

2013

# Bereaved mothers seek support online: ethnography & autoethnography in a virtual community

Catherine Holestine  
*Eastern Washington University*

Follow this and additional works at: <http://dc.ewu.edu/theses>

---

## Recommended Citation

Holestine, Catherine, "Bereaved mothers seek support online: ethnography & autoethnography in a virtual community" (2013). *EWU Masters Thesis Collection*. Paper 99.

This Thesis is brought to you for free and open access by the Student Research and Creative Works at EWU Digital Commons. It has been accepted for inclusion in EWU Masters Thesis Collection by an authorized administrator of EWU Digital Commons. For more information, please contact [jotto@ewu.edu](mailto:jotto@ewu.edu).

BEREAVED MOTHERS SEEK SUPPORT ONLINE:  
ETHNOGRAPHY & AUTOETHNOGRAPHY IN A VIRTUAL COMMUNITY

---

A Thesis

Presented to

Eastern Washington University

Cheney, Washington

---

In Partial Fulfillment of the Requirements

For the Degree

Master of Science

---

By

Catherine Holstine

Spring 2013

THESIS OF Catherine Holistine APPROVED BY

\_\_\_\_\_ DATE \_\_\_\_\_  
SUSAN STEARNS, GRADUATE STUDY COMMITTEE

\_\_\_\_\_ DATE \_\_\_\_\_  
SALLY WINKLE, GRADUATE STUDY COMMITTEE

MASTER'S THESIS

In presenting this thesis in partial fulfillment of the requirements for a master's degree at Eastern Washington University, I agree that the JFK Library shall make copies freely available for inspection. I further agree that copying of this project in whole or part is allowable for scholarly purposes. It is understood, however, that any copying or publication of this thesis for commercial gain, shall not be allowed without my written permission.

Signature \_\_\_\_\_

Date \_\_\_\_\_

## **Table of Contents**

<b>Introduction</b> .....	1
Death & Grief.....	9
Societal Expectations .....	16
Support Groups .....	21
Peer to Peer Support Groups .....	23
Online Support Groups.....	24
Empathy & Trust.....	29
<b>Parenting After a Loss</b> .....	32
<b>Methodology</b> .....	35
Ethnography & Autoethnography .....	36
Qualitative Research .....	45
<b>Data Collection</b> .....	47
Email Survey .....	48
Story Collection.....	53
Story Collection Themes .....	60
Mother & Child Relationships .....	65
Mother & Child Relationship Themes .....	69
Local Support Systems.....	73
Local Support Systems Themes .....	77
Seeking Online Support .....	80
Seeking Online Support Themes .....	83
Mother to Mother Relationships .....	86
Mother to Mother Relationship Themes.....	89
<b>Poetry</b> .....	91
<b>Conclusions</b> .....	98
<b>Bibliography</b> .....	103

## Introduction

In 1997, while expecting the arrival of my first child, I was “glowing with anticipation.” Family and friends helped celebrate with all the usual activities: baby showers, touching my expanding mid-section to feel the baby move and admiring ultrasound photos. My husband worked tirelessly painting and putting nursery furniture together to welcome our newest family member.

My due date came and went. A week later contractions sent me to the hospital. My husband and I, soon to become new parents, were excited. We looked forward to returning home, magically transformed from a couple to a family.

Suddenly, in a barren, cold, sterile hospital room my world spun out of control. Little of what was happening resembled the stories shared in our recent childbirth preparation classes. My contractions were strong and about eight minutes apart, the nurse told us there was nothing to worry about at this point. She added that we probably had a long wait ahead of us. We had heard our baby’s heartbeat countless times over the past 20 weeks, just the day before in our family doctor’s office it was strong and regular. Today I had a monitor belt around my swollen belly. The nurse was moving the monitor around my belly, but was failing to find the heart beat. She assured us the baby was probably just turned, that she would find the heartbeat. Finally, she did locate a heartbeat. The monitor was making a slow, random beat ... then it was absent.

Frantically they adjusted my position in bed, started IV fluids and oxygen, two doctors rushed into the room. I was rushed to surgery. I remember being wheeled out of the room and seeing my husband looking as bewildered as I felt leaning against the wall

watching me go down the hall. Everything swam, went dark. I woke up and reached for the comfort of my bulging belly where my baby lived. I needed to feel the comfort of the solid size of my midsection and wait for my baby's response to my touch. The bulge was gone. I was covered in thick bandages and warm blankets. There was another person in the room, but he didn't speak to me, even when I asked questions. I didn't understand and finally yelled that I wanted to see my doctor and my husband. Another nurse came into the room and told me I had to lay still, rest, that the doctors would talk to me when they could. She assured me that I was fine. When I asked about my baby she said I would have to talk to the doctor. At that moment – really before that moment – I knew something was terribly wrong. I demanded to see my husband and was told he wasn't allowed in the recovery room where I currently was. The nurse told me I had to calm down and rest before she turned and left the room.

An eternity later, a familiar doctor came into the room. At the time, we lived in a relatively small town and she was a pediatrician I had known professionally for several years. She approached my bed, held my hand and told me a story I couldn't believe. I had a beautiful baby girl! But, she didn't breathe when she was born. They had worked to make her heart beat and lungs breathe. She was on life support. She needed to be transported to a larger hospital, to a neonatal facility. They were concerned she wouldn't survive.

I couldn't grasp what she was saying. My thoughts raced back through all I'd learned in childbirth class and standing by as friends and family had their own children. Babies don't die. My baby shouldn't die. I cried and no one comforted me. I needed to feel my

baby's warmth, rub my cheek against my baby's cheek, count her fingers and toes, smell my baby.

Another doctor came into the room and stood near the doorway with a chart in his hands. He never addressed me by name and referred to my daughter as "Female Child." He cut my questions short, telling me it would be better if I didn't see my baby, that it would be easier if I didn't know her. He counseled that when she died it would be easier to accept if I didn't bond with her. He said that making a connection with my baby would only make her death more difficult. I sat there dumbfounded. I already knew her, she had been part of me for 41 weeks, for a full nine months. She would always be part of me.

My husband finally convinced the doctor to allow me to see her. She was brought to us securely encased in a large, cold, metal and Plexiglas transport unit. Her eyes and head were wrapped in bandages. Her arms and stomach were punctured with protrusions of surgical tubing. We held her small hand, stroked her warm cheek, touched her tiny toes and kissed her. We called her by her name, Audrea Makinzie or Audie for short. We entrusted her safe travel to the next hospital to a team of strangers.

I begged my husband to go to the hospital and be with Audie. She was too small and fragile to be on her own. I didn't trust anyone else to make decisions regarding her health and her care. I spent the remainder of the day and night in the hospital alone, without my family. It seemed the medical staff did not want the burden of caring for me and my situation. They were remote and cold, entering my room and checking my vital signs without talking to me. Having babies is supposed to be a happy time. I felt as though I was ruining their typically happy job. One nurse called me a "moodkiller" just outside my door. She later came to the door of my room and asked me not to cry, saying it was



making the new parents in the adjacent rooms uncomfortable. She closed my door. *Why weren't my feelings just as important as the woman's in the next room?*

In the middle of the night, my husband called. There was good news ... and bad. Audie's kidneys were functioning and he was spending time with her, changing her diapers, giving her a bath, holding her hand. Then, he told me the bad news. After extensive testing, it was determined that her brain activity was limited to the brain stem. She would never think, feel or interact with us. Audie was brain dead. I dropped the phone and cried uncontrollably. A nurse came in, picked up the phone, unplugged it from the wall and was wrapping the cord around it as he walked from the room. He closed the door behind himself. He didn't ask what was wrong or if he could help me in any way; he didn't seem to care.

Another nurse, very pregnant herself, came into the room in the dark, early morning hours. She sat down next to my bed and asked me what had happened to my baby while she checked my vital signs. I told her about Audie's condition and that I wanted to leave and be with her and my husband. She held my hand and told me Audie's condition was "God's will." She offered me medication to sleep, telling me when I woke up things would be better. She made me angry. How was sleeping going to make the situation better? The feeling that the nurses and doctors here did not care about Audie or me continued to grow.

The following day, against doctor's recommendations, I checked out. I needed to be with Audie and my husband – my family. We had limited time and I wanted to spend as much of it together as possible. My parents helped me make the two hour drive to the neonatal intensive care unit which was caring for Audie. The doctors and nurses at this

facility were wonderfully caring people. They immediately encouraged me to be with Audie and were open and honest when answering my questions, never rushing us. When I cried they stayed, even handed me a tissue. They encouraged me to spend all the time I wanted with Audie no matter what time it was.

Finally, I was allowed to hold my daughter in my arms the following morning. My husband picked her up from the bassinet, covered with tubes and wires. He proudly held her up for a candid family photo opportunity. He placed her in my arms and we were together again. I twirled her black curls around my fingers, kissed her round cheeks, changed her diapers and dressed her for hospital photos. She met her grandparents, two great grandmothers, various aunts, uncles, cousins and our family doctor.

On her second day of life, we made the difficult decision to end the life support that was sustaining her. Tests indicated her physical condition was not improving. We cradled Audie, free of tubes and wires, in our arms for hours. The room was quiet with the monitors turned off and sunlight streaming through the window. My brother snapped photos and his wife took video of extended family visiting. I cherished every moment. Her nurse and the pediatric neonatologist visited frequently to help us understand the process of her life ending and answer any questions. About 10 hours later, surrounded by family and friends, Audie took her last breath. We continued to hold her tiny, fragile body into the night. I talked to her, sharing my dreams for her that would never come to be. We assured her she would never be forgotten.

Her life, which had just begun was now over. This wasn't what we envisioned after the birth of our first child.

I never took the liberty to consider myself a fairy tale princess – until I was pregnant. I had heard all the horror stories about morning sickness, weight gain, stretch marks, labor, delivery and sleepless nights. Everyone said they would weather all the bad experiences again for their children. Everyone else’s stories had such happy endings. Their stories were filled with recollections of hearing their baby’s first cry, the warm heavy feel of the baby snuggly wrapped in soft blankets and the smell of baby lotion. The stories I had heard of bringing babies home always had a happy ending – until mine.

I had no idea that mothers could have a remarkably healthy pregnancy with no complications and return home from the hospital to a nursery which would remain unused. We should have been returning from the hospital carrying our daughter inside, followed by additional trips to bring in the diaper bag, flowers, balloons and gifts that traditionally accompany such a festive occasion. Instead we walked to our car in the hospital parking lot to confront an empty carseat silently waiting in the backseat; it wouldn’t be needed to safely transport her home.

Once home we found all the preparations we had made for its newest resident. There was the newly painted and furnished nursery, complete with stacks of diapers and baby clothing filling the closets and dresser drawers. The bathrooms even had infant bathing and changing supplies readily available on the counters. The laundry room had detergent and softeners designed for baby clothing and skin. The kitchen cabinets were stocked with bottles and smaller, more colorful versions of dishes, plates and silverware.

I sat in Audie’s room, surrounded by her things. She would never sleep in the crib, never wear the clothes hanging in the closet, never sit in the swing or go for a ride in her stroller. Over the next few days I experienced the pain of accepting flowers and opening

well intended cards and gifts that arrived after her birth from people who hadn't realized she never came home. On my fourth day home, a delivery man brought a case of baby formula and a sample pack of diapers. No one had prepared me for the possibility of living without Audie. No one had ever mentioned that sometimes parents didn't return home with their babies, that sometimes babies died.

In the ensuing weeks I found myself home and alone. My husband returned to work and did not talk about Audie. I could not return to work without medical permission because of the surgical delivery. I was trapped in an environment reminding me every minute that Audie wasn't here, that Audie died. I was isolated in my house, without my baby, solitary in my grief.

A few caring friends visited, brought food, attempted to lift my spirits. However, most were uncomfortable with the somber, heart-wrenching reality of my situation. One young couple brought a pot roast. They entered the front door, handed it to us, exchanged a few pleasant words and left. Another couple brought soup and rolls. The wife walked past me without a single word and began tidying the kitchen while our husbands went outside to talk. When I attempted to talk to my friend she began crying and went to sit in her car. I was again left to grieve alone. Later I learned she didn't want to share her grief over the loss of Audie because she didn't want to upset me.

Although having our baby die was our reference for normal, it made others uncomfortable. They did not want to talk about Audie or they felt they didn't know Audie. She wasn't real to them. They did not miss her like we did; her absence wasn't as immediate and pronounced. I was by myself in remembering Audie and trying to find a way to continue without her.

One day after checking email I Googled the phrase “death baby.” I thought the search would bring up a bunch of nonsense, people who made bad jokes and possibly medical and health information. However, I was surprised that the search engine generated a plethora of relevant, helpful information. A long list of websites and information appeared and I started to sift through them. For several days I sorted through the links provided, searching for something to validate my feelings, seeking something to help me want to continue living. I found websites sponsored by psychologists advertising their counseling services, online memorials to people’s deceased children who were soldiers killed in war, blogs offering a virtual cemetery space for deceased pets and an accounting firm’s website advertising assistance with income tax preparation after a death in the family.

I was seeking answers to questions which I couldn’t put into words. After a couple days of searching through sites offering support for raising multiple children, raising children after losing a spouse to death or divorce, I happened upon a listerv for parents who lost a child and were either raising or planned to raise other children. I read through the introductory material and was amazed there were other people like me. I was even more amazed there were enough to form an online group who wanted to talk about a topic so many others avoided discussing. I joined and soon found I was no longer alone; there were others like me with whom I could share my feelings and experience and not feel as though they were avoiding me for their own comfort.

*Death & Grief*

As an undergraduate, I studied literature. My favorite poem is Because I Could Not Stop for Death, penned by Emily Dickinson. It took on new depths of personal meaning after Audie died.

Because I could not stop for Death,

He kindly stopped for me;

The carriage held but just ourselves

And Immortality.

We slowly drove, he knew no haste,

And I had put away

My labor, and my leisure too,

For his civility.

We passed the school, where children strove

At recess, in the ring;

We passed the fields of gazing grain,

We passed the setting sun.

Or rather, he passed us;

The dews grew quivering and chill,

For only gossamer my gown,

My tippet only tulle.

We paused before a house that seemed

A swelling of the ground;

The roof was scarcely visible,

The cornice but a mound.  
Since then 'tis centuries, and yet each  
Feels shorter than the day  
I first surmised the horses' heads  
Were toward eternity.

This is the full version of Dickinson's poem. The fourth stanza is often considered to be describing a gravesite, however it has a unique meaning to me since losing my daughter. It is reminiscent of my pregnancy, the slowness of time and anticipation during the final weeks of pregnancy and my fully-rounded figure. It also describes the emptiness, both physical and emotional, that remained with me after her birth and death. How I was once full of her life and then reduced to only sustaining my own, left with the barest physical reminders of her existence. The work it took to create her life, to bring her into the world was all for naught, yet will last through my lifetime.

When we returned home from the hospital, we quickly realized that grieving the death of our daughter wasn't going to be an easy transition from the happy homecoming we had envisioned. Everywhere we turned, everywhere we looked we were surrounded my reminders of what could have been, what was taken away. Our grieving process was just beginning.

I've lost two classmates to death, a beloved teacher to suicide, two grandfathers and a grandmother passed away. A college teammate died of cancer. I had experienced the death and loss of several close friends and relatives, but nothing that created a physical and emotional response on the level of my daughter's death. These losses were heartbreaking, however they didn't force me to my knees in anguish, pain and tears. They

didn't make my chest tighten and my voice falter. They didn't make me want to shut myself away from the world.

In the weeks following Audie's death, I initially didn't realize that my husband and I were expected to keep our grief to a schedule; after that obscure timeline passed we were expected to keep our grief private, concealed. Mainstream American society constrains grief to a tight schedule – typically the three to five days of bereavement leave the workplace offers. Families and loved ones are expected to experience the loss, commemorate their loved one according to their individual traditions and return to their public life in rapid succession. Death, loss and grief aren't unique to any culture. However, it is an experience that American society expects individuals to internalize to insulate others from our unpleasant and uncomfortable emotions and experiences.

The Compassionate Friends, a nationwide non-profit group of bereaved parents, anticipates nearly 2 million parents will experience the loss of an infant to miscarriage, stillbirth, Sudden Infant Death Syndrome (SIDS) or other cause each year (2006, ¶ 3). Another accounting states that 3.1 million babies are born in the United States each year and of those 36,000 will live less than a month (Kohn & Moffitt, 1992, p. 130). Statistics accounting for pregnancy loss and bereaved parents are often confusing to lay people as there is a disconnect between what the medical community officially considers a pregnancy loss or an infant death and what a family considers the death of one of its members.

The accepted natural order of life in effectively all human cultures is that parents die before their children, that younger generations outlive their elders. The loss of a child collapses the normal order and causes a harsh, painful and frustrating shock (Ronel &



Lebel, p. 508). The death of a child is often times called the ultimate tragedy (Schiff, 1977, p. xiv) and referred to as the most painful bereavement (Barrera, et.al., 2007, p. 160). The death of an infant before or shortly after birth is significantly different from other losses in that the bereaved parents have had no opportunity to identify and build a meaningful relationship with their child, providing memories to facilitate grieving (Leon, 1992, p. 1465). The grief experience after a child dies is debilitating (Cacciatore, p. 61) and often considered one of the most vulnerable times (Brownlee & Oikonen, 2004, p. 518) of a parent's life. Most expectant parents are stunned, bewildered or confused (Brownlee & Oikonen, 2004, p. 517). In Western society, the death of a child has generally been found to elicit more intense and complicated grief reactions than other types of bereavement (Wijngaards-de Meij, et. al., 2007, p. 537).

Grief typically follows death and takes many forms. Grief is an individual as well as a societal process, however it is a process our society doesn't attempt to accommodate or apologize for suppressing. As a society we are impatient. I found myself questioning the future and rethinking the meaning of life and my decisions. Grief brings about a flood of intense reactions. It is demoralizing, strenuous to relationships and may overwhelm personal, familial and financial resources. After about two weeks I found myself alone. Everyone around me, including my husband, had returned to their regular schedules going to work, grocery shopping, cleaning their homes, going out to dinner with friends, taking their children to the park or school activities. I felt that my feelings were being ignored by family and friends; that they had forgotten about Audie, that her absence hadn't impacted their lives. My experience wasn't unusual. It is becoming increasingly more difficult for individuals as they must experience grief alone as the traditional

community we rely upon is generally becoming more removed in space and time (Johnson & Ambrose, 2006). We had committed a great deal of time to the pregnancy and were totally unprepared for a tragic outcome. Audie's birth and subsequent death was an abrupt end instead of a beginning, a sad occasion instead of a happy one (Kohn & Moffitt, 1992, p. 139). Those living in postmodern society are often depicted in academic and popular literature as nomadic, lacking a traditional community, maintaining transient relationships and fragmented family and living in isolation (Johnson & Ambrose, 2006, p. 108). This changing social structure may also contribute to the failure of family and friends to meet the needs of the bereaved. This potentially unsettling lack of social continuity not only complicates daily efforts to maintain a sense of equilibrium, but often debilitates the grieving who fight to create a sense of equilibrium during a significant life crisis (Cluck & Cline, 1986, p. 517).

The field of obstetrics, in particular, is geared toward bringing new life into the world. When death occurs where new life is expected, untrained and unprepared obstetrical staff react with anxiety and helplessness, making it difficult for them to assist bereaved families. Staff members untrained in bereavement may respond to a pregnancy loss by avoiding the grieving parents because they don't know what to say, or because they are afraid the parents will only cry and become more upset, not realizing this is just what bereaved parents need permission to do. (Kohn & Moffitt, 1992, p. 165)

When we left the hospital, there was no offer of support or assistance. When we left the funeral home, it was with a receipt we needed in order to claim her ashes. None of

the professionals who watched our loss unfold and witnessed our immediate grief attempted first-hand to console us. It seemed to us that our experience was treated as “business as usual.” Medical and funeral professionals were courteous and factual. It almost seemed as if they didn’t want to interact with us, as if we – and our situation – made them uncomfortable.

A week after Audie’s birth and the day before her memorial service, two acquaintances visited my home unannounced. They came to the door together, their arms filled with odd items. I didn’t know it, but both had recently lost a child. Having had an emergency Caesarean section I wasn’t medically released to drive or return to work. I was a captive in my own home, which was filled with painful reminders. I was home alone much of the day with only my thoughts to keep me company, thoughts which commonly returned to Audie and all that was missing from my life, never to be realized. These two women knew I would be home alone and had come to offer a sense of sisterhood and rescue, to share their experience and attempt to help me begin to heal.

One of the women shared a Polaroid of her firstborn, who was born and died less than two weeks before this visit. He was at 18 weeks gestation and was perfectly formed. In the photo he was sitting up with a tiny blue knitted cap on his head and a swaddled in a white infant shirt. His skin was a bright red color. His birth was technically considered a miscarriage. According to the medical community he was labeled a pregnancy loss, not a child who had died. His mother and I had met before, but were little more than acquaintances before this day.

The other woman, also an acquaintance, had photos of her three living and five deceased children. She also brought snack food, a book of poetry, a Bible and a box filled

with items from all her deceased children. She shared stories, telling how her children had died within hours of their birth.

The friendship bonds created that day are unparalleled. They extended themselves and bared their emotions in an effort to help me, and in turn were helping themselves. We developed a mutually assistive bond over our shared experiences that still endures over a decade later. They were willing to share their experiences, the good, the bad and the unbelievable. And, they were willing to listen to everything and anything I wanted to share.

Death ends a life, but not the relationship the deceased had with others (Toller, 2005, p. 62). Despite the lack of a socially-recognized relationship, many bereaved parents grieve the physical loss of their child as well as the loss of the promised parent-child relationship. In the case of parents who have lost an infant, the relationship between the parent and child is unique and typically restricted to parents and the child. When an infant dies, there is often an expectation that parents will rapidly return to society's ideal of normalcy, as if nothing happened. In reality, this return to daily life doesn't always occur swiftly or easily for the families involved. Parents are often isolated because others around them do not understand the depth of grief involved, or more commonly others are uncomfortable with the topic and avoid the bereaved parent rather than interact with them. In this way, the grief process is compounded as others are insensitive to the parent's needs and feelings, (Leon, 1992, p. 1468). In fact, grief doesn't follow a strict timeline. Individual grief may last days, weeks, months or years beyond the actual event of losing a child.

In the days and weeks after Audie's birth and death, my husband and I were hungry and tired. Our normal sleeping and eating routines were interrupted as grief robbed us of our appetites and salted our dreams with unpleasant themes and images. We ended up roaming shopping malls and box stores in search of diversion. We played mindless video games and sometimes just sat outside and stared at the sky and passing traffic. Anything to keep our attention focused on something other than the pain we felt. It was difficult to return to a normal routine, as during pregnancy our routines had already started to revolve around a baby's schedule. We had become accustomed to sleeping longer, resting more, quiet evenings at home and enjoying heartier meals. None of these things were enjoyable.

### *Societal Expectations*

The loss of a child from the perspective of a parent is not something everyone understands or embraces wanting to learn more about. Many of us know about infant loss or the death of children as factual items in our family history or circle of friends. But it is more a bit of information than an emotional attachment to someone who played a pivotal role in our lives.

I knew my grandmother had a son in the mid-1940s, who would have been my uncle. He was stillborn, taken from my grandmother before she had a chance to see him and buried in an unmarked grave. I knew my aunt had lost her firstborn son to SIDS in the 1960s. His death was investigated by police and her well-meaning family included all his belongings in his casket so there wouldn't be any painful reminders in their home. These are family stories that are rarely shared and they weren't events I had experienced

first-hand. As a child I couldn't be aware of the emotional impact these losses would have caused my grandmother and aunt. I didn't realize the depth of their loss until I experienced my own and lost my innocence.

The death of children in Anglo-American societies has been marked by public grieving since the 1600s (Morgan Strength, 1999, 338). However for the latter half of the 19<sup>th</sup> century and much of the 20<sup>th</sup> century, the death of a child before or shortly after birth was not considered a loss for the larger community. Women who experienced a perinatal loss, the death of an infant after the twentieth week of gestation and through at least the first month after birth (Nichols, 1989, 118), were expected to return to society as if nothing had happened. These bereaved parents were expected to act as if their child had never existed because the child hadn't been experienced by others and the death was perceived a relatively minor or socially insignificant (Doka, 1989, p. 5). Simply because others, outside the immediate parent-child relationship hadn't developed a unique relationship with the child it was considered to never have existed. These parents often received the social message that "nothing really happened," were deprived of validation and were left to mourn alone (Nichols, 1989, p. 120). This involuntary loss of their child and the grief that followed stigmatized them (Morgan Strength, 1999, 340).

Prior to the 1970s, the extent of grief following a perinatal death and its effect upon the entire family's functioning was not readily acknowledged by society. Credence was not given to the fetus as an important member of the family before his or her birth. When a perinatal death did occur, the common approach to patient care was to treat the loss as a non-event.

Families were encouraged to pretend that it did not happen and were often

counseled to forget about it and move on with their lives. Consistent with this perspective, well-meaning doctors and medical staff were noted for making insensitive comments to women such as “it was for the best” or “it’s very common.” This approach ignored the emotional and physical responses that women sustain and it isolated them from receiving much needed support. (Brownlee & Oikonen, 2004, p. 519)

Dr. Eric Lindemann is considered one of the first modern academic specialists in grief research. Having completed extensive studies on grief and death during the 1940s, Lindemann identified disenfranchised grief when studying grief reactions, and defined it as a circumstance where a person does not have the socially recognized right, role or capacity to grieve. Although we can look back today at Lindemann’s work and consider it groundbreaking and revolutionary, it did not create a change in attitude during its time.

Attitudes toward perinatal death began to transform during the 1980s. Mary Ann Hazen illustrates this fact in her study of grief and reactions in the workplace (2003, p. 148). In her conclusions, Hazen points out that social avoidance of perinatal loss and those who experienced it was pervasive before 1980, and that parents were expected to mourn the loss of their child in silence. I can illustrate this fact within the generational experiences of my own family.

My grandmother had never mentioned her stillborn son to me before Audie’s death. She didn’t share her experience directly, but cautioned me to not be too afraid to try and fulfill my desire for a family. My aunt, who was living in Europe, traveled halfway around the globe to spend time with me after Audie’s death. For the first time she shared intimate details of her son’s death and the subsequent actions of family

members, law enforcement and her friends. She said that she didn't feel free to talk about him after his death, that once he was buried he was gone and she was to return home to care for her husband and other living children as if nothing had happened. She didn't have a single item, not even a photo, to remember him by. She told me I was lucky to be able to talk about Audie, to share photos of Audie and that so many family and friends had gotten to hold and know Audie. She encouraged me to find a way to commemorate Audie's birthdate each year.

Although academic researchers began to view these deaths as legitimately causing grief, society was slower to adjust. Often people, coworkers, friends and family, are uncomfortable offering support in this situation because they fear the emotions the bereaved parents are experiencing. This experience is the disenfranchised grief earlier identified by Lindemann. The term, disenfranchised grief, is commonly credited to Kenneth Doka (1989) who refined and expanded Lindemann's original research. He defines the term as grief a person experiences when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported based on social norms. Doka also states that these social norms or "grieving rules" are commonly codified in workplace bereavement leave policies which delineate who can grieve and who they can grieve for. For example, many workplace policies allow employees bereavement leave for the death of parents, siblings or children, but not extended family, in-laws, pets, friends or domestic partners.

In today's society, the "problem" of grief is commonly perceived to be a private, individual problem, not the community's problem. Mourning is considered morbid and is not encouraged (deVries & Rutherford, 2004, p. 6). The only things considered worse



than mourning are disenfranchised grief and lingering grief. Lingering grief, or grief that continues beyond the socially acceptable time limit, is not acceptable in our modern society. However in situations like mine, the family must adapt to their new reality, as the baby who died will always be a part of their lives (O'Leary, 2005, p. 29).

After losing her 10-year-old son during the 1970s, Harriet Sarnoff Schiff (1977) wrote a groundbreaking book giving counsel to other parents who had lost a child and those who want to help the grieving parents. I believe her statement describing the loss of her son is relevant to parents who have lost a child of any age:

To bury a child is to see a part of yourself, your eye color, your dimple, your sense of humor, being placed in the ground. It is life's harshest empathetic experience and must therefore be the hardest one with which to deal. In reality, when children die, not only are we mourning them, we are also mourning that bit of our own immortality that they carried. (p. 23)

One issue most who research grief agree upon is that disenfranchised grief is an increasingly prevalent condition (Doka, 1989, p. 8) and that not only does the loss need to be acknowledged but that social support networks, which are currently readily available for those who grieve socially acceptable relationships, need to be expanded and also made available to those who experience disenfranchised grief.

### *Support Groups*

Everyone belongs to support groups of one kind or another throughout their life. I was no different. In high school I played team sports and worked with a group of parents to raise money for uniforms and travel expenses. In college I joined a math study group that met three days a week to help me through a statistics course. At work I walked during my lunch hour with coworkers in an effort to keep my energy level up and my weight down. All of these are examples of people working together toward a common goal, primarily the betterment of the people involved. In searching for a grief support group, I was taking it to another level. I wasn't looking to better myself, I was looking to save myself from the depths of overwhelming grief. I didn't want the dark foreboding emotions to overtake my life; I needed someone to help me through, someone who understood.

Grief wasn't the only issue I faced in the days, weeks, months and years that followed Audie's death. My husband and I had dreams of a family, children in our home. Others who have lost infants already have a child or children at home. Parenting a child after the death of another brings additional stressors most parents do not experience including fears and questions others who haven't experienced a loss of this kind find irrational. Most mental health and medical professionals as well as family and friends of bereaved parents expect that a living, healthy baby will alleviate the grief the bereaved parents are experiencing. However, it is a simple fact that no other child replaces the one who died (Davis, 1991, p. 212; Nichols, 1989, p. 120). The combination of isolation with the push by their community to "get over" the loss of an infant is alarming to grieving

parents. The rest of the world seems to want them to get over it, get back to what and how they were before the loss, not to talk about the loss or the loved one.

When a baby dies, parents respond with the natural and socially acceptable collection of emotions including shock, disbelief, anger, guilt and yearning (Nichols, 1989, p. 119). Many parents encounter friends and family who behave in what is perceived as an uncaring, insensitive manner. They hear comments that are meant to console, but leave the bereaved parents hurt and confused. “It is for the best.” “It was God’s will.” “You can have more children.” Bereaved parents are also shunned and avoided by neighbors, friends and family and become socially estranged as many of their young friends are not skilled in being socially supportive and are also caught up in being young adults and building their own lives and families (Nichols, 1989, p. 121). I experienced the loss of several of my friends who were also expecting or had recently had a child. Most didn’t want to face the reality of my situation, wanted to believe that bad things didn’t happen at this otherwise happy time of life. One lifelong friend limited her interaction with me, as her reaction to my daughter’s death was guilt. She felt guilty that her son was born healthy just a few days before Audie was born and died. Over time, communication with family and friends is often strained, as it is difficult for others to respond to parents’ grief (Toller, 2005, p. 57) and these parents begin to feel deserted by their family and friends. This isolation isn’t always the fault of friends and family. Pain dominates every aspect of a bereaved parent’s personal, family, economic and public life. It has the power to preclude active participation in the life of close family, prevent communication with circles of close and distant friends (Ronel, Natti & Lebel, 2006, p. 512).

### *Peer-to-Peer Support Groups*

Bereaved parents need a resource or venue to help them express their grief and incorporate it into their lives with others who are willing to listen and interact in a compassionate manner. In many cases, organizations where bereaved parents come to air their grief and listen to methods others have employed in coping can have immeasurable value (Schiff, 1977, p. 136).

Peer-to-peer support groups aren't a recent phenomenon. Support groups have historically been a successful way of improving access to social support during times of need (Hersh, 2005, p. 4). The support group setting allows people to connect with others in similar situations, providing a forum to share their concerns and compare coping and treatment strategies with similar others (Hersh, 2005, p. 8). Several, like Mothers Against Drunk Driving and Alcoholics Anonymous, are known nationally and worldwide as well as cross generationally. The number of face-to-face support groups flourished in the final decades of the 20<sup>th</sup> century. It is estimated that more than 25 million Americans have utilized one of nearly 750,000 mutual or peer-to-peer support groups at some point during their lives (Hersh, 2005, p. 4). In spite of the growing popularity of these organizations which hold regular weekly or monthly meetings at a specific location, it may be difficult for working people, the disabled and those living in rural areas to find a group in which they are able to participate (Salem, Bogat & Reid, 1997, p. 189). In today's world, the practical answer for those unable or unwilling to attend these traditional support groups, yet seeking support, is to find an online alternative.

### *Online Support Groups*

Online support groups are drastically different from their traditional face-to-face counterparts. No matter how large your community and the rules of the support group, if you meet face-to-face there is no anonymity. Members will recognize one another if they meet by chance in a grocery store. Members who see one another will always act in an effort to save face in personal relationships when discussing sensitive topics. An online atmosphere provides a sense of anonymity while at the same time offering people the chance to develop very intimate relationships. This sense of anonymity allows people a safe place to voice their feelings, their experiences and to honestly respond when others do the same. Having a safe place to express emotions that are otherwise not socially acceptable has value beyond simple scientific measure for those who need to express themselves without judgment.

Cummings, Kiesler and Sproull (2002, p. 79) define online self-help support groups as electronic gatherings of people who discuss issues and provide assistance to other participants. It is also assumed by this author that those belonging to online support groups have the required technology access, knowledge to operate the equipment and a comfort level using this communication avenue.

Online discussion groups are available for nearly every interest imaginable, from the model building hobbyists to wine enthusiasts to cancer survivors. Online peer-to-peer support groups exist for a wide variety of needs. Self-help communities in cyberspace can be roughly divided into three realms: physical health concerns, mental health concerns, and recovery/problems of living (Ferguson, 1997, p. 32). The subject group of this study fits into the third category, recovery/problems of living.

Peer-to-peer support groups were reborn in the 1980s when the internet made it possible for people with similar interests to communicate at will (Cummings, Sproull & Kiesler, 2002, p. 79). It was during this decade when the Internet became widely available that support groups made the transition from the physical to virtual space (Hersh, 2005, p. 4). Grief support groups began to spring up on the internet. This timing coincided with the social movement encouraging bereaved mothers to bond with and let go of the desired as well as the actual child. Their grief was finally socially validated and they sought out and associated with others who expressed support (Hazen, 2003, p. 163).

An online support group offers members the ability to seek interaction when they want, about what they want, effectively 24 hours a day, 7 days a week, 365 days a year rather than once weekly or monthly. While online interest groups often advertise for membership (e.g. network television's fantasy football leagues), members seeking social support groups typically seek the group themselves through online searches or are referred by health care providers, friends or family who have sought similar assistance. While facing similar life difficulties, members can come together to help themselves and others by providing an ongoing and highly available source of support (Salem, Bogat & Reid, 1997, p. 190).

Online support groups exist in a variety of settings with a wide mix of communication avenues and available tools. Some meet in chat rooms at scheduled times similar to traditional peer-to-peer support groups. Groups formed through services such as Yahoo! and msn.com follow discussion threads through an email distribution system. Threads begin when a member posts a question or comment. Every member can see the original post and all replies; any reader can post another reply or start a new thread

(Cummings, Sproull, Kiesler, 2002, p. 79). Forums, like [www.cafemom.com](http://www.cafemom.com), have conversations archived and available on electronic bulletin boards, which require members to authenticate to the site to participate in the conversation. Each individual and community must find the one or combination of tools that work best for them (Cothrel & Williams 1999, p. 20) and create the community, the relationships they are seeking.

Communities are about human relationships, and are often emotional places (Cothrel & Williams 19). Online support groups or communities are a gathering of people, in an online “space” where they come, communicate, connect and get to know each other better over time (Boetcher, Duggan & White, 2002, ¶ 2). Our definition of community is undergoing a transformation in today’s technologically-based world, and computerized communication has provided an alternative sense of community (Salem, Bogat & Reid, 1997, p. 192).

At the time of Audie’s death I was place-bound in a small, rural community. There wasn’t a plethora of support groups offered by community centers or churches as is commonly found in more urban or metropolitan areas. There was one general grief support group which met once a month at the local hospital. I attended a meeting about three weeks after Audie’s death. A middle-aged woman welcomed me into the room. During a short break she asked about the experience that had prompted me to attend. I told her an abbreviated version of Audie’s birth and death. She responded by hugging me and telling me that I was still young enough to have more children and that I wouldn’t know true loss until my husband died. I was shocked and hurt. Today, I realize that she was responding from the standpoint of her own grief. She didn’t mean to hurt my feelings or lessen my loss; she just didn’t understand my situation.

Joanne Cacciatore and Suzanne Bushfield (2007) state in their extensive research of mothers who have lost children to stillbirth that these women are helped when they are able to share their experience with and hear the experiences of others who have similar losses (p. 66). The examples provided hope, a place to validate the child's life, and a sense that survival was possible (p. 67). When these bereaved mothers gather, they are among others who feel the larger disenfranchisement and social isolation (p. 69). Cacciatore and Bushfield found that bereaved mothers reported that on-going support and connection with others who have experienced similar deaths fosters a sense of belonging and connection and is helpful to mothers as they mourn their babies (p. 76). However, social support groups for disenfranchised grievers are not common. By simple definition "disenfranchised" means to deprive of power or marginalize. Those experiencing disenfranchised grief are not embraced by society, their experience is not welcomed and that is very apparent when searching for support groups. Vanderlyn Pine (1989) states there generally are no coherent, well-organized, or readily available self-help groups for disenfranchised grievers. The result is that this potentially beneficial source of social and emotional support is typically not available for this specific population (Pine, 1989, p. 21).

A simple search on [www.google.com](http://www.google.com) for "bereavement support" lists hundreds of references and links. Online bereavement support can be found for those seeking support for the loss of a parent, a spouse, a child, a friend, a pet, someone to suicide, someone to early death, someone to murder. The list of specialized bereavement support groups is virtually endless.



Within this simple search, I found more than 25 citations for bereaved parents or mothers. The Child Bereavement Charity ([www.childbereavement.org.uk](http://www.childbereavement.org.uk)) offers support to anyone who has experienced the loss of a child of any age in Great Britain. The West Australian Bereaved Parents Group (<http://bereavedparentsgroup.yoll.net/>) was formed in 1995 for parents who have lost a child of any age to meet and support one another. The Good Grief Center ([www.goodgriefcenter.com](http://www.goodgriefcenter.com)) and Bereaved Parents ([www.bereavedparentsusa.org](http://www.bereavedparentsusa.org)) are two sites which provide access to online support groups as well as information and referrals for additional one-on-one professional support.

Groups offering support to even more specific audiences could also be found within those listed on the original search. Organized groups offer support based on religious beliefs, geographic location and family status. Jewish families can seek support at [www.bereavedjewishfamilies.on.ca](http://www.bereavedjewishfamilies.on.ca). Christian families have several sites to choose from including, <http://iam.homewithgod.angeljeh/index.html> or [www.godstinyangels.org](http://www.godstinyangels.org). South African families can seek online support at a site named Baby Angels of South Africa ([www.babyangels.co.za](http://www.babyangels.co.za)). Parents in Seattle, Wash. may join Parent Support of Puget Sound ([www.psofpugetsound.org](http://www.psofpugetsound.org)).

Parents can also choose to join a group specific to their place in life in regards to their family. Subsequent Pregnancy After a Loss ([www.SPAL.com](http://www.SPAL.com)) is a support group offering assistance only to women who are expecting a child after the loss of another. As a .com site this group is different from most other support groups found during this search. SPAL requires an application, a subscription and that the member must leave by the time their child reaches 6 months of age as the lively discussions of living children

could be upsetting to other members still making sense of their grief over the loss of their child and preparing emotionally and physically to welcome another.

### *Empathy & Trust*

It is difficult to trust people with my intimate thoughts and memories of Audie. There are very few and I want to save them for myself; they have to last my entire lifetime. It may sound selfish, but it is actually an act of self protection. All too often I've heard comments that demean my feelings toward Audie, and related that the speaker doesn't care. We've experienced people who say they are "grossed out" by photos of her, but don't complain when they see baby photos of our other children. These are the types of people who don't empathize with our experience and our continued feelings for our daughter. Therefore we can't trust with sharing these thoughts, emotions and experiences, because they aren't appreciated.

Finding people who appreciate our story and are willing to listen to any part of our experience is difficult. I am careful about the environment in which I share and with whom I share. Communication is a two-way street and successful communication depends on the speaker and the listener having similar impressions of the information exchanged.

Online parenting support groups offer users the opportunity to join an online community based upon a common interest, providing information, support and advice. Most parents who join these online support groups are women and common features of women-centered websites are a high degree of trust, support and encouragement (Madge & O'Connor, 2006, p. 208).

Emotional support is empathic, it seeks to nurture, encourage and bolster one another (Salem et al, 1997, p. 190). Empathy is an important phenomenon in interpersonal communication, which refers to one's ability to accurately infer another person's feelings and respond compassionately to another person's distress (Feng, Lazar & Preece, 2004, p. 97).

The friend mentioned earlier who responded to my daughter's death with feelings of guilt because her son was born healthy was someone I can trust with anything I needed to express. The weekend between her son's first birthday and Audie's anniversary dates, we met. I was again pregnant, her son was learning to stand and walk. As it does, life had moved on. We shared photos from a combined baby shower we had, photos of her son's first year and an ultrasound photo from my current pregnancy. We talked about the joys and despairs of being a parent. Even a year later, when most people expected me to have "moved on" she was concerned about my reaction to her living son. I explained that my emotional reaction would always include highs and lows of joy and despair, that given our experience it is difficult to not compare her son to what could have been with Audie. Our trust level is high enough that we can openly share how to truly feel about situations without worry of damaging our friendship. She accepted my explanation of mixed emotions, has always attempted to see the situation from my standpoint and we continue to be the best of friends.

Empathy breeds trust. When mothers are interacting with others whom they can share their deepest emotions and fears, they build trust, thus building community. Feng, Lazar & Preece (2004) conducted an empirical study and found a correlation between empathy and trust (p. 97). They studied online conversations via email, instant messaging

and electronic bulletin boards and found a correlation between the people providing an empathically correct response to postings and the amount of trust or confidence others sense in a relationship. They hypothesized that empathic responses would have a positive impact on perceived trust in online relationships and that trust would be highest between those who share experiences and can respond with sincere empathy (p. 99). In order for an online community to survive and thrive, it is important that there is trust between people participating in the online community to guarantee they remain a part of the group (p. 103).

Just as in our day-to-day relationships, trust is an important building block for forming online relationships. Members of support groups need to feel comfortable and trusting of other members before they are willing to freely participate in the group. Trust is built as people join the online community and abide by the established rules of interaction, keep conversations on topic and fulfill responsibilities similar to those in traditional communities. Members of online communities have a shared purpose, they interact socially by adhering to tacit and explicit protocols, rituals and roles (Johnson & Ambrose, 2006, p. 108-109).

Bereaved parents, mothers in particular, often turn to the internet seeking support, a place to share. They don't expect a support group to provide all the answers to their questions or concerns. The internet may offer an avenue to increase women's empowerment in transitional experiences (Madge & O'Connor, 2006, p. 202). From personal experience, mothers seeking to join these groups are seeking like-minded people who are willing to share their knowledge and want to interact with others who have similar life experiences. These women are seeking empathy and to interact with others

who won't minimize their emotions. I sought a supportive and non-judgmental arena in which to express myself. I sought a trusting, nurturing environment where I was safe to share the emotions of new motherhood as well as the daily victories of raising my subsequent children mixed with the grief over the child I'm not raising.

### Parenting After a Loss

We've all seen many women with parenting challenges. Some are single mothers at the tender age of 16. Others are raising children with special needs, multiples or children with drastic age differences. Some are unable to bear biological children and seek to fulfill their desire to parent through adoption. Others enjoy a traditional parenting experience for years before they lose a spouse or significant other to divorce or death and are left to parent on their own. They each face unique challenges and search for resources to help them through their difficulties.

Losing a child brings a different dynamic to the role of parenting. I didn't need to find a way to juggle daycare, work and taking care of the house. I didn't need to learn how to balance a tight budget with another mouth to feed. I didn't need to struggle through insurance or social services for food and healthcare for my child. I needed to learn to overcome the gripping fear that overtook me the minute I learned I was pregnant again. I needed to know that my anxiety about too many wet/dirty diapers a day or the belts on the car seat being too tight or too loose were okay to acknowledge. I needed to know that the crushing pain I experienced when holding my second child while seeing a photo of Audie was a normal grief reaction. I needed to find others who had similar

experiences, who wouldn't find my questions and concerns during normal conversation scary.

There are several groups available to support bereaved mothers during their next steps in life, to raise a subsequent child outside any shadow of the one they lost. There are at least three different groups offered through Yahoo! Groups and two through MSN.com services specifically for parents fitting this description. These include:

- Parenting After a Loss, <http://health.groups.yahoo.com/groups/pal-parents/>,
- Our Babies in Memory, <http://health.groups.yahoo.com/groups/OurBabiesinMemory>,
- The Angel Connection, <http://health.groups.yahoo.com/groups/TheAngelConnection>,
- The Littlest Angels, <http://groups.msn.com/TheLittlestAngels/>, and
- Angels Taken Early, <http://groups.msn.com/AngelsTakenEarly/>.

Losing a child has a galvanizing effect on parents, bringing them together into a society of others who have similar experiences. The research conducted for this study illustrates the lack of real world community support for bereaved parents and the magnitude of social support structures available online. The internet offers a place these parents can easily gather to support one another on their journey beyond grief. While society continues to minimize the loss of the child, the internet allows those grieving the loss of a child an outlet to express emotions, ask questions and confide with others who have had similar experiences.

Parenting After a Loss (PAL) is an online support group founded in 1989 by two women who had experienced perinatal losses and were seeking emotional support from those who had similar losses. They also recognized a social need to provide emotional support to other parents at similar junctions in life. The group is specifically for parents

who have lost a child and are actively parenting other children. The founding members belonged to Subsequent Pregnancy After a Loss ([www.sPAL.com](http://www.sPAL.com)), an online support group providing social support to women experiencing a subsequent pregnancy after experiencing a pregnancy or perinatal loss. As previously mentioned, SPAL members must leave the group once their subsequent living child has reached the age of six months to eliminate compounding the grief of other SPAL members by discussing living children. The founding members of PAL believed six months was too brief a time period to completely overcome all the emotional turmoil that accompanies blending the tragic experience of loss with the healthy arrival of a new baby.

Historically, the membership of PAL has been in a continuous state of flux. The group has been in constant existence since it was created. Members must supply a brief biography to group moderators and be approved before interacting with the group. Members are free to come and go as they want once approved. Messages are shared via email distribution list, with individuals sending a single message to the entire group. Currently there are approximately 60 members, some actively involved in conversation, some gleaning what they want from reading the on-going online conversations, some only checking email messages weekly or less often. There are no rules requiring active participation; members are free to be as active or inactive as they choose.

The preponderance of evidence compiled to date by academic and medical researchers illustrates good empirical knowledge of online peer-to-peer support groups, how many exist, topics covered, numbers of people who participate and categories of participation. Initially researching this topic, I questioned why no existing research was conducted from the standpoint of being a participant in one of these online groups. In

reading articles, the participant experience was nearly completely ignored; it was almost as if the experience didn't matter to researchers. Very little first-hand qualitative investigation has been done on the existence, membership and use of online support groups and even less for groups dedicated to supporting bereaved parents or mothers.

This research will examine how bereaved mothers found and continue to utilize the online support group PAL while parenting living children in the shadow of another child's death. This study combines autoethnographic and ethnographic research methods to study the online support group PAL through the interpretation of PAL member survey responses and descriptions of my own first-hand experience. The survey will explore the relationship these bereaved mothers have with their living and deceased children, how and why they sought an online support group, their other social support systems and what they believe PAL provides them. The primary purpose of this research is to demonstrate the benefit online or virtual communities, in the form of peer-to-peer support groups, offer in providing a safe, comfortable place where bereaved mothers can find continuing emotional support as they carry on with their lives and parent other, living children.

### Methodology

One late night about a week after our daughter died, my husband and I were walking aimlessly through a box store, attempting to keep busy and away from a home that was filled with unhappy reminders. We had a chance meeting with some friends whom we hadn't seen for about two months. They were elated to see us and then the inevitable happened; they asked us about the baby. Tears welled up in my eyes, my mouth went dry



and my chest tightened. I couldn't tell the story, couldn't tell anyone else Audie was gone. My husband held my hand and told them.

Our friends were saddened by the news. They offered their condolences, hugged us and went about their shopping. The next day they sent flowers, it was a wonderful and thoughtful gesture. However, after reading the handwritten message inside the card we felt disappointed and saddened. The handwritten message inside read: "We are so sorry for your loss. You are young and can always try again." We both cringed at the "try again" remark. We couldn't recreate Audie, neither could we replace her with another child. She was a unique individual, just as unique as any loved one lost too soon to a tragic event. It was at this point we began to realize Audie wasn't a concrete part of the lives of others as she was to us.

We appreciated the fact that our friends extended their friendship to us during our time of sorrow, however it was another well-meant but poorly constructed comment regarding our loss. It indicated to us yet again the reality of how many people live outside the experience of losing a child and do not understand the intensity of grief associated with the loss nor do they realize how their otherwise well-intended or traditional comments of sympathy can truly hurt someone whose grief they don't share.

### *Ethnography & Autoethnography*

To understand the bereaved mother, one must attempt to understand how their reality is constructed and how they envision society-at-large regards them. Many of these women feel social pressure prevents them from freely expressing grief, talking about their deceased children, commemorating special anniversary dates or displaying photos

of their deceased children. Many feel their grief is an inconvenience to others and experience pressure to get over their loss quickly and return to a normal outward existence for the comfort of their friends, family and workplace relationships.

To better understand the experience of this “other” – the bereaved mother – qualitative methods must be employed. I believe it is impossible to adequately quantify or represent with numbers, graphs, statistics and percentages the deeply personal emotions and individual sense of loss and grief experienced by these women. This would be a remote and insincere way to attempt to describe an experience that is very individualized, that is never the same for any two people.

This research was completed using a two-pronged qualitative approach using ethnographic and autoethnographic methods. I began by collecting specific, significant (Chase, 2005, p. 652) life histories of bereaved mothers and documenting my own personal life history in parallel using the same survey. The other women’s accounts, or the ethnographic study, was then woven and intertwined with my own personal experiences, the autoethnographic study, to create the research results.

Ethnography, or the study of human culture in a natural setting by accounting for events over time, aims to contextualize the experiences illustrated by a researcher’s subjects to allow a wider audience to learn and understand the life events of the individual. Typically the researcher is considered to be an observer and detached from the experience. Conducting the ethnographic research over the internet involved learning to “live” in cyberspace (Carter, 2005, p. 150), which some researchers describe as a challenging task as they have to learn the culture of the virtual group and to fit in with the

existing members. It wasn't difficult as I had been embedded in this group as a member long before I decided to study myself and my fellow PAL members.

Autoethnography, as a research method, utilizes personal experience and storytelling to gain deeper cultural understanding; it is a description of the personal and social process (Harris, 2011, p. 725). Autoethnography began gaining popularity among qualitative social scientists in the latter years of the 20<sup>th</sup> century (Chang, 2008; Pearce, 2010). In their essay, Laurel Richardson and Elizabeth Adams St. Pierre (2005) refer to autoethnography as a new ethnographic "species" (p. 962) that is humanly situated, always filtered through human eyes and human perceptions and bearing both the limitations and the strengths of human feelings (p. 964). According to Carolyn Ellis, autoethnography combines "heart and soul." It is:

... unruly, dangerous, passionate, vulnerable, rebellious and creative – in motion, showing struggle, passion, embodied life and collaborative creation of sense-making. I need the researcher to be impassioned and embodied, vulnerable and intimate, and the stories to be evocative, dramatic, engaging, with concrete and layered details, and when the topic calls for it, even heart-breaking. I want the reader to care, to feel, to empathize, to try to figure out how to live from the story, and then to do something. (Ellis, 2009, p. 363)

Context is the major distinction between ethnography and autoethnography. It is commonly accepted that ethnographers maintain distance, a separation of authority between themselves and the group they study; there is a perceived and intentional professional disconnection between the subject and the observer. Autoethnographers have

dual roles in research, they are both the observer and the observed; there is no effort to separate the researcher from his subject. Autoethnographers provide a rare scientific viewpoint from the inside of the social setting; their perspective is presumed to be similar to that of their subjects.

Cecilia Bostico and Teresa Thompson (2005, p. 274) claim that this unique aspect of autoethnography may provide promising alternatives to the traditional ethnographic approaches to grief research as scholars may be able to use the grieving contexts in which all families at one time or another find themselves. S.J. O'Connor (2011) agrees with this viewpoint, claiming that complex social phenomena are being investigated in naturalistic settings, by those with prior knowledge, skills and expertise (p. 421). The movement toward more autobiographical, ethnographic texts has been encouraged by the literary turn in the social sciences. Postmodernism and feminism have also encouraged texts that are more emotional, personal and complex (Sparkes, 2000, p. 36).

Simply stated, my research focuses on illustrating the reality of bereaved mothers, including myself, in our own words using our life experience and histories. We are ordinary people, living ordinary lives, but they are set apart from the majority by the loss of our children. Ordinary people's narratives of everyday experience are worthy of study in themselves (Chase, 2005, p.655). Chase illustrates the particular value of female life stories:

As feminists incorporated postmodern influences, they began to ask questions – which are still pertinent today – about voice, authenticity, interpretive authority, and representation. What does it mean to hear the

other's voice? In what sense do – or don't – women's life histories and personal narratives "speak for themselves?" (Chase, 2005, p. 655)

My research shares these ordinary lives in the first-hand words of bereaved mothers. The implementation of qualitative narratives is not the only the way to unveil these experiences for a larger audience, but it is a way to reveal the stories in a personal, rather than a mathematical or technical, manner:

This is not to argue that one notion of collaboration is superior to the other, but it is clear that "native" or insider ethnographers may have to march to the beat of a different drummer. Ethical commitments to their subjects/political allies may compel them to be collaborative in more spiritual and less procedural, methodological ways ... Each ethnographer ultimately develops his or her own notions of collaboration, positionality, and authorship. (Foley & Valenzuela, 2005, p. 231)

Autoethnography is a self-narrative (Sparkes, 2000, p. 21) in which the researcher's personal life experiences form the starting point and the central material for the research (Uotinen, 2010, p. 163). Autoethnographers aim to reveal the truth between the storyteller and the listener (Bochner, 2010, p. 161):

They dwell in the listeners' or readers' engagement with the writer's struggle with adversity, the heartbreaking feelings of stigma and marginalization, the resistance to authority of canonical discourses, the therapeutic desire to face up to the challenge of life and to emerge with greater self-knowledge, the opposition to the repression of the body, the difficult of finding the words to make bodily dysfunction meaningful, the

desire for self-expression, and the urge to speak to and assist a community of fellow sufferers. (Bochner, 2010, p. 161)

This research promises to help reveal the experiences of bereaved mothers for others to see into the private experience. Autoethnography has risen in popularity particularly because it provides insightful and illuminative accounts of individual's experience of traumatic events (Pearce, 2010, p. 1). Autoethnographic approaches may be promising alternatives to traditional ethnographic work, as scholars may be able to utilize the grieving contexts in which all families naturally find themselves at some point (Bosticco & Thompson, 2005, p. 274). The goal of an autoethnographic researcher should be to study alongside their subjects, neither being "out" (too distanced from) or "in" (too overwhelmed by) the research (Pearce, 2010, p. 5).

In studying post-accession Europe populations and the Tex-Mex culture, Kempny (2012) describes native ethnographers, or autoethnographers, as "halfies." Halfies are ethnographers who are bi-cultural or simply are an outsider who becomes a member of the culture being studied by being immersed in it (Kempny, 2012, 40). This theory has been adapted to this research as most bereaved mothers have parallel experiences in our culture. On the surface, we appear as normal as other parents facing the daily struggles of raising subsequent children. However, a deeper evaluation reveals that while we are members of the wider society, we are also simultaneously members of a social minority, a hidden minority.

My survey was a simple, written form of mediated interview. Interviewing is inextricably and unavoidably historically and contextually bound, firstly by its placement in time and space and secondly by being recorded. This boundedness refutes the whole

tradition of the interview as gathering objective data to be used neutrally for scientific purposes (Fontana & Frey, 2005, p. 695). The information gathered should paint a deep, rich story of the women's experiences. The stories will provide what some qualitative researchers refer to as "thick description" (Stake, 2005, p. 450).

Narrative inquiry or narrative ethnography, in this case employing the survey, lends itself to the first-person point of view or voice. Chase (2005, p. 666) claims that researchers utilize the words and emotions of their subjects to undermine the myth of the "invisible omniscient author." In considering voice, I retained the individual respondent's voices in the results. Each woman should be allowed to tell her own story. In collecting life histories in this manner my research is beginning at the point of the first person. A narrative ethnography makes the narrator the protagonist, either as actor or as interested observer of others' actions:

Like traditional ethnography, this approach involves long-term involvement in a culture or community; like life history, it focuses heavily on one individual or on a small number of individuals. What makes narrative ethnography distinct is that both the researcher and the researched are "presented together within a single multivocal text focused on the character and process of the human encounter" (Chase, 2005, p. 659).

For example, although I am a bereaved mother, I do not speak for all bereaved mothers; nor does my experience represent the experiences of any other bereaved mother. If I were not a bereaved mother, researching and interacting with other bereaved mothers would imply that I would not be invisible nor omniscient to them or the audience. By

including both my own experience – autoethnography – and the self-reported experiences of others – ethnography – the results should paint a very broad reflection of the experience of bereaved mothers.

This broad reflection is often times difficult for researchers to develop for a variety of reasons. One of the primary reasons is the social taboo already described surrounding expressions of grief, especially grief related to the loss of a child. It is also difficult to obtain the level of authenticity because this type of research requires real, honest written or oral responses to open-ended questions, rather than the limited responses to the methods more commonly utilized by quantitative researchers including Likert scales, yes/no or multiple-choice questions. The intention of this research project is to build a genuine representation of the experience of the bereaved mother from the mother's point of view.

Drawing from my own experience, institutional scrutiny may dissuade academic researchers from pursuing groundbreaking autoethnographic research. I was cautioned by fellow students and some faculty that my research proposal would be complicated and possibly declined because of the perceived vulnerability of my research subjects, the bereaved mothers. I stopped and thought about how vulnerable I was. I didn't consider myself vulnerable for sharing something that actually happened to me.

A hearing before the institutional review board was scheduled to approve, deny or alter my research proposal. After checking with my thesis chair, it conflicted with her schedule and I had to attend alone. No other students in my courses had been through this experience, they had no knowledge or experience to offer. One faculty member wished



me luck and said that he intentionally chose research topics that do not involve people in any immediate mode because that is a primary trigger for a review board hearing.

The week prior to my hearing was very stressful, very anxiety filled. I did not know what kind of questions to anticipate, what concerns there may have been about interviewing people about their dead child. When expressing this to a classmate, I realized I was angry. I was angry that there were questions about whether or not these stories should be shared. I was angry there would be desire on the university's part to not allow my research under the guise of protecting these women perceived as vulnerable. I kept asking myself, what are they protecting us from and who are they to protect us? Have any of them ever lost a child? It was my opinion that the taboo of sharing these stories had even infiltrated academe. My anger and my anxiety were washed away with relief when my research proposal was approved without a formal hearing.

Being allowed to delve into the thoughts, feelings and experiences of bereaved mothers and document them for a wider audience has academic and social value. In the 15 years since Audie was born and died, we've never met another family who has lost a child in exactly the same manner we did. Most parents who have lost a full-term baby know how and why their child died. Soon after most unexplained deaths in our culture, medical professionals investigate and provide a reason why death occurred. Audie's birth certificate indicates she was alive when she was born. Her death certificate, signed two days later, indicates asphyxiation as the probable cause of death. Doctors told us they didn't know why her oxygen was depleted, it could have been an accidental constriction of the umbilical cord, the placenta may have abrupted or a range of other things may have

gone wrong. There were no tests that could be done to find the single, true reason for her death.

Just as we've never met another family who lost a child in the same manner we did, we've never met another family who worked through their grief the same way we did. We know people who were denied by hospital staff the opportunity to see their child. Others who chose to never hold their child. Others lost their pregnancy before there was a baby to hold in their arms. We have friends whose marriages did not survive their common grief. We knew one mother who committed suicide after her son died. Most of these families cling to the minimal reminders they have, hand and footprint cards, a lock of hair, snapshots, or the clothing they planned to dress their child in to bring them home. Many have nothing tangible to remind them of the child no longer with them.

### *Qualitative Research*

As I explained above, the experience of bereaved mothers cannot be quantitatively compared and contrasted, neither to the experience of another bereaved mother or the loss experience of any other loved one. Each experience of loss is unique, deeply personal and a singular event.

This research, by definition, is a qualitative intrinsic case study (Stake, 2005, p. 445) because of my personal journey in the particular situation of grief and the fact that something socially valuable can be learned from the single, individual situation.

Qualitative case studies are typically characterized by researchers spending extended time on site, in personal contact with the subjects and constantly observing activities of the case, attempting to record the natural happenings in the setting and assigning the

values of those who live the experience (Stake, 2005, p.450). Qualitative case study also concentrates on experiential knowledge of the case, or individual experience, and pays close attention to the influence of its social contexts (Stake, 2005, p. 455).

Although this is an intrinsic case study, this research is not intended to generalize my own experience or the experience of these bereaved mothers to larger populations. In fact, many qualitative researchers claim that generalization should not be emphasized in all research nor should it be the goal of qualitative research (Stake, 2005, p. 455; Saukko, 2005, p. 350).

Another, and possibly the most important reason this research may be considered a qualitative case study is that case studies often deal with matters that are of public interest but for which there is neither public nor scholarly right to know (Stake, 2005, p. 459). In this case, the loss of our children, our grief process, the stories we tell about ourselves are private matters, not public events. As I've argued, common cultural practices teach us to hide our grief, to keep it private. We are taught that it is more valuable for the majority of people to be comfortable not knowing our grief rather than comforting those who grieve. The larger population goes about their lives not understanding or caring to understand the plight, the experience, of bereaved mothers. Unlike the commonly held presumption that grief is a private matter, this research will attempt to illustrate the need to educate people about the experience, not shroud it in secrecy or force grieving parents into hiding their feelings and experiences. Autoethnographic research seeks to understand ourselves in an attempt to share that truth with others (Pearce, 2010, p. 12). The purpose of this research is to bring these experiences into a new light, to bring them to the surface for discussion.

Wouldn't it be wonderful if this research helped one person respond in a sensitive, caring manner to a friend or stranger who has lost a child?

Qualitative researchers are trespassers in the private lives and places of the world. By utilizing a combination of ethnography and autoethnography, I will be trespassing – with limited permission – into the experiences of others and revealing my own personal experiences to help those outside better understand those of us who live inside the experience. Autoethnography attempts to “heal the split between public and private realms by connecting the autobiographical with the ethnographical, illustrating the interplay between the individual and the society (Harris, 2011, p. 726) Losing Audie put me in a position of being on the inside looking out. Today, as a researcher I am in two places at once. I'm still on the inside looking out, however I'm also on the outside looking into the hearts of others who have grieved the loss of a child.

### Data Collection

As I matured and experienced more complex adult situations, my parents often told me, “You can't criticize another until you've walked a mile in their shoes.” It is a common adage, but one I didn't truly understand until losing my daughter and the dreams I had for our lives together. I didn't fully realize the power of this statement until I was unwillingly thrust into the role of a bereaved mother.

Our experiences are inescapable and each experience shapes and reshapes who we are. We cannot eliminate an experience from our memory nor can we deny knowledge we possess after an event. We cannot forget people that touch our hearts to the core.

### *Email Survey*

Narratives were collected via electronically-distributed survey, rather than a traditional face-to-face interview. I chose this method as members of PAL live in a variety of locations around the globe, including Europe, Canada, Australia, the United Arab Emirates and several locations across the United States. PAL members are accustomed to interacting with one another via electronic communications, primarily email and occasionally chat rooms. It made sense to utilize a mode of communication with which the group was familiar and comfortable. As a group, a community, we have learned to and accepted interacting with one another socially using the tacit and explicit protocols and rituals dictated by internet technology (Johnson & Ambrose, 2006, 108). If I had chosen to contact them via telephone or formal written survey, it would have added another layer to our relationship. It would have forced us to implement another communication tool over those we are accustomed to using in our daily interactions. We have interacted for years using primarily email, and have developed a solid sense of trust, reliability, accountability and empathy with one another. We are all very comfortable interacting with one another, either in group settings or one-on-one using electronic communication, e.g. the internet and email.

Collecting research data electronically is a comparatively new medium for academic research, however it was entirely appropriate for this study. Collecting data electronically has been happening since the Internet gained popular and widespread use in the early 1990s. Because this group exists only in a virtual world, the survey can be considered an efficient, safe and practical resource (Walker, 2013, p. 33) for gathering qualitative data from its members. As members of PAL, we have no coffee shop to gather

in and thousands of miles along with multiple country borders separate us from one another. Email is our chosen method of interaction so it was a natural choice for this research project.

The stories collected primarily focus on the interaction bereaved mothers share to express the loss of their child or children and their descriptions of the similarities and differences between localized and online support systems. The survey also collected basic demographic data and descriptions of the social and familiar setting of participants. Just as each woman is an individual; her familial setting will be unique to her life. This takes into account whether or not these women were married or already have other children at home, which will affect how they grieved, alone or alongside the ones they love and their need or desire to seek outside support.

Each woman who participated is a member of my personal friendship network as I've been a member of PAL since 1998. One member and I met in a different support group prior to joining PAL. All have the shared experience of losing a child, however each lost their child or children due to different circumstances.

These three sources of information – biography, history and society – are commonly known as “Mill’s famous trilogy.” Mills called these three the co-ordinate points of the proper study of man (Chase, 2005, p. 651), making them vital to the ethnographic and autoethnographic nature of my study.

Additionally, my research considers the PAL environment, or the online forum which creates the meeting place and communication center for these women. This message center is a database which stores all the forum messages shared between members since it was created in December 1998, as well as working as a real-time

communication forum. Members can post a message, by beginning a message thread or responding to already posted messages, any time day or night. They don't have to wait to attend a meeting or to join a chat room at a specified time. The forum is available 24 hours a day, 7 days a week, 365 days a year. If a member is having a difficult day or wants to remind her friends of an important anniversary date, she can do it immediately. Fellow members can respond immediately or when their schedule allows.

At any given time, more than 50 bereaved mothers typically belong to PAL. The group is hosted through Yahoo! Health Groups. The intention of the group is to provide personal emotional support for families who are parenting a living child after experiencing the death of another through miscarriage, still birth, complications, prematurity or a variety of other causes. The only prerequisite to joining PAL is that a member has lost a child and is seeking to communicate with people who have had similar life experiences.

The survey consisted of 10 questions. The entire PAL membership was invited to participate. The survey was distributed to PAL members via direct individual email messages. The message included a cover letter introducing myself as their long-time friend and a member of PAL, as well as a graduate student conducting research. Sending the survey via email allowed participants to respond to the questions either within the body of an email or a Microsoft Word document and electronically transfer the file directly back. The survey questions were as follows:

1. Please describe yourself:
  - a. Age
  - b. City, state, country of residence

- c. Education level (e.g. high school diploma, some college, college graduate, etc.)
2. Please describe your children.
  - a. Living children (date(s) of birth, sex)
  - b. Deceased children (date(s) of birth, sex, cause of death)
3. How long after your child died did you find PAL?
4. Why did you join PAL?
5. When you joined, what did you initially think the group would provide?
6. Have your perceptions of PAL membership changed since you first joined?
7. Please share your loss story.
  - a. Describe your child(ren), pregnancy, birth or delivery, the time you had with them, any details you feel best illustrate your experience.
  - b. Describe your personal relationship(s) with your deceased child(ren).
  - c. How did this experience impact (include positives and negatives) your life?
8. Describe your relationships with PAL members.
  - a. Are your relationships with some members closer than relationships with other members? Describe these relationships.
  - b. Do you feel a sense of support from the group?
  - c. Do you feel a sense of support from individual members?
  - d. Have you ever felt as if your membership has had a negative impact?
  - e. What benefit do you bring to the group?
9. Describe your local support system.



- a. What kind of support did you receive from family, friends, medical staff, workplace when your child(ren) died?
  - b. Describe any long-term or ongoing support you receive from family, friends, medical staff, workplace.
  - c. Describe long-term or ongoing support you receive from PAL.
10. Are you willing to participate in follow-up questions regarding this survey? If so, please include the email address you would prefer to use for this correspondence.

I completed the survey myself before distributing it to PAL members who expressed an interest in participating. It took about an hour to complete.

The survey was offered to a group of approximately 40 potential participants, nine women agreed to participate and six completed surveys were returned by the stated deadline. Five were completed by PAL members and one was completed by myself. One recipient contacted me after receiving the survey and declined to participate, stating that her family was not supportive of her sharing intimate, personal information for use in a published report. One participant did not respond to the survey questions, however submitted a list of poetry. The other two who received the survey failed to respond by the deadline and to a follow-up request.

Respondents were all female and ranged in age from 33-years-old to 45-years-old. Four live in the United States, one in Canada and one in Finland. The respondents who completed the survey are all active members of PAL, posting and responding to messages on a regular basis. Four of the five respondents hold bachelor-level college degrees, the other reported attending some college. All the survey respondents' names and other familial identifiers have been changed to protect and respect their privacy.

These women reported a wide range of personal experiences regarding pregnancy, childbirth, the death of their child and their grieving process. Maggie reported 11 miscarriages over a seven-year period. She is raising her own biological daughter and an adopted son. Doreen experienced four miscarriages, delivered a stillborn daughter and is now raising four healthy children. Patty delivered a full-term stillborn son before the successful births of her living son and daughter. Alice's 14-month-old toddler died from injuries suffered in a car accident. She then experienced two miscarriages before her daughter was born. Beth's son died unexpectedly just a few hours after birth; she is currently raising her daughter.

Upon a preliminary review, the answers provided were honestly and thoughtfully compiled. The responses related intimate details of experiences and a range of emotional responses. Most replies were extensive and included information that – as a bereaved parent myself – wouldn't necessarily be openly shared with anyone who hasn't "walked in our shoes."

### *Story Collection*

Participants were asked to share their loss story by describing their child(ren), pregnancy, birth or delivery and time spent together. Participants were informed in a cover letter introducing the survey that responding to these questions would ask them to explore deep emotional and personal experiences. It also reminded participants they weren't required to answer any questions that made them uncomfortable and that participation was voluntary.

One participant, Alice, wrote a very succinct statement in response to this request as the birth of her son was removed in time from his death. For others, the birth and death of their children were relatively close in time. All participants provided a loss story.

*Maggie*

Maggie has two living children, a biological daughter and an adopted son. She experienced 11 early term miscarriages. Maggie and her husband wanted to start a family as soon as they could and she was happy to find herself pregnant two months after their wedding. She suffered a miscarriage two months later and another one before the end of that calendar year. She reported that her doctor told her the miscarriages were probably related to her being overweight and that he really couldn't investigate the cause of her miscarriages until she had experienced three. She was devastated by his response and sought assistance from another physician. Under treatment by a new doctor, Maggie underwent a battery of blood tests and it was discovered that she tested positive for a blood abnormality and was prescribed a daily medicine. Two years after they began trying to build a family they were rewarded with a healthy baby girl. Like most first-time parents they were elated and content and as Maggie reported, "we figured our problems were behind us and we could now add to our family whenever we decided the time was right."

Those positive thoughts weren't realized. Two years after their daughter was born, the couple decided they wanted another child. Maggie suffered a series of miscarriages in March and December of 2002; April, August and December of 2003; May and October of 2004; and January and July of 2005. The miscarriage in July of 2005 was a set of female twins who died at 20 weeks gestation as the result of a blood clot.

Maggie said, “During this time we decided we had to stop somewhere and we decided to adopt.” Before the adoption of their son was finalized in October of 2005 Maggie was diagnosed with Lupus, which she feels was a more than adequate medical explanation for her miscarriages.

*Doreen*

Doreen suffered her first miscarriage at home while her husband was deployed. She said it didn’t negatively affect her emotionally at the time. “I honestly didn’t take it that hard, it was kind of a fluke,” she wrote. Two years after the miscarriage she had made it to the top of the list at the military hospital infertility clinic, which served the base where her husband was stationed. She became pregnant and they happily informed their extended families and started planning a nursery.

As her pregnancy progressed, Doreen was required to attend a large group meeting of expectant mothers at the military hospital. All expectant mothers with babies due during a certain month were scheduled for a group appointment, where they watched a video in an auditorium, filled out hospital paperwork and marched en masse to the lab for routine blood and urine tests. She noticed blood spotting during the lab tests, went directly to the emergency room for an ultrasound and was sent home. After two more emergency room visits for increased bleeding over the next two days, she was informed that her pregnancy ended days ago. “I learned all that was left was a sac,” Doreen reported. “Worse, they knew at the first ER visit and no one gave me any warning then that the pregnancy was already over.”

Doreen chose to seek the medical assistance of a civilian obstetrician where she was treated with progesterone supplements. She experienced two healthy pregnancies and gave birth to two healthy daughters.

Eighteen months after her second daughter was born, Doreen shared the happy news of another pregnancy with her family. Her husband had been re-stationed across the United States and she and the children followed, moving far away from family and close friends. About eight weeks into the pregnancy, Doreen noticed bleeding and went to the hospital located on the military base. She reported that her previous doctor had prescribed progesterone treatment, but the same treatment was not offered by the military hospital. The pregnancy ended a few days later. She could not contact her husband and spent the following weeks recovering home alone caring for two toddlers. The following year she experienced another miscarriage during the holiday season.

The next year she was “trying not to be too hopeful” about another pregnancy that had advanced beyond 13 weeks. During a routine exam at 22 weeks gestation, the doctors could not find a heartbeat, her baby had died. “It wasn’t until almost an hour later that the reality hit me,” Doreen said. “This isn’t a miscarriage. I was past 22 weeks. I’m going to have to deliver a baby that has passed away.” Delivering her baby took four days of attempting to chemically induce labor. All three of Doreen’s living children had been delivered via caesarian section and she wasn’t accustomed to the process of labor and delivery. When the medications finally worked, Doreen was alone at the hospital.

“The nurse brought her in nestled in a basket and for the rest of my life I will regret not picking her up,” Doreen remembered. “I allowed myself to feel rushed by the presence of the chaplain, who kept a guarded hand on the basket the entire time. My

husband was supposed to take pictures but honestly I should have done it myself because we ended up with very few.”

As a matter of routine, the hospital staff approached Doreen and asked about the handling of her daughter’s remains. The hospital could arrange cremation and the family would be contacted later by the crematorium for arrangements. Doreen and her husband decided to make private arrangements. “After my discharge, I found that this service was a group cremation . . . I was so mortified and yet so relieved that I declined the service,” she said.

Two years later Doreen delivered a healthy little boy, her fourth and final child.

*Beth*

Beth had a normal pregnancy and was beyond her due date when she and her husband elected to induce labor. During the delivery, her son aspirated or inhaled meconium, a tar-like substance that is the first waste product of an infant. A specialized team of medical professionals was on hand in case of emergency and the baby was quickly taken to a neonatal intensive care unit (NICU), intubated and stabilized. “We were told he would spend a day or two in the NICU as a precaution but that he would be fine,” Beth said. The family was informed by the physicians in charge of his care that they believed he would recover and be perfectly healthy.

“As the evening wore on, more and more complications presented themselves and the staff began to prepare us for the possibility that Colin would not survive,” Beth reported. “It was important to me to be with him and eventually Colin had a pulmonary hemorrhage while I rocked and sang to him.” Beth spent fewer than six hours with her son, all of that time in an impersonal hospital setting.

*Patty*

Patty was 32-years-old when she became pregnant for the first time and experienced an uneventful pregnancy until her 30<sup>th</sup> week of gestation. “Pregnancy felt like something you could get through using common sense and without turning it into a supervised performance evaluated by childbirth experts,” she said. “I enjoyed feeling my baby kick; we had communication; s/he had a nickname and we were looking forward to getting to know him/her.”

On a Sunday evening, Patty was reading and experienced several sharp, strong kicks. She interpreted this to mean her baby was healthy and active. The next day she noticed her baby hadn’t moved, but wasn’t alarmed. “As the morning wore on I became more and more concerned, and left work to go to the maternity hospital,” she remembered. “There I was seen by first one, then several staff who all worked hard to find a heartbeat that was no longer there.”

After being induced and enduring 17 hours of labor, her son was delivered still. “Nobody had prepared me for this type of pain; the stillbirth had occurred before my childbirth classes had a chance to start and I had no idea what to expect. It was terrible,” Patty said. “It hurt. The baby was breech, that didn’t help matters. I was not a trooper; I was in pain and I was screaming for someone to take it (the pain, the baby, who knows) away. Maybe the people around me would have been happier to see me try and be brave about it, but to this day I fail to see why I was supposed to make everyone else comfortable.”

They were allowed to see and hold their son. “It was February. It weather outside was bitterly cold,” Patty said. “I held my son and didn’t know what to do or say. ‘Poor

little boy,' I said to him." The hospital staff members took photos and gave them to Patty and her husband.

Patty said that while she and her husband spent time holding and talking to their son during their stay at the hospital, she regrets giving his body back to the hospital staff and not holding him longer. "I realized that my opportunity to hold him had been and gone," she said.

After a ceremony in the hospital chapel, Patty and her husband carried their son's body and the casket away from the hospital in the back seat of their car. They went to the crematorium. "When we went inside someone told us to take him round to the back, and when we got there, there was only a loading platform and some workers in overalls," Patty said. "So we placed our little casket on the loading platform and that was it. We had to leave him there."

After the cremation, the boy's ashes were placed in an urn and laid to rest near his grandmother's. "We laid our son to rest, but not before we had walked around the cemetery and told him about it, about the big trees and the breeze, the squirrels and his grandmother who would take care of him now," Patty said.

### *Alice*

Alice's story differs from the others in that she did not lose her child during gestation, at or shortly after birth. Alice was driving home with her 14-month-old son when her vehicle hit a patch of black ice. She lost control and hit another vehicle. During the collision the toddler and the carseat he was secured in were thrown through the windshield. He was killed on impact. "I was seriously injured and had to be extracted



from the car with the jaws of life,” Alice said. “I had two broken legs, a broken arm and a broken heart.”

*Catherine*

*My personal story of childbirth and loss was told in detail as the introduction to this research project.*

### *Story Collection Themes*

As a researcher, finding consistent themes in these loss stories isn't difficult. The difficulty lay in hearing or reading the stories, reliving the experience through the story, internalizing their and my own emotions and opening myself up for analysis (Pearce, 2010, p. 11). Grief is an ever-evolving experience, something people live with throughout their entire lives. Grief doesn't go away, it may dissipate over time and our stories help us build our new reality around our experiences. Our loss stories don't have and aren't expected to have happy endings. Bostico and Thompson refer to bereaved individuals as “wounded storytellers” (2005, p. 391) and our stories clearly reflect that fact. Our stories are as much about the children we've lost as they are about our lived experience, our emotional responses and how we have woven all that back into our daily lives. These stories are how we portray ourselves to others; we use these stories to develop our new social identity (Brownlee & Oikonen, 2004, p. 526).

In addition to sharing my loss story as part of this research, I had the added difficulty and responsibility of being the researcher. This responsibility meant being responsible for other women's stories and how they were portrayed and represented to the world. It was up to me to ensure they were documented in a fair and professional

manner and to safeguard the identity of the research subjects and their children. It was also my responsibility to make sure my experience and emotions didn't taint their stories. It is important to keep all our stories separate, to give each their own place. Caroline Pearce explains the autoethnographic storytelling process as:

Autoethnography shows the significance of being conscious of reactions, responses, thoughts and feelings no matter how small or insignificant they may seem. I learnt that I had to claim my prejudices, my weaknesses, limitations, and strengths, and realistically evaluate my contribution to the research encounter. ... As a researcher I had a responsibility to the women that participated in the study to listen and provide space for their stories to be heard. Providing space in order for the participants to be heard did not have to entail devaluing or repressing my own responses. Instead I had to accept my emotions, prejudices, and memories will always be present, much like my grief, and seep into the narratives I listen to. (2010, p. 11)

Modern grief research is bringing to light theories that contrast Kubler Ross's popular early theory that grief unfolds in five distinct stages, a fact she addresses in her subsequent book *On Grief and Grieving*. She writes that telling and retelling the tale of loss reinforces that the loss mattered (Kubler-Ross & Kessler, 2005, p. 63). Much of today's researchers focus less on strictly defined stages and elapsed time and more on meaning making and other forms of coping (Terry, 2012, p. 356). As bereaved parents we use our loss stories to help us understand our own experiences, manage the powerful effects of our loss (Bostico & Thompson, 2005, p. 409) and maintain a connection to the child we lost.

Sharing our loss stories is a painful process, both for us and for the person hearing it for the first time. Creating a narrative makes the experience permanent, sets it chronologically in time and space (Pearce, 2010, p. 11), makes it real for others who live outside the immediate experience and helps dissipate the pain of loss (Kubler-Ross & Kessler, 2005, p. 63). By telling these stories, we are not only making sense of the experience for ourselves and others, we are reconstructing ourselves by weaving that child and the loss of that child into our lives (Pearce, 2010, p. 366). The story is a ripple on the pond that reminds us our children were here (Weaver-Hightower, 2011, p. 464) and truly existed. The loss of our children is a permanent part of our life and history and is never forgotten (Kohn & Moffitt, 1992, p. 26).

Over the years of belonging to PAL, each member has repeated our own loss story, listened to new members' loss stories when they join the group and revisit one another's stories when we introduce ourselves to new members. This sharing back and forth is actually part of the healing process. Frequently, our best teachers in life are those who have gone before us. The same is true for bereaved parents; our best teachers are the parents who experienced loss before we did, the people who listen, empathize and are with us are those that help us heal (DiMarco, Menke & McNamara, 2001, p. 140).

Members of PAL communicate daily with written email messages via a listserv. The method allows us to reply to a single email address which distributes the same message to all members; and we can all respond to the same message as the listserv keeps them all in a single thread.

When I first introduced myself to the group in 1999, my loss story was very detailed and full of emotional statements. As time passed, when a new members joins

PAL, the story I tell has become abbreviated. The same is true for many of the women who participated in this project. Usually when they disclose their loss story to a new member it is much more succinct than the versions shared here. My condensed story includes the simple facts that my daughter was delivered via emergency Caesarian section after experiencing trouble during labor, she lived two days and died in my arms. This synopsis has developed because of unpleasant responses when I share my experience in the real world. I keep my story limited as a method of self-defense to avoid difficult interactions and troubling questions. It is a trust issue. If people really care to hear more, they will ask, I will judge their true interest and I will decide how much I want to share.

I believe the women who participated were more trusting and open-minded in sharing their experience with me than they would have been with a random researcher because of the depth of shared trust between us. In fact, over the past 12 years, PAL members have been approached by a group of two academic researchers (other than myself) and a self-described book author. PAL members declined participating as a group in both proposed projects. It was apparent in their proposals that these researchers were not approaching the subject from the standpoint of a bereaved parent and did not have a level of sensitivity needed to entice us to participate. The book author even stated to potential participants that submitted responses would be edited to be “medically” and “psychologically” correct.

A consistent theme several of these mothers relate or allude to in their loss stories is the impersonal or detached treatment received from medical professionals they came into contact with before, during and after their child’s death. Maggie, Doreen, Patty and

myself all reported some sort of detached treatment from medical professionals. This may be attributed to a lack of personal knowledge on the part of medical professional for the situation these women experience, a reluctance to want to learn more about this difficult experience and possibly a desire to avoid the bereaved parents in their time of grief as it is uncomfortable. Being professionally detached and able to treat patients without becoming emotionally invested may be considered a positive characteristic by the medical community, but many people describe this attribute as poor bedside manners. This behavior may also be described as a form of denial because our medical community and our society do not readily accept death:

We live in a death-denying, grief-dismissing world now. In America, we don't die well and we don't grieve well anymore. Illness moved into the hospitals in the 1940s and death moved into the funeral home. We rarely gather as a family as our loved one dies. And, if we do, the medical system forces us to do it in shifts. If we mention our feelings of anticipatory grief to the doctor he has a pill for us. The doctors and nurses are caring and well meaning, but in a system designed to cure, there is no clear direction when someone is dying. (Kubler-Ross & Kessler, 2005, p. 205-206)

Oftentimes when a child dies, medical staff will respond by allowing the family to have privacy, as reported by Doreen, Beth, Patty and myself. In other words, they withdraw and allow the family to cope with the situation on their own. It is not surprising that medical staff retreat from women and families after a miscarriage or prenatal death as their medical knowledge and skills are no longer pertinent and they feel helpless (Kohn & Moffitt, 1992, p. 165). Parents desire early acknowledgement of their loss

(Estok & Lehman, 1983, p. 17) and gestures of caring, however in our modern society death has been sequestered (Riches & Dawson, 1996, p. 151). The death of a child or fetus is often times treated more as an inconvenience (Bosticco & Thompson, 2005, p. 273), unlike the importance that typically surrounds the death of an older child or adult who has ties to community members. It is critical for bereaved parents to receive emotional as well as professional support from their healthcare providers, as the families are most likely to return to a support network of family and friends who have not experienced perinatal loss and therefore do not understand the depth and intensity of the parents' grief (DiMarco, Menke & McNamara, 2001, p. 136). Beth is the only bereaved mother who reported that the hospital staff "prepared" her for what was coming and provided more than basic physical care.

Some autoethnographic researchers claim that sharing these stories may help change the perceptions and reactions of medical professionals. These stories could over time contribute toward de-stigmatization of the difficulties by communicating crucial experiences, including being on the receiving end of unsympathetic services, and someday end the us-them relationships (Grant, 2010, p. 582) or the divide between the knowing and the unknowing.

### *Mother & Child Relationships*

Participants were asked to describe their personal relationship with their deceased children. This question was intended to illicit verbal illustrations from bereaved parents showing a deep, strong association or relationship with their children. Many bereaved parents are guarded in openly expressing that relationship. Even when sharing this

sensitive, intimate relationship with another bereaved parent, it is difficult to put into words. Even though they share a similar loss, no two parents experience or express the relationship in the same way. Their relationship perceptions are as unique as the individuals involved.

*Maggie*

Maggie felt a very strong connection to her first pregnancy and although she has no proof, believed it to be a girl. They had chosen to name their firstborn daughter Ashley Veronica. After the miscarriage, Maggie stated that she didn't want to feel "a similar connection" during her subsequent pregnancies and that she was more emotionally guarded in announcing and publicly celebrating the fact that she was pregnant. She said losing the pregnancy, losing her child, became her expectation. "I expected bad news. I expected another sonogram picture with no heartbeat. After our first loss we stopped picking and discussing names," she wrote.

*Doreen*

Most of Doreen's losses were also miscarriages and she reported that she didn't have a "real relationship with her babies" after so many losses. She did report that her experiences taught her not to announce her pregnancies until she had passed the 13-week gestation mark when she felt it was safe. "I remember trying to not talk about being pregnant, didn't even mention pregnancy until after that magic self-imposed time frame," Doreen said. "When I was about 20 weeks pregnant I felt a joyous rush that things were going to be great and I allowed myself to feel happy. I got caught up in that feeling, finally allowing myself to sort through the baby clothing I had, imagining a new little girl

wearing those tiny outfits. That day will forever haunt me.” Doreen delivered her stillborn daughter two weeks later.

*Beth*

Beth spent the first two years after her son’s death writing to him almost daily. She still writes him letters on special occasions. “It is important to me to talk about and honor Colin as our first born,” Beth said. “There are pictures of him in our home ... we hang a stocking for him at Christmas ... we make charitable donations in his memory regularly,” she said.

*Patty*

“How do you describe a fledgling love that was never allowed to bloom?” Patty wrote in answer to this query. “During pregnancy, the love is already in the making. Then suddenly there’s no one there to give your love to, and you’re left with a huge reservoir of emotions. Where do you put all that love that’s no longer necessary? I make a point of remembering him on his anniversary; I talk to his headstone; I have certain private rituals; and yet I can’t know if I’m doing it for him or for myself. If he doesn’t exist anywhere at all, then I’m just doing the motions for myself. But if even his mother doesn’t remember him, then he’ll have nothing at all. This said, I’m not sure I have a ‘relationship’ with him in the present tense, since he can’t reciprocate. I have a love that was never allowed to bloom, a love that was encapsulated in me, in time, and I have a relationship with the events that constitute my first pregnancy.”

*Alice*

Alice chose not to share any information about the months she and her son shared together before his death. She does describe the relationship as evolving over the years



since his death. She celebrates his birthday and anniversary dates, has photos of him displayed in her home and her daughter knows she had an older brother. “He is part of me, part of who I am but I am not thinking about him, missing him every day, every minute like I was in the beginning,” she said.

*Catherine*

*I remember holding my belly and asking where my baby was as I regained consciousness after my c-section. The physical connection she and I shared for 40 weeks was severed, but I still felt connected. I can't explain how but I knew the baby was a girl and that she was somehow injured before anyone told me. I had an unexplainable need to touch her and a desire to have her tiny hands reach out and touch me. When we were reunited in the NICU, I held her for every possible minute. I touched every finger and toe, ran my fingers along her tiny ears, breathed in her new baby smell, kissed her curly baby fine hair and listened to every breath she took. Knowing she was going to die, I was attempting to memorize every detail with all my senses. We have a treasure trove of photos and videos. I can bring back the image of her easily, but not the feel of her, not the smell of her, not the reality of her existence.*

*Over the years, I have realized that the connection I hold between myself and Audie is a selfish one. On the one-year anniversary of her death we received two remembrance cards in the mail and a telephone call from our family doctor. After that anniversary passed, it seems my husband and I are the only ones who remember her. It is difficult as I experience daily reminders of Audie – her three younger siblings – but at the same time they may not be anything at all like she would have been. I live without my*

*daughter, struggling to reconcile the meager memories I have of her with the unrealized dreams I had for her.*

### *Mother & Child Relationship Themes*

When is a woman considered a mother? This question should go hand-in-hand with the decades old legal question of when does life begin. But, the former isn't a question for a court of law, it isn't even considered a question for social debate. Quite simply, our society defines mothers as women with children, and more specifically living children. Women who have lost children to miscarriage or perinatal death commonly aren't considered mothers.

Motherhood is a central discourse in the societal construction of 'woman.'

A child's death has major implications for the identity of each parent, but motherhood is historically and contemporarily built upon potent symbolic meanings central to the reproduction of society. For many mothers, to lose a child is to lose that role relation which is central to the view of self.

(Riches & Dawson, 1996, p. 157)

Bereaved mothers – like their counterparts with living children – experience significant dates recognized by our culture, Mother's Day, Father's Day, birthdays and family-centric holidays without their children. They were perpetually exposed to other mothers happily spending the day smiling, laughing, kissing, holding and loving their children. They commonly encounter families posing for group photos as a memento of their time together, mothers and children shopping for the holidays, photo opportunities

with Santa Clause or the Easter Bunny, mothers chasing their children to the school bus for a first day of school photo.

Holidays aren't the only special dates that may make memories of their lost child surface. Anniversary dates are also important. Anniversaries of the due date, birth or death often bring a resurgence of grief known as "anniversary reaction" (Kohn & Moffitt, 1992, p. 21) or "shadow grief" (Capitulo, 2004, 306). Many of us do not realize how many special days there are until we have to experience one without someone we love:

We are aware that there will be anniversaries of the day our loved one died ... whatever happiness they once brought, now they bring memories of deep loss. Every symbol of the anniversary of a death matters to us: the one-month anniversary, six months, a year. (Kubler-Ross & Kessler, 2005, p.115)

The bereaved mothers who participated in this research project were denied those experiences when their children died. The term bereavement refers to the state of having lost a loved one (Barrera, et.al., 2007, 162), but too often society has told bereaved mothers to pack their grief away, to hide it from the outside world, that they really haven't lost a loved one. Modern medical technology has allowed the relationship building to extend beyond the immediate physical connection between mother and babe. Ultrasounds and sound amplification devices have allowed parents and extended family members to integrate the unborn child through photos and heartbeat recordings into the family at a very early gestational age (Brownlee & Oikonen, 2004, 519).

I believe that with the advent of the medical community's shift in the 1980s to recognizing that prenatal loss and infant death is just as valid and traumatic an experience

– if not more traumatic – than other losses was the leading edge of the wave for helping parents express their grief and finally incorporate it into their lives. First, recognizing the “loss” as the death of a loved one will validate the child’s existence for parents.

Secondly, recognizing the death gives parents the freedom to grieve and move forward with their lives as if they had experienced any other traumatic death of a loved one. For much of the 19<sup>th</sup> and 20<sup>th</sup> centuries, women and their families were counseled by the medical profession that they didn’t need to grieve for a child they didn’t really know:

It was assumed that parents would not grieve the loss because, after all, “They never really had a chance to know their baby.” Parents were admonished for feeling upset or sad, because these feelings were considered destructive and unhealthy, evidence the parents were “dwelling on the baby” or “crying over spilt milk.” Parents were pressured to forget about the baby and think about having another one. They were dissuaded from cradling their dying baby, for fear that they might have to endure more painful memories. After death, the baby was whisked away to spare the parents the sight of the child and the grief they might have experienced if they had been allowed to hold the baby. (Davis, 1996, p. 7)

Maggie and Doreen both experienced early miscarriages. This loss is commonly treated as an everyday occurrence, almost trivial, by the medical community. In fact, bereaved parents often get the message that “nothing *really* happened” and are deprived of validation (Nichols, 1989, p. 118). From reading their loss stories, the reader can tell both women felt a true loss, however they were left on their own to do the work of grieving their child and mourning:

Our culture is highly ambivalent about the value of a newly born or defective infant. There is often an erroneous assumption that because the relationship between a newly born infant and a parent is one that is expected to exist primarily in the future, that the bonds that are joined throughout pregnancy are thus negated or nonexistent. Those who hold these attitudes are apt, then, to be unresponsive toward both the loss and the grieving parents. (Nichols, 1989, p. 119)

It is common for expectant mothers to conceal their pregnancies after a loss until they feel they are safe, the baby has reached a safe gestational point of development or are comfortable sharing the good news in an effort to not share the bad news of another miscarriage. Patty knew her son had died before he was delivered. Many in our society consider mothers of stillborn babes to have had no relationship with their child; the concept is similar when a mother loses a child to miscarriage. However, any woman who has been pregnant knows there is a relationship between mother and child before it is born. These mothers lived with the child day-in, day-out for 40 weeks. Mothers learned the rhythms of their child's daily activities. The baby learned to recognize its mother's voice, and sometimes responded with movement.

Beth, Alice and myself, all spent time with our living child outside the womb. Patty's son was stillborn. We all speak of validating or recognizing our child on special anniversary dates, holidays and family celebrations. We honor a relationship to which our society doesn't necessarily lend credence.

While most people don't recognize that a relationship existed between a mother and child who has died as early in life as these women and children experienced, these

bereaved mothers have documented a recognized relationship between themselves and their children.

Society is at odds over the term “mother.” It considers women who have endured the physical phenomenon of pregnancy and live childbirth to be mothers. However, having a miscarriage, a pre-term birth of a non-viable baby, or a stillbirth puts a woman in an extended period of liminality during and after the ritual of childbirth. She is caught between the known categories of woman and mother and unable to reintegrate into society.

(Campbell, 2000, 15)

Consistent with the stories shared by this group of bereaved mothers, grief research shows that parents who appropriately kept a meaningful connection to the child and were able to integrate their pain and loss into their lives eventually had vivid memories and stories to tell as cherished recollections (Morgan Strength, 1999, p. 347). These women, who are mothers, should not be marginalized only because their child is deceased. Their experiences should be held as an example or model for social scientists as well as medical professionals to consider developing future research and holistic treatment programs.

### *Local Support Systems*

Often times a positive emotional recovery from traumatic life and death health situations has a lot to do with the support system of family, friends and healthcare providers that a bereaved mother can rely upon. In the case of a child’s death people tend to shy away from being too involved as a way to shelter themselves from the

overwhelming emotions involved. However, most bereaved parents find a new sense of normal with family and friends – and often times find a new source of support and friendship.

*Alice*

Alice reported that when her son died her family and the medical staff members involved in her care were a wonderful source of support. She reports still getting greeting cards, email and telephone calls from many of these people on her son's anniversary dates. She said the other members of PAL allow her to be herself. "I don't know what I'd do without them." Since joining PAL Alice has met a few fellow members face-to-face and looks forward to meeting more in the future.

*Maggie*

Maggie felt that all her friends and family were wonderful in the beginning. However, as she began to experience more and more miscarriages she "couldn't take the 'it was meant to be' or it is 'God's plan' comments anymore." She had several close friends she could lean on for support, but really no long-term support from family or her doctors. When she joined PAL she found a welcome environment. "It was nice knowing that there is someone out there who understands, whether it is being unable to go to a baby shower, or unable to walk down the infant aisle in Target, someone else has been there and they won't judge you for feeling that way," Maggie wrote of the support and camaraderie she feels with other PAL members.

*Doreen*

With a wide range of pregnancy loss experiences, Doreen has a variety of support experiences. While her family was supportive and worried about her, they also expected

her to be “ok” a week after a miscarriage. Being a patient at a military hospital, she was offered a pamphlet about miscarriages, but no sort of emotional support. She even reported losing a job because her boss thought she “faked a miscarriage” so that she didn’t have to work while her husband was home from deployment. Doreen said finding PAL was “finding the right support at the right time.” Her father and sister attended the memorial service for her daughter, but few friends or other family members continue to recognize the loss. “While in some ways the wonders of the internet have caused some dysfunction in society, some disassociation of people, at the same time I think it allows us to find people that we have more in common with. This is especially true when dealing with a loss, I’ve found more compassion in online friendships than in real life. At this point, almost 4 years after our stillbirth, only one friend and one of my family members even seems to remember her name.” Doreen said she can celebrate the joyful occasions of her living children as well as remember her own sad anniversary dates with members of PAL.

*Beth*

Beth was a hospice employee at the time of her first pregnancy and when dealing with the birth and death of her son. “The hospice staff were at my bedside immediately and continue to be supportive to this day,” she wrote. “Most of my support came from professionals and other bereaved parents. Family and friends just didn’t know what to say.” Beth attended an in-person support group, Healing Our Lost Dreams (HOLD). A social worker at the hospital introduced her to an online support group and eventually she learned of PAL and found that it fit her needs. Beth reads PAL posts daily and “feels very



connected to the women on the list. I know that if I'm having an issue in my life (even unrelated to parenting) I can post and get support."

*Patty*

Immediately following her son's death, Patty didn't find much support from medical professionals, family or friends. "I think the hospital pastor came to talk to us, but after that we were on our own. Family were of course shocked and upset, but their support was passing and fairly useless. Friends, ditto, with few exceptions. If you haven't lost a child, there's next to nothing you can say or do right when it comes to supporting a bereaved parent." Her husband has been a constant source of support, but they both realized early in their grief that they remember and grieve differently. Patty honestly expressed that in hindsight during her early grief she was occupied with her own feelings and didn't acknowledge the goodwill of others. "My loss has set me apart, and what I feel is nobody's business but mine unless I choose otherwise," she said. She attempted to find a therapist specializing in grief, but couldn't find one to suit her needs. She ultimately joined a SIDS organization, but said continuously hearing the stories of loss and grief only made her feel worse. She said she considers the daily PAL postings contact with a group of women she considers friends. "If there's a parenting problem, I turn to them. If there's a grief or other related issue, I turn to them. If I need someone to shoot the breeze with, I can turn to them."

*Catherine*

*My husband has been a steadfast source of support since our daughter died. I learned early in my experience that I wasn't the only parent who lost a daughter, whose dreams were ended and whose chosen future course was altered. Our families were very*

*supportive. During her stay in the NICU, Audie was visited by two of her great grandparents, all her grandparents, most of her aunts and uncles and several of her more distant relatives. A decade later, we celebrate her birthday and remember her death alone. During the days spent alone at home recuperating after her birth and death, I found PAL and found a lifeline. This was a group of women with whom I could share my fears, my feelings and my experiences without judgment. Over the years I have been able to boast about my living children and their accomplishments as well as remember Audie and share all the fears for my living children that can never truly be set aside by a bereaved parent. I've tried to share these fears with friends and family only to be told that I "worry too much," or can't anticipate bad things happening just because something terrible happened once. The problem is that you can't escape the fear and people who haven't experienced it cannot imagine it. Finding a place to safely share these feelings was a freedom.*

#### *Local Support Systems Themes*

All of the bereaved parents in this study reported they experienced some family or friends who provided short-term support after a child's death. Some participated in face-to-face support groups for a short time. However, none found the on-going, long-term support they felt needed until finding PAL. This was not surprising to me as the study originated by my personal participation in the group because my support network of family and friends was lacking.

While family and friends are often cited as the most helpful in the grief process, bereaved parents often feel isolated in their grief (Brownlee & Oikonen, 2004, p. 523)

even among family and close friends, because our culture doesn't allow open, honest conversation of their lost little one. In fact, finding support in our culture is difficult if the affliction is uncommon, hidden or culturally devalued (Cummings, Sproull & Kiesler, 2002, p. 78), as grief over an infant or pregnancy commonly is. Kohn and Moffitt (1992) offer this advice:

If friends and family seem unsure of what to say or do, it is probably because they have not experienced a similar tragedy. People seem to have lost a common thread of custom, as well as a willingness to share misfortunes with each other. The fact that pregnancy loss can be a hidden, almost taboo subject is also partly to blame. Even family members who suffered a loss may have kept it a secret until you told them about yours. (p. 222)

The only place I feel I have been able to freely express stories about Audie or share my fears 15 years after her death is with another bereaved parent. Davis describes this connection between two bereaved parents as a "lifeline" (1996, p. 167). Bereaved parents are often alone in their grief as the rest of the world moves on, not having or knowing the close bond between the mother and the baby. Feeling isolated while grieving is normal, but the feeling is amplified when others don't grieve your loss along with you. You can be in a large group of friends and relatives and feel as disconnected as if you were lost in the desert (Kubler-Ross & Kessler, 2005, p. 81). Befriending other parents who have experienced this tragic loss can reduce feelings of isolation (Davis, 1996, p. 41). Empathy is an important phenomenon in interpersonal communication. Empathy refers to the ability of accurately inferring another person's feeling and responding

compassionately to another person's distress (Feng, Lazar & Preece, 2004, p. 97).

Empathy is strongest when people have similar experiences and can identify shared experiences with one another (Feng, Lazar & Preece, 2004, p. 99).

As members of PAL, we have created a virtual community by validating one another and our losses, supporting one another and building our relationships on mutual trust and providing a sense of belonging (Silverman, 2001, p. 237) to one another. Communication is key to maintaining this relationship. It is also one of the key factors in relationship breakdown while grieving. While our loss stories are very important to developing our new social identity, it is often difficult for us to grieve our child's short life because there are so few memories (Bosticco & Thompson, 2005, p. 13). We have few memories and our family and friends have even fewer – sometimes no memories – of our children.

The level of friendship and camaraderie that has developed over the years I have been a member of PAL is surprising. Members have come and gone as friends and acquaintances always do in life. This core group of women truly discusses everything – and more – than we would normally discuss with our closest friends and family. Nothing is off limits, including the tragic stories of our losses, commemoration of anniversary dates, the exchange of holiday cards, family vacation stories, divorce, death, troubles with teenagers, recipes, school issues, arguments with our spouses and new additions to our families. We have conversations that matter in the real, everyday world, we ask questions that everyone has a stake in (Cothrel & Williams, 1999, p. 21). In many ways we have become an extended family. We are able to share the most intimate of feelings and life details, even those they could never discuss with the closest of friends and

family, making the group an essential part of our social support system (Ferguson, 1997, 32). Boetcher, Duggan and White (2002) refer to this active phenomenon as augmenting reality. It is the state where you are acting as yourself online, not behind an anonymous screen name, trying to deal with real issues in your life and allowing the group and its members to become progressively more entwined in your life.

### *Seeking Online Support*

Each PAL member must find her own way to the virtual support group. Joining one of these groups is not done with a simple internet search and a single click of the mouse. PAL and similar groups do not openly advertise for membership. On Yahoo! Groups ([www.groups.yahoo.com](http://www.groups.yahoo.com)) searching for a group for bereaved parents brings a lengthy list of specialized groups to choose from. At the time this research was conducted there were several active groups offering support to bereaved parents. eLIMBO is a group for parents who have experienced fetal loss through selective reduction or other fertility related treatment. CALM is designed for parents who have experienced loss in a multiple birth situation. GRACE PIL Support is a forum for parents to express grief for their lost child, however discussion of living children is strictly prohibited. PBTAngels is for parents who have lost a child or are experiencing the end of their child's life due to a brain tumor. Anencephalyblessingsfromabove is a group specifically for pro-life parents and relatives of an infant carried to term who died from natural causes or died from natural causes en utero.

As a gate-keeping measure, people requesting to join PAL are required to provide a short biography including at least first name, age, city or country of residence, names of

deceased and living children. They are also asked to share their loss story. This allows moderators to screen new members and only allow access to the group files and discussion if they meet the basic requirements. Once approved, new members are asked to introduce themselves to the group; moderators do not share the information provided in the biography.

*Maggie*

Maggie joined the group one year after her first miscarriage. She expected the group members to provide the support and sympathy that were lacking in her daily life. “I was looking for an outlet, as most people did not understand the grief or my thought process,” Maggie responded.

*Doreen*

Doreen was alone when she experienced her first miscarriage and found PAL within a few days of this loss. She and her husband had just relocated across the country. He was deployed, unable to return home. “I had no one in real life to lean on,” Doreen wrote. “PAL would help provide the support that I couldn’t or possibly didn’t want to look for in real life, especially in the early hours of the morning when I couldn’t sleep.”

*Beth*

Beth joined PAL 14 months after her son died. She had belonged to two support groups, one that no longer exists and Subsequent Pregnancy After a Loss Support (SPAL) while pregnant with her second child. SPAL is a group where members are allowed to express grief over the pregnancy that was lost or child that died as well as their concerns about a subsequent pregnancy, however discussion of living children is discouraged. Beth was referred to PAL by fellow members of SPAL. “I was still actively grieving Colin and

most of my friends and family couldn't understand why I was still struggling now that I had a living child," Beth reported. "I hoped that the group would be able to validate my experiences and feelings."

*Patty*

The grief Patty experienced over her first son's death was still new and raw when her second son was born 18 months later. She had been a member of SPAL, but found that members of this group became easily "inflamed" when living children were mentioned as many members were unable to conceive or had not yet experienced a pregnancy with a healthy outcome. She joined PAL to find others like herself. "On a 'normal' parenting forum I would have felt very odd; I had so many conflicting feelings and other emotions and my loss was quite recent," Patty wrote. "There was an overwhelming need to find others like me in this respect."

*Alice*

Alice lost her son as a toddler. Alice reported that she joined PAL shortly after her daughter was born, four years after her son died. She said she was looking for moral support and assistance "being a parent again" with the conflicting emotions of the joy of new motherhood and the refreshed grief of her son's life and death.

*Catherine*

*Initially, I joined two online support groups, PAL and another for bereaved parents who have experienced the unexplained death of a child. At the time we lived in a fairly rural area and far away from family. An online support group was a good fit for my needs – to reinforce that I wasn't alone in my grief and to express my thoughts and feelings as I adjusted to the new life path I found myself following. At the one-year*

*anniversary of my joining and half way through my second pregnancy, the other support group notified me that I would have to pay \$24.99 a month to remain a member. I ended my membership. I tried other support groups for expectant parents, but my concerns didn't match most of the ones expressed by non-bereaved parents. While other expectant mothers were worried about whether or not to find out the gender of their baby or what kind of theme was appropriate for their nursery. I was worried about my baby dying. I realized I didn't belong as a participant in a support group for normal expectant mothers, however I did realize that the members of PAL were there for their betterment as well as my own. It was a virtual home.*

#### *Seeking Online Support Themes*

All participants in this research project reported that they sought out PAL as a safe place to share their emotions and experiences with like-minded people. They were seeking a place they could express themselves when and how they needed to, where others would listen, not place judgment and make them feel as if they weren't alone.

One theme is apparent in all the responses: these women were looking for others like them to share and validate their experiences and find hope in the future. While they all found their way to PAL at different times or places in their grief and healing process, they were all seeking a safe place to share their unique, conflicting emotions. They wanted to know there were others like themselves. While most people would anticipate an expectant mother to be happy and the mother of a newborn baby to be thriving, these women were fraught with a myriad of conflicting emotions that people who hadn't lost a child couldn't understand and didn't want to be repeatedly exposed to. These conflicting



emotions aren't depression, they aren't the baby blues, they aren't post-partum depression. They are grief.

The reasons for seeking and joining an online support group are as many and varied as the people who join. PAL is valuable as a support group in the sense that it typically provides a safe place for people experiencing the conflicting emotions of grief to express themselves and develop positive relationships around their current state in life. Support groups like PAL may amend the sense of aloneness these women have and encourage intimacy in relationships, interdependence, and reciprocity, helping to alleviate traumatic stressors associated with the child's death (Caccitore & Bushfield, 2007, p. 74).

These groups offer the possibility of encountering many different perspectives on a problem, or finding people with similar experiences and pain, and, at the same time, of communicating in comparative privacy and psychological safety. For these reasons, the Internet seems especially suited to, and valuable for, those who lack real-world support.

(Cummings, Sproull & Kiesler, 2002, p. 80)

Not all people who join support groups have a goal in mind, enjoy the experience or find success. I reached out to the first grief support group I joined out of desperation. I had called the human resources office at my workplace and was told I couldn't return to work for two more weeks because of the surgical procedure; it was company policy to allow employees adequate time to return to the workplace healthy. This sent me into an emotional tailspin. I couldn't remain home, alone in my vacant home with all the reminders of our lost happiness and dead child. On the Internet I found a local hospital bereavement support group specifically for parents who had lost a child and called. The

regular monthly meeting was the following evening. I joined and found a group of women who were all going through the same motions and emotions of life. But, the monthly meetings were not enough for me. In fact, research shows that formal support groups may not be helpful for all people who experience perinatal loss (DiMarco, Menke & McNamara, 2001, 139).

I needed an outlet for all the pain, anger, disbelief and questions I had surrounding Audie's death. One study on parents involved in a perinatal support group reported that the primary goal of the members was to master feelings of pain and find meaning in their child's existence (Brownlee & Oikonen, 2004, p. 522). At the other end of the spectrum from me were women in the group who only wanted and needed the social connection to others like them every once in a while to reconnect with their memories, to share their child's story one more time or to possibly cry along with another mother who had joined our secret society. One ethnographic study of support groups found that members found a sense of belonging and affiliation, a reversal of isolation and a validation of their experience (Cacciatore & Bushfield, 2007, p. 66) just from the simple fact that they had joined a group of people like themselves.

I spoke with the moderator of the group and she explained to me that the differences between the members was primarily because we were all at different places in our grief journey and had different needs. My grief was new and raw. Others, including herself, had lost their children years ago. As time marched forward, I realized this was true. We enter support groups with a need and our needs change overtime. Sometimes those needs are met and sometimes we have to find another source of relief as our needs change. Whatever the members' needs are, these groups where bereaved parents are able

to air their grief and listen to methods others have employed in coping have immeasurable value (Sarnoff Schiff, 1977, p. 136), both for the individuals and their families.

Shortly after joining the face-to-face group, I found PAL and this group answered my long-term needs. For many years the only connection I had to these women was the black and white text on my computer screen as emails loaded into my inbox throughout the day. None of us needed the face-to-face contact to develop a sense of belonging. Within the virtual boundaries of the group, we had developed our own sense of community, which some researchers define as: multiple members having a shared emotional connection, members having influence over one another and members reporting a fulfillment of their support needs (Blanchard, 2007). I believe most of the PAL members would agree with those characteristics. However, I think they would add Bochner's theory of "unfinished business" (2012, p. 168) as one of the characteristics that keeps our group together. As I claimed before, grief never ends.

### *Mother to Mother Relationships*

Online relationships develop and mature over time just like traditional face-to-face relationships. The survey participants have all been acquainted with one another for several years. Alice, Patty and myself have been PAL members the longest, joining in 1998 and 1999. Doreen was the last survey participant to join the group in 2005.

As illustrated above, members initially joined seeking support for their current situation of grieving a child while learning to parent another. As time progressed, their relationships evolved. Participants were asked two questions they interpreted to be

regarding their relationships with other PAL members. Question number eight specifically asked members to describe their relationships with other PAL members. Question number six asked if their perceptions of PAL membership have changed over time; all provided responses mentioning how their involvement, discussions and relationships with other PAL members have changed over time.

*Maggie*

Maggie reports that she feels a sense of support from members and interacts with some members outside of the PAL forum. However she expressed that she has a negative reaction to some people's messages to the group. "Sometimes you just want to say to some people 'wake up' but you can't as each person deals with the grief process differently," she wrote. "While I remember all of my children, I can't continue to yearly think about anniversaries, it would ruin my life."

*Doreen*

Doreen remains a member of the group after several years because she continues to feel a sense of support from the other members and that she herself continues to provide a sense of support for other members. She said that she is drawn to develop closer relationships with members who have children the same age as her own and those who have similar interests.

*Beth*

Beth said that over the years she has noticed that group members need less grief support and have bonded together to provide general support to one another for parenting and life issues. She has never met another member face-to-face, but interacts with some on other forums, including direct email and Facebook.

*Patty*

Patty's responses echoed those of Doreen and Beth in that she is no longer seeking or providing immediate grief support, but has transitioned into providing parental support to her friends. "Our discussions are no longer as grief-centered; the grief is still there, we all know what it is and what loss does to us," she wrote. "Since most members' losses happened years ago, the discussions now focus on daily life, but a different daily life than most. Daily life after losing a child is never really the same. Parenting is precious, but the innocence is forever gone." Patty is the only survey participant who lives outside North America and doesn't share the American or Canadian background and cultural values. "I sometimes privately disagree with statements that I know stem from a particular culture," she wrote. However, she said that her interaction with PAL members has provided her a valuable insight into modern American society as well as enhancing her circle of friends.

*Alice*

Experience is the greatest asset Alice reported bringing to PAL. Alice's loss was one of the earliest among PAL members and she feels that her experiences and resilience over time are a positive aspect. "I think it is positive for new members to see someone who is farther down the grief road," she wrote.

*Catherine*

*When I first joined PAL I felt intimidated by the other members. I had been lost and alone in my grief for months and didn't really understand how to move forward with my life. I am no longer intimidated and believe I offer a calm and informed personality to the mix of the group. I can share comments, dreams, reactions to life experiences and*

*share thoughts and anniversary commemorations with these women that would be considered unacceptable conversation by many friends and family.*

*About 10 years after joining PAL, I volunteered to be a moderator of the group. In this role I am the first point of contact for new members and approve or reject applications.*

#### *Mother to Mother Relationship Themes*

At first these women were anonymously interacting with one another. They shared shirttail details of one life event – the loss of a child – to create a limited bond between themselves and relative strangers. Many would consider someone they had never met and only conversed with via email an acquaintance. But, over time these relationships have evolved into what most of us believe to be a true friendship. On the forum, we are all comfortable sharing family information, stories about our workplaces, hobbies and discussing our marital relationships. We share the good, the bad and sometimes the ugly. This sense of connection and support is a bittersweet oasis, within a world which frequently dismisses, ignores and minimizes the painful loss (Cacciatore & Bushfield, 2007, p. 66) of our children.

These relationships are significant as they began as most relationships do, with people who have a limited amount of interests in common coming together in a single place. Over time, the depth of our sharing has solidified that bond beyond a single, common shared experience into true friendship. The grief resources used for this research offer no information regarding the development of relationships like those discussed in this research which may develop after a significant loss of a child. They focus on specific

suggestions for the individual, including coping methods, places to seek emotional support, the different ways people grieve and discussions about subsequent pregnancies. Publications by Davis (1996) as well as Kohn and Moffitt (1992) discuss the marital relationship and touch on the differences men and women experience in grief and offer suggestions how couples can maintain their relationship through intense grief. Sarnoff Schiff (1997) dedicates one sentence in her book to relationship building of this kind. She states that groups where people can share their grief and coping methods have “immeasurable value” (p. 136).

From the reports of all participants, the reader can see that they have experienced a transformation in their relationships with one another over the years of belonging to PAL. Doreen, Beth and Patty all report that they remain active members not for the grief support, but for the general support they provide one another. Patty actually refers to the members of PAL as members of her “circle of friends.”

Pulling from my experience as a PAL member and stories shared on the forum I can provide at least two examples to illustrate the transformation. About five years ago, one member mentioned her family’s vacation plans on the forum. She was staying at a hotel about a 10-minute drive from another PAL member’s home. They made arrangements to meet. They now have an annual coffee date and share photos of their meeting with the rest of the members. About a decade ago, one of the members organized a holiday card mailing list. The members still continue this tradition. Members participate on a voluntary basis. We send holiday greeting cards with the standard end of year letter, photos of our living children and most include a memento or notation of their “angel” child. One year, a new PAL member included an angel ornament with her cards to

commemorate her recent loss. I have kept all of these cards I've received in my memory box of Audie's things.

With the advancement of more immediate social media, specifically facebook, over the past decade, these relationships are ever-evolving. All of the women who participated in my survey have facebook accounts and are linked as friends on the site. There we share not only the daily fun that facebook is known for, but book lists, vacation photos, highlights of our living children's lives, our personal successes and, of course, silly things. Often times we will share our child's anniversary dates with a message about how much we love and miss them. Sometimes, there are very few responses outside of PAL members and those close family and friends who understand.

There are always reminders and there are very few people who realize, understand or empathize with a bereaved mother as the years between her loss and today grow. We will always feel the pain as an anniversary passes, others probably won't. It is wonderful to have a group of women who know, understand and won't trivialize your emotions. The PAL forum is a place they can share information about their lost child years after the actual death without fear of getting callous remarks about "being over it" in response.

### Poetry

As mentioned above, an unsolicited list of poems was provided by one respondent. As a member of PAL, I searched the group's message database and found each of the poems included in postings to the group, dating back to a few months after the group formed to much more recent postings. They are usually posted around an



anniversary date, birthday, death date, Mother's Day or holiday dates of significance to the member posting. I've included several of the poems below as they provide a more unconventional and creative insight into the bereaved mother's emotions, complimenting their reported stories and experiences.

my arms, my heart  
open wide  
my baby, her eyes  
unopened, never cried  
she lay so still  
her tears  
now onto my cheeks spill

~ Catherine Lyons-Holestine

She Cries

She sits alone in an empty room.  
Once a place of dreams but those  
Dreams ended too soon.  
The crib is empty her arms are too.  
She cries for the child the world never knew.  
There was a time when joy filled her face.  
Now life's such a lonely place.  
She cries for the child who  
Was here such a short while.

She prays that her tears  
Could bring back that child.  
Why can't she turn time back some how?  
Why didn't she know the things she  
Knows now?  
She leaves the room and closes the door.  
She wonders if she will ever feel joy once more.

~ unknown

You can only imagine the pain we have suffered;  
But we do ask that you try.  
You don't know what it is like to stand there helplessly  
holding your son as you watch him die.  
Only the Lord can give us the strength we need to pull through.  
Kindness, caring, and compassion is what we need from you.  
Because he came early, our son is a bigger part of our life than yours.  
Let us share our memories. Please do not close all doors.  
Some people choose to say nothing as not to address the pain.  
But that only leaves us feeling as if we were left out in the rain.  
Just always remember he is a big part of our family. Now he is in  
heaven where he awaits the arrival of you and me.

~ In memory of Casey Emily Hughes

You're free  
baby dear of ours  
to play among  
rainbow-coloured clouds  
to walk in warm  
silver-soft showers.  
You are our baby angel,  
born with gossamer wings.  
The first sounds you heard  
were angels singing  
a chorus of love  
inviting you in.  
You are our baby angel  
for all Eternity.  
You touched the face of God  
before you could touch mine.  
God's love keeps you warm at night  
just as my arms would  
if I could hold you tight.

~ by Debbi Dickinson

Only memories never die  
The time we got together, just wasn't meant to last.  
Say, who ever could have guessed, that life would end so fast?  
It seems that all the years, were taken just for granted.  
I never got to know you, quite as well as I would have wanted.  
I didn't take the pictures, I want to look at now.  
But then, how could I ever know? Know when, know where, know how.  
What's the purpose of this all? Please tell me, I implore!  
The unfair fact we have to grasp – you're not around us, any more.  
It's difficult to comprehend, but this was for the best.  
Your pain has now subsided, you'll get your well earned rest.  
It's impossible to understand, no point in asking why.  
The only truth there is to know: the memories will never die.  
You'll always live inside my heart, long after my tears dry.  
For the one thing I will always have - the memories that never die.

~ Magnus Johnson

Remembering  
Go ahead and mention my child,  
The one that died, you know.  
Don't worry about hurting me further,  
The depth of my pain doesn't show.  
Don't worry about making me cry,

I am already crying inside.  
Help me to heal by releasing  
The tears I try to hide.  
I'm hurt when you just keep silent,  
Pretending he didn't exist.  
I'd rather you mention my child,  
Knowing that he has been missed.  
You asked me how I was doing.  
I say "pretty good" or "fine."  
But healing is something ongoing,  
I feel will take a lifetime.

-by Elizabeth Dent

A snowflake fell into my hand  
a tiny, fragile gem;  
a frosty crystal flower  
with petals, but no stem.  
I wondered at its beauty,  
of its intricate design.  
I breathed, the snowflake vanished  
but for one moment, it was mine.

~ author unknown

These poems were all shared at various times on the forum by bereaved mothers in memory of their children. After cross referencing the PAL message database I discovered most were posted on individual anniversary dates or during the month of October, specifically October 15<sup>th</sup>. October is recognized in the United States, Great Britain and Canada as Pregnancy and Infant Loss Awareness Month. Specifically, October 15 is National Pregnancy and Infant Loss and Remembrance Day, a day on which many bereaved mothers light a candle or otherwise signify their support for women who have experienced this loss.

*Empty Cradle, Broken Heart: Surviving the Death of Your Baby*, is a standby book for many bereaved mothers. It includes dozens of poems. One is on the dedication page, others are inserted throughout chapters where their subject seems to fit with the book's current topic. There is no discussion of poetry as to how it pertains to grief, yet it is included. There is one poem in a chapter discussing a father's grief (p. 121) that is introduced with a sentence discussion journal writing to work through emotions.

The first poem listed I wrote to commemorate Audie's first birthday and my emotional experience that day. I wrote the poem to maintain memories (Weaver-Hightower, 2012, p. 464) which is part of the normal grieving process. Typical first birthdays celebrations include chubby toddlers covered in cake and frosting surrounded by smiling and doting parents, phone calls from close family and friends who can't be present for the party. We didn't have a toddler, a cake or celebratory phone calls and cards. The anniversary loomed ominous. The day was quiet and unpleasant, only because we longed for what we didn't have. Parents never forget their children's milestones events, but these traditional events of celebration carry a different meaning for parents

whose children are not present any longer. The first birthday, the first holiday, the first family gathering, the first anniversary of their death, are laden with cheerlessness for bereaved parents as these poems illustrate.

The response included two other poems, but I chose not to include them because the subject matter didn't align with the focus of this research. One was written for a father who never met his child, the other was titled *You will always be my Daddy*.

### Conclusions

Bereaved parents are like snowflakes. From a distance they all appear as little puffs of white falling from the sky. Upon closer inspection, you notice distinguishing differences. Some are tiny, some large, some medium sized. Some are several flakes gathered together in clusters, some remain solitary. Some float to earth slowly like a feather falling, some fall with the force of tiny bullets toward the ground. Looking even closer you see their individual characteristics. No two snowflakes are alike. Each forms its own distinct crystalline structure, with its unique arrangement of bridges, gaps, peaks and points.

The same is true of bereaved parents. As a group, we share similarities. We all share the experience of losing a child. Considering bereaved parents all the same at this superficial level without discovering more intimate details is an easy and comfortable generalization for most to make. Looking closer, bereaved parents can be categorized in a number of ways. How old was our child was at death? Was the death a natural death, car accident, miscarriage, stillbirth, drowning or other cause? Was our child a crime victim?

How long our child suffered from an illness? What were the family dynamics at the time of our child's death? Have these family dynamics changed since our child died?

Compassionate friends and relatives may comfort bereaved parents during early moments of sorrow, listen to stories and let them cry. But, even the closest friends and most loving relatives may not understand the depth of grief or length of time it can take for bereaved parents to return to a sense of normality. It is difficult to help others cope with sorrow and bereaved parents typically feel ill-equipped to guide their family and friends (Kohn & Moffitt, 1992, p. 214) through mourning. Our society's focus on pregnancy loss remains a taboo subject.

However, as social scientists, we should endeavor to understand bereaved parents in the wake of their loss rather than simply categorizing them based on their child's life and death. This research project endeavored to delve deeper into the bereaved parents' experience, draw from their personal knowledge, provide first-hand accounts of what they have lived through; from anticipation that accompanies pregnancy to the heartbreak of shattered dreams when one day they return home without their child. In other words, instead of simply studying the snowflakes by observation and interpretation, I looked at the group from the inside, from a true insider's perspective. This report will hopefully add another voice, or voices, to the compendium of academic knowledge already amassed about bereaved mothers and their experiences.

I grew up with the knowledge that my grandmother had a stillborn son and my aunt had lost a son to SIDS. These were just facts in the fabric of my family life, just pieces of information that didn't mean much to me as a child or young adult. True to the times in which my grandmother and aunt lived, there were no stories shared about these



babies, what happened or how they struggled to overcome the emotional trauma in the wake of their child's death. My grandmother never mentioned her son to me. My aunt rarely spoke of her son. However, there were subtle reminders of their existence and importance to my grandmother and my aunt that I realized once I had to say goodbye to my own daughter.

My aunt and grandmother understood and empathized with my loss, but couldn't sympathize with the depth of my loneliness; and they realized this. My aunt's son was her fourth child, her only son at the time. My grandmother's son was her third child, her second son. Audie was our first child. While we all lost a child at or near birth, our experiences are as unique as we are. Our experiences are as distinctive in how our children died as well as in incorporating the absence of our children and our plans for the future into our daily lives.

The research questions used in my survey were intended to bring to light this process by bringing to light the first-hand stories of those who have lived the experience. I believe we need to see the journey through the eyes of those walking the path of loss rather than in a second-hand manner through observation and interpretation.

In the late 1970s, Harriet Sarnoff Schiff made statements about bereavement support groups that were ahead of most other social scientists investigating this phenomenon:

Probably more when a child dies than in any other situation, a positive example of people functioning can have great impact. Frequently organizations where bereaved parents come to air their grief and listen to

methods others have employed in coping can have immeasurable value.  
(p. 136)

This observation is becoming more common in today's world, especially with the growing organization of online support groups. Kathleen Leask Capitolo noted in a 2004 article that for many bereaved mothers life never would have been the same but joining an online perinatal loss community meant they would never be alone (p. 305).

The information gathered and reported in this study represents a single social support group for bereaved mothers. It is a snapshot in time, both for the participants and those who choose to read it. This report brings to life what it is like to be a bereaved mother from several individuals' standpoints. It tells the first-hand stories of the relationships these women hold between themselves and their children as well as with other women who have had similar experiences. This research project brings these life histories and subsequent relationships between bereaved parents to light for society. These are topics which aren't directly investigated in existing grief, bereavement or communication academic literature.

This research project focused on a small community of bereaved parents. This was both empowering as well as limiting. There are many tiny details which emerged from the survey responses that raise future questions to consider, but the one that is most interesting to me is the migration to social media. The PAL site is still active and the members still have conversations there that pertain to our bereavement, lost children and anniversary dates.

Members of PAL are beginning to migrate conversations and interactions to Facebook. Not only have many of the mothers “friended” one another on the popular social media platform, they have also created a private Facebook group to share private conversations in a more immediate fashion. As friends, we interact in similar fashion to any other “friends.” We share family photos, highlights of our and our children’s lives, silly jokes and updates on our jobs. We comment freely on one another’s status updates. Our conversations are about our day-to-day life.

As asserted from the beginning, the primary value of this research is the combined use of ethnography and autoethnography to observe and report the value of an online bereavement support group. By observing and being a participant in the subject group at the same time I deprivatized the personal experience (Chase, 2005, p. 659) and made sense of the culturally and historically experience (Chase, 2005, p. 659) for the wider society by developing an account of not only the bereaved mothers and their individual experiences, but also by including a first-hand autoethnographic account that paralleled the ethnographic report. This weaving in the similar and simultaneous experiences of myself and others lends validity, credibility and value to the changing and growing body of knowledge communication researchers endeavor to develop.

## Bibliography

- Barrera, Maru; Mammone D'Agostino, Norma; Schneiderman, Gerald; Tallett, Susan; Spencer, Lynlee; Jovcevska, Vesna. (2007). Patterns of parental bereavement following the loss of a child and related factors. *Omega*, 55(2), 145-167.
- Blanchard, Anita. (2007). Blogs as virtual communities: Identifying a sense of community in the Julie/Julia project.  
[http://blog.lib.umn.edu/blogosphere/blogs\\_as\\_virtual.html](http://blog.lib.umn.edu/blogosphere/blogs_as_virtual.html).
- Bochner, Arthur P. (2012). Bird on the wire: Freeing the father within me. *Qualitative Inquiry*, 18(2), 168-173.
- Bochner, Arthur P. (2012). On first-person narrative scholarship: Autoethnography as acts of meaning. *Narrative Inquiry*, 22(1), 155-164.
- Boetcher, Sue; Duggan, Heather; White, Nancy. (2002). What is a Virtual Community and Why Would You Ever Need One?  
<http://www.fullcirc.com/community/communitywhatwhy.htm>
- Bosticco, Cecilia & Thompson, Teresa L. (2005). Narratives and storytelling in coping with grief and bereavement. *Omega*, 51(1), 1-16.
- Bosticco, Cecilia & Thompson, Teresa L. (2005). An examination of the role of narratives and storytelling in bereavement. In Harter, Lynn M., Japp, Phyllis M., & Beck, Christina S. (Eds.), *Narratives, Health and Healing: Communication Theory, Research and Practice* (pp. 391-411).
- Brownlee, Keith & Oikonen, Jodie. (2004). Toward a theoretical framework for perinatal bereavement. *British Journal of Social Work* 34, 517-529.

- Cacciatore, Joanne & Bushfield, Suzanne. (2007). Stillbirth: The mother's experience and implications for improving care. *Journal of Social Work in End-of-Life & Palliative Care* 3(3), 59-79.
- Campbell, Beth. (2000). Shattered futures, mended lives: The ritualized mourning of mothers of stillborn babies. (Doctoral dissertation). Arizona State University, Phoenix, Ariz.
- Capitulo, Kathleen Leask. (2004). Perinatal Grief Online. *MCN*, 29(5), 305-311.
- Carter, Denise. (2002). Living in virtual communities: An ethnography of human relationships in cyberspace. *Information, Communication & Society*, 8(2), 148-167.
- Chang, Heewon. (2008). *Autoethnography as Method*. Walnut Creek, Calif.: Left Coast.
- Chase, Susan E. (2005). Narrative Inquiry: Multiple Lenses, Approaches, Voice. In Norman K Denzin & Yvonna S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> ed., pp. 651-679).
- Cluck, G. & Cline, R. (1986). The circle of others: self-help groups for the bereaved. *Communication Quarterly*, 34(3), 306-325.
- Cothrel, J. & Williams, R. (1999). Understanding On-Line Communities: Getting the Most out of on-line discussion and collaboration. *Strategic Communication Management*, 16-21.
- Cummings, Jonathon N.; Sproull, Lee; Kiesler, Sara B. (2002). Beyond hearing: Where real-world and online support meet. *Group Dynamics: Theory, Research and Practice* 6(1), 78-88.
- Davis, Deborah L. (1991). *Empty Cradle, Broken Heart: Surviving the Death of Your Baby*. Golden, Colo.: Fulcrum Publishing.

- deVries, B. & Rutherford, J. (2004). Memorializing loved ones on the world wide web. *Omega*, 49(1) 5-26.
- DiMarco, Marguerite A.; Menke, Edna M., & McNamara Tiffany. (2001). Evaluating a support group for perinatal loss. *The American Journal of Maternal Child Nursing* 26(3), 135-140.
- Feng, J.; Lazar, J., & Preece, J. (2004). Empathy and online interpersonal trust: A fragile relationship. *Behaviour & Information Technology*, 23(2), 97-106.
- Ferguson, T. (1997) Health care in cyberspace: Patients lead a revolution. *Futurist*, 31(6), 29.
- Fontana, Andrea & Frey, James H. (2005). The Interview: From Neutral Stance to Political Involvement. In Norman K Denzin & Yvonna S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> ed., pp. 695-727).
- Grant, A. (2010). Writing the reflexive self: An autoethnography of alcoholism and the impact of psychotherapy culture. *Journal of Psychiatric and Mental Health Nursing*, 17, 577-582.
- Harris, Genevieve. (2011). Inward, outward, onward: Autoethnography of a dissertation in (qualitative) transitional space. *Qualitative Inquiry*, 17(8), 725-731.
- Hazen, Mary Ann. (2003). Societal and workplace responses to perinatal loss: Disenfranchised grief or healing connection. *Human Relations*, 56(2), 147-166.
- Hersh, Alyssa. (2005). *I know how you feel: A person-centered approach to analyzing supportive messages in online breast cancer groups*. Paper presented at the annual meeting of International Communications Association, New York.

- Johnson, G. J., & Ambrose, P. J. (2006). Neo-tribes: The power and potential of online communities in health care. *Communications of the ACM*, 49(1), 107-113.
- Kempny, Marta. (2012). Rethinking native anthropology: Migration and auto-ethnography in the post-accession Europe. *International Review of Social Research*, 2(2), 39-52.
- Kohn, Ingrid & Moffitt, Perry-Lynn. (1992). *A Silent Sorry: Pregnancy Loss. Guidance and Support for You and Your Family*. New York: Dell Publishing.
- Kubler-Ross, Elisabeth & Kessler, David. (2005). *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. New York: Scribner.
- Leon, Irving G. (1992). The psychoanalytic conceptualization of perinatal loss: A multidimensional model. *The American Journal of Psychiatry* 149(11), 1464-1472.
- Madge, C., & O'Connor, H. (2006). Parenting gone wired: Empowerment of new mothers on the internet? *Social & Cultural Geography*, 7(2), 199-220.
- Morgan Strength, Janice. (2005). *Grieving the loss of a child*. *Journal of Psychology and Christianity*, 18(4), 338-353.
- Nichols, Jane A. (1989). Perinatal Death. In Kenneth Doka (Ed.) *Disenfranchised Grief: Recognizing Hidden Sorrow*. (pp. 117-126).
- O'Leary, Joann M. (2000). The baby who follows the loss of a sibling: Special considerations in the postpartum period. *International Journal of Childbirth Education* 20(4), 28-30.
- Pearce, Caroline. (2010). The Crises and freedoms of researching your own life. *Journal of Research Practice*, 6(1), 1-15.

- Riches, Gordon & Dawson, Pam. (1996). Communities of feeling: the culture of bereaved parents. *Mortality* 1(2), 143-161.
- Ronel, Natti & Lebel, Udi. (2006). When parents lay their children to rest: Between anger and forgiveness. *Journal of Social and Personal Relationships* 23(4), 507-522.
- Salem, D., Bogat, A., & Reid, C. (1997). Mutual help goes on-line. *Journal of Community Psychology*, 25(2), 189-207.
- Schiff, Harriet Sarnoff. (1977). *The Bereaved Parent*. New York: Crown Publishers, Inc.
- Silverman, Toby. (2001). Expanding community: the internet and relational theory. *Community, Work & Family*, 4(2), 231-238.
- Sparkes, Andrew C. (2000). Autoethnography and narratives of self: Reflections on criteria in action. *Sociology of Sports Journal*, 17, 21-43.
- Stake, Robert. (2005). Qualitative Case Studies. In Norman K Denzin & Yvonna S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> ed., pp. 651-679).
- Terry, Alice W. (2012). My Journey in Grief: A Mother's Experience Following the Death of Her Daughter. *Qualitative Inquiry* 18(4), 355-367.
- Toller, P. (2005). Negotiating of dialectical contradictions by parents who have experienced the death of a child. *Journal of Applied Communication Research*, 33(1) 46-66.
- Uotinen, Johanna. (2010). Digital television and the machine that goes "PING!": Autoethnography as a method for cultural studies of technology. *Journal for Cultural Research*, 14(2), 162-175.
- Wall, Sarah. (2008). Easier said than done: Writing and autoethnography. *International Journal of Qualitative Methods*, 7(1), 38-53.



Walker, D. (2013). The internet as a medium for health services research – Part 2. *Nurse Researcher*, 20(5), 33-37.

Weaver-Hightower, Marcus B. (2011). Waltzing Matilda: An autoethnography of a father's stillbirth. *Journal of Contemporary Ethnography*, 41(4), 462-491.

Wijngaards-de Meij, Leoniek; Stroebe, Margaret; Schut, Henk; Stroebe, Wolfgang, van den Bout, Jan; van der Heijden, Peter G.M. & Dijkstra, Iris. (2007). Patterns of attachment and parents' adjustment to the death of their child. *Personality and Social Psychology Bulletin*, 33(4), 537-548.

## VITA

Author: Catherine L. Holestine

Place of Birth: Spokane, Washington

Undergraduate Schools Attended:

University of Idaho  
 Blue Mountain Community College  
 Central Washington University  
 Big Bend Community College

Degrees Awarded: Bachelor of Arts, 1994, University of Idaho  
 Associate of Arts, 1991, Blue Mountain Community College

Honors and Awards:

Graduate Student Appointment, Communications Department,  
 2008-2009, Eastern Washington University

National Council for Marketing and Public Relations District VII,  
 2008, Silver Medallion, logo design

Professional Experience:

Transition Coordinator, Spokane Community College, Spokane,  
 Washington, 2012 – present

Foundation Director, Newport Hospital & Health Services,  
 Newport, Washington, 2009-2012

Public Information Officer, Big Bend Community College, Moses  
 Lake, Washington, 1999-2008

Conferences and Presentations:

Eastern Washington University Women's and Gender Studies  
 Contemporary Issues in Feminist Research program speaker,  
 E.V.E.: The New Disney Heroine

Northwest Communications Association annual conference, Coeur  
 d'Alene, Idaho, Grieving Online: A Mother's Experience and  
 E.V.E.: Breaking the Mold of the Disney Heroine