My hope was to welcome new life, not bid life goodbye. My nurse mentors were equally distressed when faced with a fetal demise. Back then, we determined the difficult assignment by drawing straws. That's what we did, we drew straws. The nurse who possessed the short straw was assigned to walk alongside the couple through the delivery of their dead infant. Drawing straws seemed to be my only chance of getting out of this uncomfortable obligation. I recall how difficult it was to just give the physical care they needed and had no knowledge base at all to care for them emotionally. To this day, many nurses don't know how to manage care for those experiencing perinatal loss. After thirty seven years at the bedside, I have replaced this shameful beginning with a passion to know. To know what can help, to know I can make a difference, to know that there is still much to learn by exploring the grief journey through research.

Models and theories are helpful because they describe, predict, and explain nursing practice. Nurses can utilize grief models and theories to enhance their clinical expertise. Having a theoretical foundation for care enables the nurse to replicate interventions, to examine the results, and have consistency in practice. Just as a nurse follows the rules of medication administration so as to provide consistent, safe care, approaching perinatal loss guided by grief theory supports the patient and provides a personal comfort level. Rather than being an abstract, unhelpful academic exercise, theories become useful tools to guide therapeutic interaction with the bereaved parent.

My participant Flamingo made a clear point when she shared the reflection that both nursing and medicine guide decisions of newly bereaved parents as they start their grief journey.

The whole situation starts with the caretakers, the nurses and the doctors, because obviously they know all of the medical stuff, but they can make or break the experience even worse than ya know what it already is, and if I didn't have my nurse and I had some girl who was awkwardly talking to us, I think that would of um hurt us more. She had a lot of different options for us on just things to think about and we were able to ask her, like, what do you do in situations like this and she said, some families do this and some families do that but her advice was sound ... and she didn't rush us at all too, she told us to take our time, she definitely influenced a lot but she was very knowledgeable in that, I can't even explain it but just the way she talked to us was very comforting. We didn't even know she had had a loss until we had asked her, so she wasn't making it about her at all either, she definitely made it about us and comforting us, she knew what we needed and what we needed to hear. Her slowing down the pace helped us to make the decisions, the fact that she wasn't in a hurry, she gave us a lot of answers and so we left there knowing things.

The participant calls out the importance of the nurse in this instance, recalls appreciation for her guidance and care and recognized her as a therapeutic and helpful agent. How might we make this type of relationship a gold standard in the care of the patient experiencing perinatal loss? What happens if medicine and nursing are not following the same theories to guide their practice? Might this be confusing to the patient? Is it the first of many lessons about the awkward and uncomfortable reactions they will witness on their journey?

In order to discuss my findings in relation to where they fit in current theoretical thought, a review of present day observed practice and usage of theories is reasonable. Witnessed current practice is not necessarily congruent with current theory.

Detachment Theory of Grief

Munson and Leuthner (2007) discuss that medical clinicians may strive to prevent a strong bond with a dead baby believing that it may lessen the pain of the loss. They purport that prevention of this bond may be the driving force behind the recommendation to terminate a pregnancy that has been diagnosed with a fetal fatal concern. Packman, Horsley, Davies, and Kramer (2006) also correlate the medical model with detachment, branding this as the historically essential finished adaptation to bereavement. In this light, medical best practice for perinatal grief moves the patient on from a failed pregnancy as quickly as possible, learning from the experience to guide care for future pregnancies that may become successful. This model does not consider the need to process the current loss or even delegate the failed pregnancy into a meaningful place before moving on (Uren & Wastell, 2002). Detachment may not support the needs of many parents who prefer to seek out continuing bonds with their child or make the more

abstract decisions in grief as seen in Table 5 of where they will place this child in their life story.

Uncovered in my study were the thoughts of my participants regarding the decisions they recall making at the time of their loss. The thought expressed about how quickly the decisions came at them and how they didn't realize how these decisions would affect their eventual ability to feel healing on the journey deserves some consideration as to slowing down the process for the parent and allowing time to process information at their own pace.

Dual Process Model

Contemporary bereavement models introduce the dual process model (DPM) of bereavement (Stroebe, Schut, & Stroebe, 2005), one wherein the bereaved oscillate between two different states in their bereavement; one state that confronts the grief, a loss orientation mode and the other, the avoidance of the grief, pain and the need for distraction from it, a restoration mode. This sometimes takes the form of engagement in activities of daily life that continue despite bereavement.

Table 5. Examples of decisions to keep moving, concrete and abstract decisions

Decision to Keep Moving Emotional Ambulation	Making Concrete Decisions	Making Abstract Decision
Get out of bed everyday	Burial or Cremation	Deciding to be okay with it
Go to the Gym	See hold and touch after death	Accept it
Take Care of other children	Have a funeral or memorial	To feel joy again
Not just sit with it	Decide to try again, have more children	To dream again

<p>Got on the elliptical and sweated and cried and sobbed</p> <p>Get up off the couch and take care of the child I already have</p> <p>Moving forward</p>	<p>Get a tattoo</p> <p>Share the knowledge of his death with others, make him visible to others</p> <p>Stay within a relationship or not</p> <p>Avoid making decisions that are too hard right now. Decide to not deal with it.</p>	<p>To let light in</p> <p>To hope again</p> <p>To not end in death</p> <p>Place the child in my life story</p> <p>Grow, find meaning from the experience</p>
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Parents often meet this experience of grief together with their partner. A recent study concluded that cohabitation and marriage is at a significant risk of relationship failure after miscarriage and stillbirth compared to relationships that come through childbearing with a live birth (Gold, Sen, & Hayward, 2010). When an explanation of DPM ensues, parents may have a good tool giving each individual the permission to oscillate in their grief separately and asynchronously. Parents may realize that caring for other children in the household or doing other distracting duties becomes a way to put aside grief temporarily adding to restoration. This may tie into the initial decision of my participants for the need to continue to move, getting out of bed every day and putting one foot in front of the other as they navigate their paths. Sparrow illustrates part of the model here:

I don't know if I could have gotten up every day if I didn't have these two children looking to me with love. Umm, "Mommy come play, mommy read me a story, mommy, are you okay?, I'll rub your back, Mommy, I love you, it'll be okay, Mommy, Momma, let's go outside and play", ya know, how can you not suck it up and move on, I love these girls ...

One of the first decisions my participants remembered when queried about decision making recalled from the perspective of looking back on their journey was the decision for what I labeled emotional ambulation. When they decided to keep moving, the ability to make more concrete decisions regarding their relationships and whether they would have more children or try to get pregnant again followed for each of the participants as they recalled their experiences and shared their recollections through interview. I have no intention of making the claim that the decisions displayed in Table 5 follow in a linear progression. Each participant was eventually able to make the more abstract decisions to hope, dream, accept, grow, and find meaning in their experiences. It was interesting to note though that even Eagle, although she lived in anticipatory grief during the interview, was also able to call out abstract decisions she had already made.

Middle Range Theory of Chronic Sorrow

Another theory to consider is the theory of chronic sorrow. Eakes, Burke, and Hainsworth (1998) maintain that it is important to declare that chronic sorrow should be conceptualized as a pattern that falls within normal grief, not pathological grief. It is anticipated that perinatal loss will result in normal periods of grief and immobility in the process as “Chronic sorrow is characterized as pervasive, permanent, periodic, and potentially progressive in nature” (p. 180) and the

Theoretical premise of chronic sorrow allows that people may periodically re-experience the pervasive sadness or other grief related feelings that occur when initially confronted with the loss. Although each episode of sadness abates over time, circumstances or situations in which the individual is confronted with the disparity created by the loss trigger recurrence of the grief-related feelings. Because of the cyclical nature of chronic sorrow, periods of happiness and

satisfaction are interspersed with episodes of re-grief, thereby preventing the grief from becoming incapacitating. (p. 180)

In the previously done unpublished study (Jonely et al., 2009), there was a theme of due date emotions that brought up the renewed grief of the mother in a way that resonated with the theory of chronic sorrow. Lily relayed in that study,

I just passed when my due date would have been, oh just like three weeks ago, four weeks ago and people kind of tend to forget that time frame, that it kind of happens all over again and gets worse and harder as you get real close to the due date because you're just thinking about how old the baby would be now and what I would and wouldn't be doing right now if I had the baby and cause up until that point its, its kind of like you're, you're still pregnant and the baby wouldn't have been here yet anyway so there's a loss but it's kind of an absent feeling of loss and then once you get to the due date, it's like it's a real loss all over again. (p. 4, Lily transcript).

Even though normal grievers may be affected by chronic sorrow, these women were able to show, especially when considering their abstract decisions, that it wasn't a constant state wherein they dwelled. Instead, it may have been a direction that their grief journey followed for varying amounts of time and even returned to intermittently when triggered by events that made them sad.

Blending of Available Models

It is possible that the blending of all of these models is necessary when meeting the needs of the perinatal loss population. One model is not necessarily completely wrong or the other model completely right. It is important to recognize the potential strengths, benefits, and risks of each model as applied to perinatal loss parents and at

each new relationship with differing families. Application then becomes thoughtful, personal, and patient-centered in each circumstance, becoming just what that patient needs and based on consideration of the available evidence.

The medical model has its place in this collaborative care because information collected from a failed pregnancy is valid and needed for future fertility concerns of the couple. Physiological homeostasis is also imperative during the intrapartum process. Some parents themselves do not assign the need for continuing bonds to a failed pregnancy but instead view a miscarriage as a needed medical procedure as opposed to the loss of a baby. Intensity of grief cannot and should not be predetermined, assigned, or assumed by anyone other than the persons experiencing it. As long as the parents are the ones assigning the need for detachment, and not the medical care provider who is dismissing the loss, there is nothing wrong with following this model. Many people, when faced with the initial news of perinatal loss, feel as though they want to speed the process up and detach from the pain as soon as possible. It remains the decision of the parent and not the caregiver as to how the best way to journey through their grief might be. Relationship-based care in perinatal bereavement occurs after informing and educating about all options and then the best path to take is decided by parents. This way of supporting may need to be taught and considered by all disciplines (Limbo & Kobler, 2010).

Illustration of a Potential Grief Trajectory Model

Complicating my own theoretical thoughts are considerations of whether being stuck, having complicated grief, or experiencing chronic sorrow are all the same, or different and whether it is completely normal to experience these all at times in grief in a

teeter-totter motion that occurs over time. The discussion within the chronic sorrow model (Eakes et al., 1998) is that chronic sorrow is considered normal grief and not pathological. Figure 1 shows the normal fluctuations of normal grief between a trajectory of healing and meaning making and being stuck or experiencing chronic sorrow still all within normal expectations after perinatal loss. The trajectory could be constantly in motion or become fixated either in an eventual upward or downward path depending on the individual experience of the griever with differing influences able to tip the trajectory for each patient one way or the other either temporarily or for a considerable amount of time.

The systematic review of Gold, Dalton, and Schwenk (2007) indicates that more than 1,100 studies over the last 40 years demonstrates opportunities for hospitals, nurses, and physicians to improve the care of parents who are coping with perinatal loss. These include options that promote contact with the baby, encourage parental participation in important decisions after the death, and provide parents with information and care options in a timely and supportive manner. (p. 1163)

Figure 1 is an illustration of the fluctuations potentially present in a normal grief trajectory where the griever moves between normal variations and periods of: a.) a healing journey, meaning making, or restoration orientation, and b.) periods of being stuck, having chronic sorrow, loss orientation, and/or complicated grief.

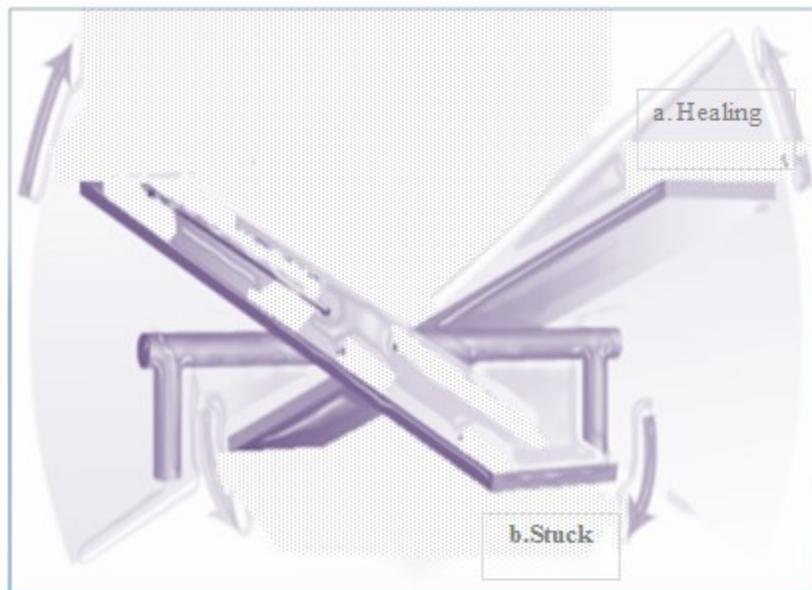


Figure 1. Illustration of potential grief trajectories

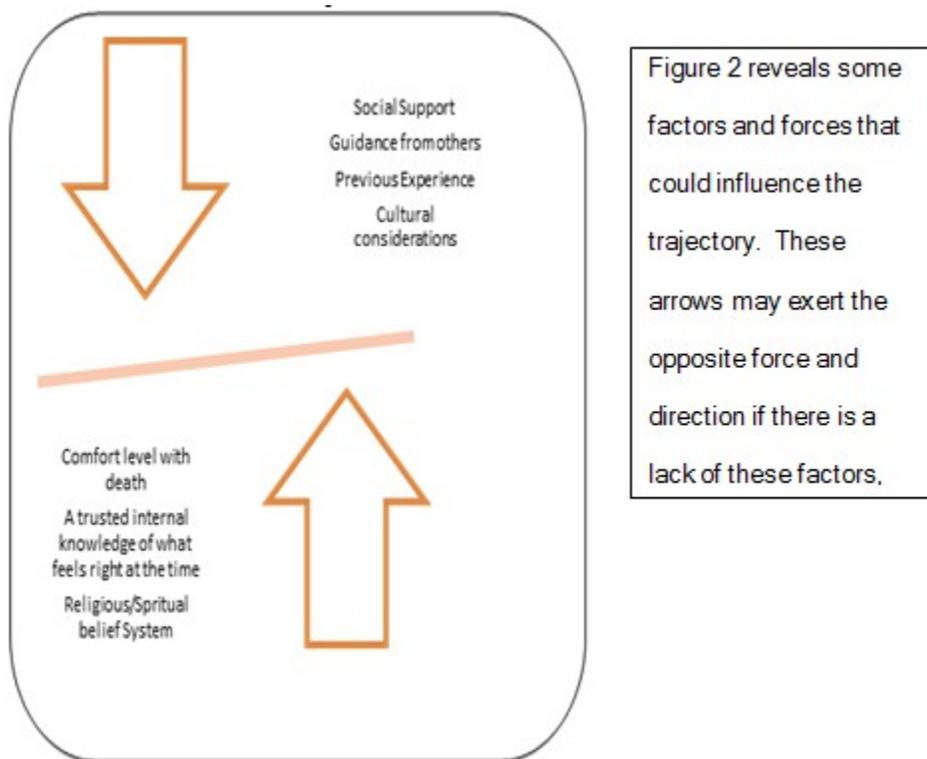


Figure 2 reveals some factors and forces that could influence the trajectory. These arrows may exert the opposite force and direction if there is a lack of these factors.

Figure 2. Forces that exert on trajectories

Along with these influencers are the parent's social support systems outside of the hospital, their own personal beliefs, and comfort with death or what might feel meaningful and important to them at the moment. These might all be manipulating elements that cause either oscillation or stability in their trajectory and ultimate journey.

The model, as shown in Figure 1, is placed on a fulcrum that represents the ability for the arrow of the trajectory represented to be tipped in either direction, one towards healing and the other toward being stuck. It is my question in this discussion as to whether it is the grief experiencer who propels towards one direction or the other based on the forces exhibited surrounding their experience? Is one direction toward a healing journey; is the other towards complicated grief often compared to being stuck or the model of Chronic Sorrow (Eakes et al., 1998)? Does a normal response to grief have the arrow rocking up and down depending upon moments throughout the days, weeks, or months following the loss as found within the Dual Process Model (DPM) of grief in following loss or restoration orientation (Stroebe et al., 2005)? Is the tipping of the trajectory back and forth from their combination of thoughts and feelings combined through passage of time with other thoughts and feelings they and they alone experience as Rosenblatt and Bowman (2013) have described? Does time stabilize the movement so that parents can make the abstract eventual decisions about the journey when looking back, allowing themselves to feel peace, joy, and acceptance, or letting light in again, or possibly the abstract decision to feel traumatized and unresolved in their grief journey from long-lasting decisions of regret?

This really does reinforce the role of the nurse in the healing journey of the perinatal loss parent. Slowing down the decisions and providing explanations that these

decisions are the start of their healing process is clear from Flamingo's perception. It was my intention to study how parents of loss decide at all of the crossroads on their path what might be meaningful, healing, or detrimental to their healing process in perinatal loss.

After this inquiry, I still think that the answers may be individual for each person and intuitive to some degree, and still complex and ambiguous in agreement with Rosenblatt and Bowman (2013). It is the 'intuitive to some degree' that I pick out here to discuss. If guidance from a care provider at time of loss does help or hinder the ultimate journey, then more research into these phenomena is necessary. More knowledge in this realm could help us clearly realize that the concrete decisions made right after loss may have an effect on the abstract decisions that follow later. Arming ourselves with knowledge to share and becoming comfortable ourselves in talking about death and knowing all options and choices to present to parents of loss would then become very important as a supporting role. Translating research knowledge through education to the nurse practicing at the bedside would then be beneficial to this population. Hart (2012) states, "A large body of research supports that people follow different trajectories after a loss of a loved one, with a broad range of religious and cultural differences in the way that they grieve" (p. 145). It would not be that nurses or physicians would determine the ultimate path of a griever, because the care providers do not make decisions for the parents of loss, but instead it may just be the supporting role of shining light to the paths and decisions available.

Limitations

The first and most obvious of the limitations of this study were the sample size. There were only five participants, all of the same ethnic background, all married and within one community. While I did not request to know the religious background of each participant, general sharing of religious beliefs was present in some of the interview data. When shared, it also presented a broadly analogous Christian background. While the participants represented different kinds of perinatal loss, was it of further limitation to note that there was only one participant of each type of loss in the study present? Five participants of each type of perinatal loss may have been more ideal to show a pattern of typicality in each type of loss.

Time for this study was also a limitation. This study aim could become an entire life's work project. Placing this study into the time constraints and study aim of a single master's level thesis project was a limitation unto itself. While this may be a limitation for this particular study, I hope that further work will start in this arena, which may make this limitation productive. It is hopeful to think that this study produced a curiosity in other investigators who might want to know more than the scope of this study could produce.

Emden and Sandelowski (1999) state that a "properly done" study possesses rigor, while Holloway and Fulbrook (2001) discuss the complexities of a 'properly done' study and include the discussion that follows:

In nursing and midwifery research, the researcher may know all of the participants and this previous association may influence the content of the interview. This might contribute to the potential for a halo effect, described

above, but on the other hand, it might enhance the interview environment by promoting a more relaxed and friendly atmosphere. (p.548)

I would have to call this 'halo affect' possibility out in my study as a potential limitation as well. Holloway and Fulbrook (2001) bring up the 'halo effect' as a potential occurrence when the investigator knows the participants creating their desire to want to say 'the right thing' because they want to be perceived in 'a favorable light.' Although the participants were advertised for, I knew 4 out of 5 of the participants who responded to the advertisements. Since the subject of inquiry is a very sensitive subject and requires trust to be established, this may have been of benefit to allow the participants to feel open to investigation of the subject allowing for more ease of data to flow instead of it being a limitation; however, I still want to acknowledge it. I could not sense a desire for the participants to be seen differently in their responses because we had known of each other before the interviews, however I will call it out as a potential limitation.

Implications for Further Research

While the decision to keep moving seemed to be intuitive knowledge within each participant, some of the women reflected that concrete initial decisions such as seeing, holding, and disposition were decisions that they welcomed help in making. Flamingo specifically asked her nurse, "...like what do you do in situations like this?" One suggestion for further research would be to question the way nurses practicing at the bedside of the parent of loss see their role for providing options. How do they help parents with their decision-making duties? How do they slow down the process allowing for acceptance of decisions that parents don't want to make eventually being made and appreciated? A multidisciplinary study to inform about differences or similarities

between medicine, nursing, spiritual care, and social work would also be advantageous for this population. Is medicine alone responsible for assisting parents with the “big” and “difficult” decisions while “smaller decisions” delineated to nursing? Is nursing comfortable with their role or are they even aware of it? Does spiritual care, when available, feel as though they own this role and are they comfortable sharing it with nursing? Does nursing prefer that social work take care of the emotional needs of this population? There may be “cultural” norms in each institution for these questions or well established pockets of those who “take on the role” because they are “good at it”, leaving others to deny it as part of their own practice repertoire because of lack of education, lack of expertise, or assumptions about whose role it is.

According to McCreight (2009), physician care, in terms of perinatal loss, is viewed as insincere and abrasive. Aho, Tarkka, Astedt-Kurki, Sorvari, and Kaunonen (2011) found that only 11% of fathers experiencing a loss found the doctor helpful for their loss scenario. Gold (2007) performed a systematic review spanning 4 decades of literature. These U.S studies included more than 6,200 bereft parents, 90% mothers and 10% fathers. Gold found that physicians were the least helpful of any type of staff described as cold or neutral by 15 out of 28 parents in one study. In seven studies, parents put the blame on medical staff for minimizing their concerns wondering whether their infants might have survived had they been taken more seriously. Rushing parental grieving is perceived as dismissive and may exacerbate these feelings.

Gold (2007) concludes that although nurses tended to be rated as more supportive than other staff members or physicians, a large number of parents experienced poor support from nurses too. One project had only half of the parents believing their nurses

listened to them. Another study concluded that a full third of the nurses were cold or neutral. The most frequent condemnation was the lack of emotional support or in some cases, blatant insensitivity. Some nurses find themselves incapable of caring for this patient population. Jonas-Simpson, McMahon, Watson, and Andrews (2010) related that there is limited published research in the nursing literature regarding obstetrical nurses' experiences in caring for families with perinatal loss but also noted that obstetrical nurses rarely anticipate death as being a part of their nursing practice.

Within the theme of deciding to share or not to share seemed to be a longing within the participants for the ability to share their children with others without having to deal with the uncomfortable, awkward, and "weird" responses they received in return. Most parents of live children enjoy the ability of others to see their children present with them, to have knowledge of their parental status from seeing a live child beside them. The parent of a live child does not make that decision. It is not a choice because their children are visible and an obvious fact. Sharing knowledge of a deceased child is optional and includes the possibility of unwelcome responses from others. I was able to uncover that my participants considered the potential consequences sharing involved and generally did not want to hurt others but instead wished for a society that allowed sharing to be a positive experience. The knowledge that they cannot openly share their children without a possible positive or negative response from others was something that each one of them learned along the trajectory after loss. The participants recalled the positive responses as very meaningful events and cherished them. Some of the negative responses recounted by my participants were unwelcome sharing of beliefs as platitudes of religious merit. Yet to be explored might be the uncovering and realization of not agreeing with

the religious beliefs after loss of the “norms” of a certain religious community, yet knowing one identifies within that community. Does this foster eventual growth or cause a faith crisis? Does sharing regardless of response equal honoring the child to the parent? Does enduring the negative responses create strength? Do parents measure their progress on the grief trajectory or their assessment of healing response by how much it hurts or their ability to cope with a negative response?

Implications for Education

A 9-study systematic literature review to answer the research question of “in what ways is end-of-life care included in US medical school training?” (Bickel-Swenson, 2007) provided a large variance to the answer. Further analysis concluded that frequently end-of-life care remains to be an elective course. It is hopeful to note that programs for hospice/palliative care have increased from 17 in 2000-2001 to 52 in 2005.

Directly related to nursing education, Steven, White, Marples, and Atkinson (2014) used an assessment tool that showed low confidence especially in communication regarding end of life care in their study, which showed the ability for improvement in confidence after an education pathway was completed by the nurses. Before the educational intervention, nurses continued to report a low level of confidence in communication offering up terms such as “clumsy,” “not streamlined,” and the colloquialism of “making a right mess of this” when talking with patients on the subject of death. Gilan, van der Riet, and Jeong (2014) also report a current continued lack of end of life nursing education when they state “Education of death and dying continues to have a minimal and inconsistent presence in most undergraduate nursing curricula and training is neither adequate nor appropriate” (p. 331-332).

I would concur that most physicians and nurses still continue with a relative discomfort with end of life discussions and practice and that education on the subject could certainly improve comfort with care and a lessening of the awkward and uncomfortable moments that parents of loss in my study noticed and wished were not a part of their experiences. One suggestion would be to incorporate interdisciplinary education to both physicians and nurses together so that discussion and learning from each discipline can occur. According to Humphris (2007), “there is a growing need for more collaboration between professionals, agencies, providers and above all, the people they seek to serve” (p. 53). The focus of interprofessional education theory is that we are able to see the world through the eyes of other professions so that the outcome of collaboration in care is enhanced. Characteristics of cooperative, collaborative, and social learning emerge as interactions among participants who contribute their understandings and come together to form new knowledge.

Implications for Nursing Practice

Nursing practice draws from the continuing bonds theory, which involves making memories and slowing down the event of separation to process, attach, and assimilate the loss. The notion of continuing bonds theory developed in disagreement to detachment theory. In the 1980's, White, Reynolds, and Evans (1984) brought continuing bonds into the purview of perinatal loss. They noted that to establish normal grieving, the bereaved parents must accept the reality of the person who has died by creating a bond with a brief and memory-inhibited life.

Davies (2004) concludes that indeed there is a changing understanding of parental grief that holds a place for continuing bonds theory. Arnold and Gemma (2008)

reformulate parental grief as a life-long process and state that “parents do find a multitude of ways to remain connected to their dead children, including using the senses like smell and sight, images and rituals” (p. 670).

Fetal loss occurs in various settings and not all intrapartum, emergency room, or surgical nurses have had training for bereavement care. Nurses in one study reported having fear of saying or doing the wrong thing for parents in this circumstance (Jonas-Simpson et al., 2010). Nobody wants to deliberately injure an already hurting family. In their fear of injury, nurses may make themselves more comfortable by socially isolating the patient. Spending as little time as possible with parents, in their own minds, reduces the opportunity to do harm. These were my thoughts when I initially started to care for perinatal loss parents as a new labor and delivery nurse. In my analysis, this act in itself does further damage. From this, the patient senses the need to separate from society, hide grief expression, and not offend others with their pain by sharing their grief or the knowledge of their dead child with others. My study showed that mothers were aware that the sharing of their child with others might produce a positive or negative experience. Might the awareness begin as parents are exposed to the comfort levels of their nurses or doctors in hospital as they decide their courses? Much can be done through education to make the care providers more comfortable, less awkward, and therefore more therapeutic as an agent at the bedside and beyond.

Summary

Much research is still needed in order to draw conclusions from the data obtained in a small qualitative descriptive study such as this one. One might say that more questions than answers were propagated by doing this study and it is my hope that more

investigators would be intrigued by the questions generated by this study and pick up the research mantle to continue to explore based on findings from this project. I found it interesting to explore the ideas that concrete and abstract decisions after perinatal loss continue to be made well into the grief trajectory, which maintains the thought that healing from perinatal loss can be a life-long journey. Improving awareness of the need for perinatal loss parents to have caregivers who understand their unique needs and a community that allows parents the ability to share their needs in a comfortable way seems reasonable as a conclusion.

CHAPTER VI: REFLECTIONS

The exploration of self-growth derived from this project seems very intense as I sit today writing about the feelings and responses I experienced through this incredible academic exercise, my thesis. Many of the responses I noticed within myself, to hurt and experience joy at the same time, to love and hate the work simultaneously, to feel deep sad empathy and great joyful excitement as I discovered new ideas surprised me, and at times seemed at odds. I could not help but contemplate how my population of interest must also make sense of something so at odds as birth and death experienced together.

The Art and Science of Nursing

I reflect on the combination that nursing is both an art and a science and rarely can I divide them. It is with my practice of nursing that I see these two elements fused, one unable to function without the other. Obviously, a thesis and research must reflect strongly only the science side of nursing for that is what research and thesis are, and there is no room at all for the art of nursing within. While this is mandatory, I also found it frustrating. In this experience of reflection therefore, I will take the opportunity to note the influence of the arts on my thought process along the way.

After my first and second interviews, I was emotionally drained because I listened to heart wrenching stories regarding ongoing relationship struggles with my participants and this was something that I was not expecting. I was blindsided as I did not anticipate this to be a focus of my work. I was prepared to listen to distressing stories of loss and

grief but not ongoing struggles with relationship even though I was aware that this was an element of perinatal loss. It was difficult for me to explore a new and challenging ongoing issue for my population and I sought out a trusted mentor in order to debrief and refresh my perspective. I went on to find that there were other participants who had experienced a bonding and strengthening of their relationships post-loss.

I have explored the need within my population for artful expression of feelings as a possible healing activity and a suggestion or option after loss for journaling or journaling in art forms, even the process of SoulCollage® are of interest to me. In exploring these alternative art forms for grief, I have found personal expression within art can be a useful tool to release negative or burdensome feelings. Since I was somewhat burdened after my first interview, my mind for comfort in thought process decided to concentrate on something I found beauty in. In order to protect the anonymity of my participants, the idea of a genre of names for pseudonyms was needed and my heart followed the playful image of the beauty in the bird world.

The relationship struggles that my first participant was experiencing made me feel blue and depressed for her and therefore, I designated her as Blue Jay. My continued thoughts were those of the strong aggressive blue jays I had come across when I had lived in Southern California. These birds used to swoop down on my cat as I watched from my room as a child and squawk about their rights to their territory. They let my cat know in no uncertain terms what their needs were in our garden. Blue Jay, my participant, also seemed to be able to express her needs along her grief journey. She may not have realized them before the journey started, but I could see growth in her ability to voice

them now. This made me, in a way, very proud of her strength and I wonder if it may be something she will still very much need along her journey.

I christened my second participant as Sparrow because she had referred to her knowledge that her God, even through her struggles, was very aware of every one of them including her relationship struggles. I recalled a bible verse that reminded me of her general attitude during the interview in Matthew 29:10 where it reads,

Are not two sparrows sold for a penny? Yet not one of them will fall to the ground outside your Father's care. And even the very hairs of your head are all numbered. So don't be afraid; you are worth more than many sparrows.

The name of my next participant became Eagle because despite her being right in the middle of intense and current loss, she exhibited an attitude that reminded me of the soaring that an eagle does. She was exploring her feelings and open to positive aspects of the experience even though she was in the middle of anticipatory grief reactions. Although she has not experienced the full extent of what her grief journey will be, she was remarkably stoic and transcendent to the chaos of the time she was living through and with her eagle eye, looking for positive pieces to pull from the overall experience.

My fourth participant attained the name of Finch after her interview. A finch is a song bird by nature and my participant Finch had a lot to say and spoke so quickly during the interview that in transcribing her interview, I frequently would reflect on the name as perfection to her quick performance of notes and sometimes with repetitive choruses. I enjoyed her recollections, found them enlightening but also difficult to make sure I wrote down each and every note in her presto tempo.

My final participant received the title of Flamingo. I think of flamingos as birds of intense color and beauty surprisingly strong as they balance on their thin based legs. This participant is engaged in pageantry competitions and her platform that she ran on was the need for perinatal loss to be acknowledged in our communities for the allowance of public awareness. I was in awe of the strength in the thin legs of the bird to stand, weakened by the experience of loss, yet so strong to allow others to stare at her beauty and thus she received this fitting name.

I knew that I would want to assign the alias names in the grouping of a genre and the thought of birds came to be as I had previously used flowers in another study and it would be my little way of including an artful thought in a secret poetic sense. I mused that it would be a subtle and tender way for me to keep the confines of the science clear and under the defined need to protect identity in the strictest form of adherence to a scientific method and at the same time relish in the thought of an artful expression of who my participants were to me.

Another experience of how the arts have influenced my continued work into perinatal loss came about during my journey through graduate school as I was privileged to attend a Western Institute of Nursing (WIN) conference in Portland during my first year. My son lives in Portland and is a student of Portland State University. While this conference was scheduled, my son was also performing in an opera as he was the principal oboist for the Portland State University performing orchestra. I was able to attend the dress rehearsal for the opera *Dialogues des Carmelites* and it became a very meaningful part of my thoughts and journey toward the understanding that a *good death* is possible versus *just death* or even a *bad death*. A synopsis of the opera reveals

struggles during the French revolution of fear of death and the spiritual struggles that are present with the knowledge that we all shall die (The Metropolitan Opera, 2014).

I was amazed at the timing and the intense identification this opera promoted in my heart for finding a way to make way for members of my population of interest to be able to experience what was portrayed so artfully in this opera as the meaning of a *good death*. From this experience, further contemplation gave birth in my thoughts to want to explore the pathways of the grief journey for parents of loss. What makes some look back upon their journey as good and others bad? The possibility of different pathways and how I might influence a good versus bad experience was born or further focused from this cultural expression of art and beauty found hidden in an obscure opera.

This immediately affected my practice from that time forward. It had given rise for me as a beginning point in starting the conversation of the planning of a good death for the children of those who have to say goodbye way too soon. Prior to planning for a good death, I find it imperative that parents are given tools and versed in the concept of a good life for their child as was defined earlier in my paper by the life of Rose, the 19 day old child. Guidance that can help a parent experience moments of joy and delight during a fated pregnancy is an activity that feeds me internally. I look forward to supporting Eagle in the coming weeks and was thrilled that she took the lead to concentrate on making a good life for her first daughter A____. She has three sons and my suggestion that they each take their sister out on a date during her pregnancy made for some charming and beautiful experiences for her family, journaled by her mom for memories never forgotten. Her three year old brother took her sister in utero out for a gumball date at Walmart. A____'s five year old brother took her for ice cream and her seven year old

brother took her to Grandma and Grandpa's house, his favorite place to be. We recorded her heartbeat to be placed in a *build a bear* toy as another tangible memory of her sweet short life. These are definitely experiences garnered from my educational journey that I have applied to my practice in the real world.

If I consider my own death, I have the vision of a good death compared to a bad death in my imagination. If I were to choose my good death, it would take place in a warm bed, at home with a cat curled close by to my body so I could feel his warmth. It would take place after I had participated in the perfect wedding of my youngest grandchild to the most perfect of spouses. It would be peaceful and full of music and without regrets. At the other extreme, my imagination takes me to the worst death feasible in my imagination and it would be as one of the victims of the 9/11 terrorist attack and having to decide between a fiery death and one caused by jumping from the tall building to my death. I cannot even imagine how horrible that decision must have been. Making choices, having decisions to make, is an opportunity to create the semblance of a *good death* or a *bad death* and each person is allowed to decide what the elements imagined might be for themselves. Obviously, not many people are given the opportunity to plan or be involved in the planning of their own death and I say this with the exclusion of the category of suicide. I am in no way referring to suicide with this discussion. But instead of an unplanned death and if they were, it could be an opportunity and one to be orchestrated with the most options and the most knowledge of choices available. In planning a known perinatal death with my population of perinatal palliative care parents, an opportunity to have some control, some imaginings into what a *good death* might look like and plans for making it so can be comforting for parents of loss. At

least, that is what my musings involve as I work with this population in hopes of helping them.

I find that it has been my deep preoccupation with the subject of death for my population of interest that has spurred me on to want to know what can be done to make death a more palatable and healing journey for them. Since I cannot change the outcome of death, it is the journey surrounding death that must be changed. I have often taught in classes regarding perinatal loss that the more comfortable with the subject of death we can become, the more therapeutic we can be to those around us experiencing the death of a loved person. That is why I promote the thinking about death to those around me, even the thoughts of our very own eventual deaths.

In Summary

Chapter One introduced the problem statement that health care providers, family and friends will add either comfort or damage to the already devastating experience of perinatal loss. It is my hope that other providers might start to think deeply about the subject of death as a taboo subject in our society and try to change that within themselves first and then openly in our communities around us. When one thinks historically, just a couple of generations ago, death was not a taboo subject but instead it was a well-known subject that was openly discussed and those left behind were appropriately supported because it could be talked about. People back then exhibited comfort in touching and saying goodbye to deceased loved ones after death. Children were invited into the experience of the grief of their families. That same generation could not talk openly about sex. Today, we frequently reference remarks about *Fifty Shades of Gray* as an appropriate subject to bring up at most anytime in daily conversation but could never

discuss death in such detail. Wouldn't it be growth to realize that both sex and death could be openly discussed as a progression in the next generation? I would like to paint that picture of possibility and know that if it were to come to be, it would benefit society as a whole.

Chapter Two begins the discussion on the qualitative methods used for this small descriptive study and will hopefully engage future researchers to explore in more depth with larger studies producing more results. This conjures up for me a place where my canvas would be placed next to a grouping of other studies, giving a clearer picture and fitting into a collection of portraits that express the needs of the population of perinatal loss parents. Showing the study from different angles becomes an artful expression within itself, just as the angles shown from the eye of a photography artist envision where light is shown on different angles of a subject.

Chapter Three relays the exact methods I chose to use for analyzing my data and have hopefully produced a transparent review of how I came to the conclusions I decided upon. I found this portion to be the most fascinating of the whole process. There are definitely nuances of artful understandings in the scientific methods of coding and recoding, memo writing, and understanding the data within a new and abstract lens. I could have lingered here in the study much longer if time had not been a constraint. I would have loved to have obtained many more interviews and spent much more time analyzing the data. There was definitely room here for interpretation and to me that has an artful connotation. That is why it is so important in this portion of the study to make sure the bridling of rigor is followed so that the work doesn't become art but instead stays

true to science to be trusted and respected by others. Still, many more hues and colors would have been a beautiful addition.

Chapter Four presents my findings. The findings are relevant to my practice for new knowledge regarding the bereavement journeys of perinatal loss parents that I relate to and have expanded my understanding of elements of their journey that are new to my awareness. I will be forever grateful to my participants for this deeper understanding. It is my hope that journeys of my future patients will have more gifts and beauty in them because of the new knowledge. I want to thank my beautiful “models” for posing for me to capture their stories in print.

And finally, Chapter Five was an experience in critical thinking. I doubt that the thinking will cease after this paper has concluded but will continue to be discussed within my own thoughts and with those who have interest in this topic around me for years to come. The metaphors may never stop yet I feel they help me to understand through an artful lens, perinatal loss in a better light.

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APPENDIX A

Letter for Assistance in Recruitment

Dear Colleagues,

Many of you work with me in Labor and Delivery and already know of my program for perinatal palliative care and loss. For those of you who don't, I'd like to introduce myself as a patient care nurse who wants to improve the care of patients experiencing the difficult situation of perinatal loss. I have recently certified in perinatal loss care from the national board for certification of hospice and palliative nurses. I am also a graduate student working on my thesis and would like to inform you of a research project that will be underway after formal IRB approval.

I would like to enlist your help in recruitment for my study and would ask you to fill out the bottom portion of this form letter and return the letter to me so that I can assure the IRB that my study is feasible to complete because I have help in recruitment.

My selection criteria includes: English speaking patients who are at least 18 years of age who have experienced perinatal loss of any type and at any time in their past. It will be a qualitative study involving two interviews with parents of loss. Confidentiality is a priority of the study.

Because this is such a sensitive subject, it may bring up renewed questions or needs from this population of patients. I will place a card in the participants' possession at the time of the first interview that would refer them back to you, their obstetrical care provider, if they still have questions about future pregnancies or current health condition/needs that would be better addressed by you. I will not be giving medical advice.

I would appreciate your help in any recruitment of participants (patients who meet the selection criteria above) and can provide you with letters/flyers that you could provide to patient(s) who might be interested in participating.

Please contact me if you have any further concerns or questions I would be happy to answer for you. Thank you very much, in advance, for your time and assistance with my research project request.

Sincerely,

Jennifer Jonely



Yes, I am willing to help you recruit for your study, please send me flyers.



No, I respectfully decline.

Signature

APPENDIX B

Flyer for Recruitment

Have you experienced a perinatal loss?
A miscarriage, a stillbirth, a neonatal death or sudden infant death?

I am conducting a nursing research project that will help us to better understand this difficult part of life's journey and other parents of loss could benefit from your experience. The research project will involve one taped interview, approximately one hour in length, with the possibility of a request for a shorter second interview. Your privacy will be completely protected during this study. You must be at least 18 years old and English speaking to participate in the study.

If you are interested in participating, please contact:

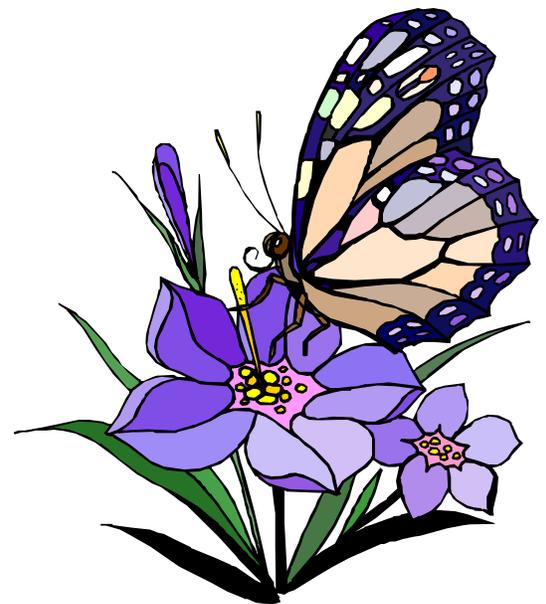
Jennifer Jonely, RN

Text or Call: 283-3848

Or email

J_Jonley@msn.com

jenniferjonely@u.boisestate.edu



APPENDIX C

Resource Card

Thank you for participating in my research study on perinatal loss. I understand that this is a sensitive issue and would like to offer you the following options if you should have questions about future pregnancies or if you feel the need for further support.

Please feel free to contact any of these resources:

Your OB/GYN provider

SHARE of Idaho Contact: Misty Whipple by email
Mistysunshine3@gmail.com

New Parent Line/Post-Partum Depression Line
706-5770

Judy Cross, RN, Clinical Nurse Specialist 381-2699

Spiritual Care Department @ 381-2100

Your Own Clergy or Spiritual support person

For those employed: A counselor in your Employer's Employee Assistance Program (EAP)

For BSU Students: Boise State University Student Clinic, through SHIP insurance, Counseling Services are available



If you have questions regarding the study, you may contact
Jennifer Jonely, RN @ 283-3848

APPENDIX D

Scripting for First Contact

Scripting for First contact with participant:

Thank you for responding to my flyer. The purpose of my nursing study is to help better understand your experience of perinatal loss and how that might help other parents of loss in the future.

Firstly, I must make sure that you can be included in my study. Can I ask you a few questions to determine this?

How old are you?

Have you experienced a perinatal loss?

The study involves 2 interviews with you and the first one may last up to an hour. I would like to audio tape the interview, would that be okay with you?

The time allotted for the interview would be approximately 1 hour but could stop if you feel tired or want to end the interview sooner for any other reason.

Do you have any questions about the study that I could answer for you?

Would you like to have your partner present during the interview?

When could we meet for the interview?

I would like you to be in a comfortable environment during the interview. Where would you like to meet?

APPENDIX E

Complete Interview

Semi Structured Interview Questions:

- 1.) I understand you experienced a perinatal loss; (if one, it would be known from the demographic sheet), tell me about this experience. (If more than one experience, tell me about each experience).
- 2.) As you think back on your experience(s) with loss, who or what was helpful in your experience?
- 3.) As you think back on your experience(s) with loss, who or what was unhelpful in your experience?
- 4.) Do you remember any decisions you had to make right away? Tell me about them.
- 5.) Did you make these decisions by yourself or did somebody help you? Who? Anybody else?
- 6.) Do you remember any decisions that you took your time making over the long experience of grief and loss?
- 7.) How do you feel today about the decisions you made both right away and over time?
- 8.) How did those decisions affect where you find yourself today in your grief?

- 9.) Are there different pathways that you could have taken in your grief experience? Tell me about those.
- 10.) Is there anything else you would like to share about your experience of perinatal loss that might be helpful for others or myself to know?

APPENDIX F

Consent Form Used for Informed Consent



BOISE STATE UNIVERSITY

INFORMED CONSENT

Study Title: Grief Pathways after Perinatal Loss on the Metaphorical Journey of Loss

Principal Investigator: Jennifer Jonely

Co-Investigator: Leonie Sutherland

Sponsor: Nursing Department

This consent form will give you the information you will need to understand why this research study is being done and why you are being invited to participate. It will also describe what you will need to do to participate as well as any known risks, inconveniences or discomforts that you may have while participating. We encourage you to ask questions at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form to keep.

➤ **PURPOSE AND BACKGROUND**

You are invited to participate in a research study to learn more about grief pathways after perinatal loss. The information gathered will be used to better understand the impact decisions made at time of loss have on a grief journey of parents who have experienced perinatal loss. You are being asked to participate because you have experienced a perinatal loss, are a volunteer and over the age of 18.

➤ **PROCEDURES**

If you agree to be in the study, you will be asked to participate in an interview that may last up to an hour but can be stopped at any time you are uncomfortable or feel that you do not want to continue. A second interview would be asked for in order to check with you to make sure that what we understood from your first interview is accurate in a way that you wanted to be understood. Each interview would be audiotaped so that we know the information you are providing us can be accurately recalled and studied. You will be asked about your recollections regarding the grief you experienced after perinatal loss in a gentle way and a way where the interviewer is completely comfortable in the sharing of tears should they occur. The interviewer is familiar with caring for the population of parents who have experienced perinatal loss and is aware that sometimes it is a validating experience to be able to talk about a perinatal loss with someone who is comfortable with the subject and can acknowledge the loss of a child or pregnancy openly. The interview will be audio-recorded and the researcher may take notes as well.

➤ **RISKS**

Some of the questions asked may make you uncomfortable or upset. You are always free to decline to answer any question or to stop your participation at any time. Should you feel discomfort after participating and you are a Boise State University student, you may contact the University Health Services (UHS) for counseling services at (208) 426-1459. They are located on campus in the Norco Building, 1529 Belmont Street, Boise ID, 83706. A resource care card will also be provided to you for some other options for seeking help after participating that may be easy to access. Although this is a difficult subject to discuss, I want you to be completely comfortable knowing that you can decline to answer any or all of the questions, can take your time and interrupt the interview to take time to express tears and that unconditional listening will be provided to you by the interviewer.

➤ **BENEFITS**

There may be no direct benefit to you from participating in this study unless it benefits you to tell your story of perinatal loss to an unconditional listener. However, the information that you provide may help other parents of loss and their care providers to understand what may help to make a more healing journey after perinatal loss.

➤ **EXTENT OF CONFIDENTIALITY**

Reasonable efforts will be made to keep the personal information in your research record private and confidential. Any identifiable information obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. The members of the research team and the Boise State University Office of Research Compliance (ORC) may access the data. The ORC monitors research studies to protect the rights and welfare of research participants.

Your name will not be used in any written reports or publications which result from this research and if you desire, we can assign an alias name by which to call you by during the interview such as the name of a flower or any other alias you would like to go by. Data will be kept for three years (per federal regulations) after the study is complete and then destroyed.

➤ **PAYMENT/COMPENSATION**

There are not monies set aside for participation in this study and no other compensation is available for participation.

➤ **PARTICIPATION IS VOLUNTARY**

You do not have to be in this study if you do not want to. If you volunteer to be in this study, you may withdraw from it at any time without consequences of any kind or loss of benefits to which you are otherwise entitled.

➤ **QUESTIONS**

If you have any questions or concerns about your participation in this study, you should first contact the principal investigator at jenniferjonely@u.boisestate.edu or (208) 283-3848.

If you have questions about your rights as a research participant, you may contact the Boise State University Institutional Review Board (IRB), which is concerned with the protection of volunteers in research projects. You may reach the board office between 8:00 AM and 5:00 PM, Monday through Friday, by calling (208) 426-5401 or by writing: Institutional Review Board, Office of Research Compliance, Boise State University, 1910 University Dr., Boise, ID 83725-1138.

DOCUMENTATION OF CONSENT

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible risks have been explained to my satisfaction. I am aware that I will be audiotaped during the interview. I understand I can withdraw at any time. I have received a copy of this form.

Printed Name of Study Participant

Signature of Study Participant

Date

Signature of Person Obtaining Consent

Date

Approved IRB Protocol Number: 187-SB13-117

APPENDIX F

Demographic Questionnaire

Please fill out this questionnaire which will give me background information about you for my study. This information will be kept completely confidential.

Age _____

Ethnicity _____

Marital/Partner status _____

Partner present in interview today? _____

How many times have you been pregnant? _____

How many living children do you have? _____

How many perinatal losses have you had? _____

How far along in your pregnancy/pregnancies were you when you experienced perinatal loss?

What alias name would you like me to call you?

Did you consider your perinatal loss to be (check all that apply)

- a.) The loss of a pregnancy
- b.) The loss of a baby
- c.) The loss of _____

Date of Interview _____