

Breaking the Silence of Stillbirth through Personal Narratives: Constructing Meaning and  
Creating Awareness in the Greater Social Context

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### Prologue

*“Saudade (Portuguese) – One of the most beautiful of all words, translatable or not, this word ‘refers to the feeling of longing for something or someone that you love and which is lost.’” (Levin, 2011)*

It was a warm Friday evening in July of 2008, and I was exactly 28 weeks pregnant when I started to feel like something was wrong. No one tells you of the many aches and pains in pregnancy, and the extra 30 pounds on my normally thin frame made me uncomfortable on a regular basis. However, this was different: my baby was turned sideways, and I couldn't get “Baby” to turn. Standing in my bedroom staring blankly at my nightstand, I remember thinking, *“Should I bother the doctor after hours? I don't want to be that woman who calls about every little thing.”*

On the previous Monday, I had seen the doctor shortly after a long flight from New York had left me unusually swollen. The baby's heartbeat was normal, and just as the doctor predicted, the swelling went down during the next couple of days. My regular monthly appointment was scheduled for ten days later, so when my discomfort started that Friday evening that fell in between those two visits, I talked myself out of calling the after-hours nurse line.

However, that night the discomfort prevented my sleeping more than two short hours. Over the course of the weekend, I felt worse: I felt spacey, I shattered a jar of salsa on the kitchen floor when my hand involuntarily released its grip; but I talked myself out of each worry thinking that it was probably just pregnancy. I didn't want to be a bother. I never considered that Baby could die. Finally around midnight on Sunday, I felt my baby turn and drop before I crawled into bed. It was instant relief. I slept through most of Monday and Tuesday.

My baby, whom we later named Isaiah, was not a morning baby in the womb. Each day he awoke promptly at 10am. When I entered my 9am check-up on Wednesday, I wasn't concerned that he wasn't moving. However, as my doctor used the Doppler to search for his heartbeat, she asked when I last felt the baby move, and I couldn't remember. I had experienced an awful weekend and had slept through the beginning of the week. A few minutes later in the ultrasound room, my doctor spoke the words that forever divided my life into before and after, "I'm so sorry Abbie, but your baby has died." I was blind-sided.

*"Our species thinks in metaphors and learns through stories." (Bateson, 1994)*

After my son died, I had desperately sought books about mothers who had experienced a stillbirth, and later I researched literature on stillbirth for papers. However, I found that the stories of women's actual experiences were widely unavailable. Any information I did find was apparent only after much digging. Meanwhile, in a support group, I heard women say again and again that they had no idea a stillbirth could happen to them; and each time they spoke of their personal tragedy I saw relief while sharing, the power and beauty of their story, and I felt the urgency to inform other people that stillbirths happen.

Perhaps stillbirth awareness could have caused prevention, but at the least a societal awareness of such tragedies might help reduce the stigma most families confront in their grief. Stillbirth statistics make it clear that as an event affecting a "disproportionately large number of people within a community" and being "excessively prevalent" stillbirth is a largely unknown epidemic and that entire families have suffered the silence of cultures which do not speak about it (Epidemic, n.d.).

According to Lawn et al. (2011) in the *Lancet* article, "Stillbirths: Where? When? Why? How to make the data count?", at least 2.65 million babies worldwide are stillborn annually and possibly as many as 3.79 million (p.1448). In the United States, stillbirth is ten times more common than Sudden Infant Death Syndrome (SIDS), and stillbirth statistics match all other types of infant deaths combined (CDC, 2009; NIH, 2003). However, because stillborn babies are often unseen and unrecognized, the occurrences remain largely unheard of in many societies.

A year into my International Care and Community Development master's program, I considered my upcoming thesis topic and felt committed to a thesis project including the necessary statistical research to underscore a narrative of women's personal stories of stillbirth.

While unclear regarding the shape and qualitative research method of this project, I began asking mothers in the Seattle area to share their personal stories of their stillborn babies. Although fathers' stories are also incredibly valuable and under-represented, I had better access to these women. I also started to recognize that my personal story, and the questions I sought answers to after my son's death, had merit when weighed in with the stories of other mothers. An NU professor also challenged me to consider stillbirth not only as a social justice issue from a social sciences perspective; but also to look at stillbirth advocacy from a theological perspective, thus confronting my growing disappointment in the Christian responses, or lack of responses, to my tragedy.

As the project became more of a discovery endeavor and less of a research question to be proven, a Narrative Inquiry as qualitative research method became the best fit for the process. According to Clandinin & Connelly (2000), narrative inquirers do not approach a study with a research problem or a research question which "carry with them qualities of clear definability and the expectation of solutions" (p. 124). Instead narrative inquirers re-search a puzzle as we think through our phenomena by engaging with stories lived and told to create socially significant meaning (2000). Therefore, my research puzzle at the outset of this inquiry was that few people talk about the worldwide health epidemic of stillbirth. In the US it happens frequently, yet the stories of stillborn babies are not commonly told or known in society. I went in to this project with the idea that sharing stories might have a great impact on creating awareness and might be powerfully used for advocacy. However, as the inquirer in the project I also began with an open mind to see what powerful themes and messages were contained within the stories themselves to be emphasized in the process of creating awareness. Thus my writing follows this discovery process to some extent. A focus on stillbirth awareness told through



shared stories, and aimed at both prevention and compassionate care, could help alleviate suffering. Christians, according to their beliefs, have a unique opportunity to lead the way in culture change by offering appropriate responses to women who suffer, and also advocating for stillbirth prevention. Thus, advocacy efforts telling the stories of the stillborn might be powerful to create inner personal change which will lead to societal and policy changes.

Using a narrative inquiry approach, I recorded interview conversations of “stillbirth” mothers’ stories to discover how continued story sharing might further awareness. Next, I compared their stories to a literature review and theological perspectives on stillbirth advocacy to discuss stillbirth as a social justice issue that merits attention through advocacy efforts. Factually and narratively supported, my conclusion regarding our cultural responses and the societal significance of sharing stillbirth stories emerged.

The narrative inquiry approach as a qualitative research method for this project leveraged my personal experience while maximizing the benefits of findings discovered through the participants’ story-telling. According to Clandinin & Connelly (2000), in *Narrative inquiry: experience and story in qualitative research*, as researchers:

We are not merely objective inquirers... On the contrary, we are complicit in the world we study. Being in this world, we need to remake ourselves as well as offer up research understandings that could lead to a better world. (p. 61)

Impersonal narrative could hardly create awareness for this topic. However, by highlighting the power in the “particular” and personal knowledge through the act of story-telling balanced with the “general” knowledge in existing theories, narrative inquiry showed the personal richness which, in turn, may inform actions in specific contexts leading to greater impact (Pinnegar & Daynes, 2007). Narrative inquiry as a qualitative research method also valued my personal

experience, and became an asset that could lead to new understandings geared toward change-making (Clandinin & Connelly, 2000). As a stakeholder in my research, I will work towards creating momentum for social change where leadership and voice for my cause may rise out of the ashes of my loss (Palmer, 2000).

Four women have entrusted me with the precious stories of their stillborn children. I have recorded and coded the four narratives, field notes, and a journal to note common themes. The themes in order of frequency from high to low are:

1. “After.”
2. Medical experience and medical caregivers.
3. Support.
4. Social norms, customs, and rituals.
5. Knowledge and awareness.
6. “Before.”
7. Story sharing.

Much of the content in these themes is inter-related (i.e. the influence that social norms may have on support, or the role of previous knowledge in the mother’s experience before stillbirth; the theme of “After” can be woven through every theme, except “Before”). I compared themes with my personal story and current literature. This report details the findings in thick description listing the themes in a more chronological order for the sake of the narrative:

- “Before”,
- Medical experience and medical caregivers,
- Support,
- Social norms, customs, and rituals,

- Knowledge and awareness,
- “After,” and
- Story sharing.

The findings are followed by a literature review and discussion.

## **Methods**

### **Narrative Inquiry**

For a number of reasons, a narrative inquiry approach best suited this research. When I first designed this project, I wanted to capture the stories of mothers in their own words realizing that these stories would contain pieces of information that I had not previously seen in stillbirth literature and that they would be powerful to create new understanding. However, as a researcher, I knew it would be difficult to remain an objective observer since I had also experienced a stillbirth. Regardless, I hoped to see what themes might organically arise from the stories of these mothers. Considering my past experience and continued connection to stillbirth families, I already sensed that these stories could speak to a desire for further awareness about stillbirth, yet the discovery of important themes contained within personal stories was central to the project. I struggled to find the most appropriate qualitative research method.

According to Andrews et al. (2008) in Saldana's (2013) *The Coding manual for qualitative researchers*, a clear definition of “narrative” does not exist. However, as the oldest form of data gathering, oral history interviews are the most common form of narrative inquiry and the interviews often turn into “dynamic,” “dialogical,” and collaborative conversations with the inquirer (Clandinin & Connelly, 2000; Giovannoli, (n.d.), p 5). Researchers using a narrative approach start with their own experiences that are informed either by theory or life events and by also putting themselves within the research report (Pinnegar & Daynes, 2007). Narrative inquiry

reports are typically autobiographical as the researchers are not expected to remain objective (2000). In fact, Clandinin & Connelly (2000) considered that assuming a researcher/narrator could be objective would be, at best, “deliberately self-deceptive” (p. 62).

The stories of these mothers are personal experiences within a social context. Narrative inquiry has as its goal to make meaning by looking inward and outward from the perspectives of both the researcher and participant, as well as backward in time and forward to future social implications (Clandinin & Connelly, 2000). Stillbirth occurs in a social context where it is not talked about. Women/parents are surprised when it happens to them. The past of not knowing or hearing stories about stillbirth has continuity with the shock mothers experience when it occurs to them, and then, in turn, the isolation of parents perpetuates the problem. This pattern will continue until broken by creating new social meaning and awareness regarding the possibility and experience of stillbirth. Therefore, for the purposes of story-telling, participating as a researcher/inquirer/mother, and working to create meaning around future social implications, narrative inquiry was the best approach for my research project.

### **Participant Selection**

Over the course of three years, I asked nine women to share their personal experience of their child's stillbirth. These women were simple to locate because they were: (a) already participating in a support group for miscarriage, stillbirth, and early infant death; (b) members of the Stillborn Still Loved Guild; or (c) a participant of a parent panel on the subject of stillbirth at a Resolve Through Sharing seminar. Of the nine women asked, eight agreed to participate, and one did not respond. Out of those eight women: (a) four women participated, (b) two were not chosen because their child's death did not fall within the gestation parameters defined as a stillbirth, (c) two did not respond to requests to schedule the interview. All resulting four

participants happen to be middle-class American women with education beyond a high school diploma and access to healthcare. Three women are Caucasian, and one is African-American. Each mother chose not to remain anonymous.

### **Interview Process**

Three of the interviews were filmed using a video camera, and one was audio-recorded due to equipment availability. My process was to ask each woman to tell the story of her stillborn baby starting as far back as she felt necessary and continuing until she felt the story was complete. I also asked a series of questions either during or following the interview, especially if the women had not already answered them within their own telling. The initial list of questions came prior to the first interview, and then through the telling of Ashley's story, it became apparent that certain aspects of her story and questions that arose were common to all mothers of stillborn babies. I then modified the list and wove it into the next three discussions (See Appendix A). Following the interviews, I again watched and listened to each recording at least twice while recording field notes to annotate emotion and context. Via email, I also followed up the interviews with further clarifying questions.

### **Coding Qualitative Research**

I professionally transcribed each interview into a Word document then reviewed for errors once more before I emailed each mother a copy of her transcribed interview, asking each to notify me of errors, changes, or omissions. The data was pre-coded and arranged into stanzas (Gee, Michaels & O'Connor, 1992; Saldana, 2013). I applied an eclectic combination of attribute, in-vivo, holistic, descriptive and emotion coding to the qualitative data and manually

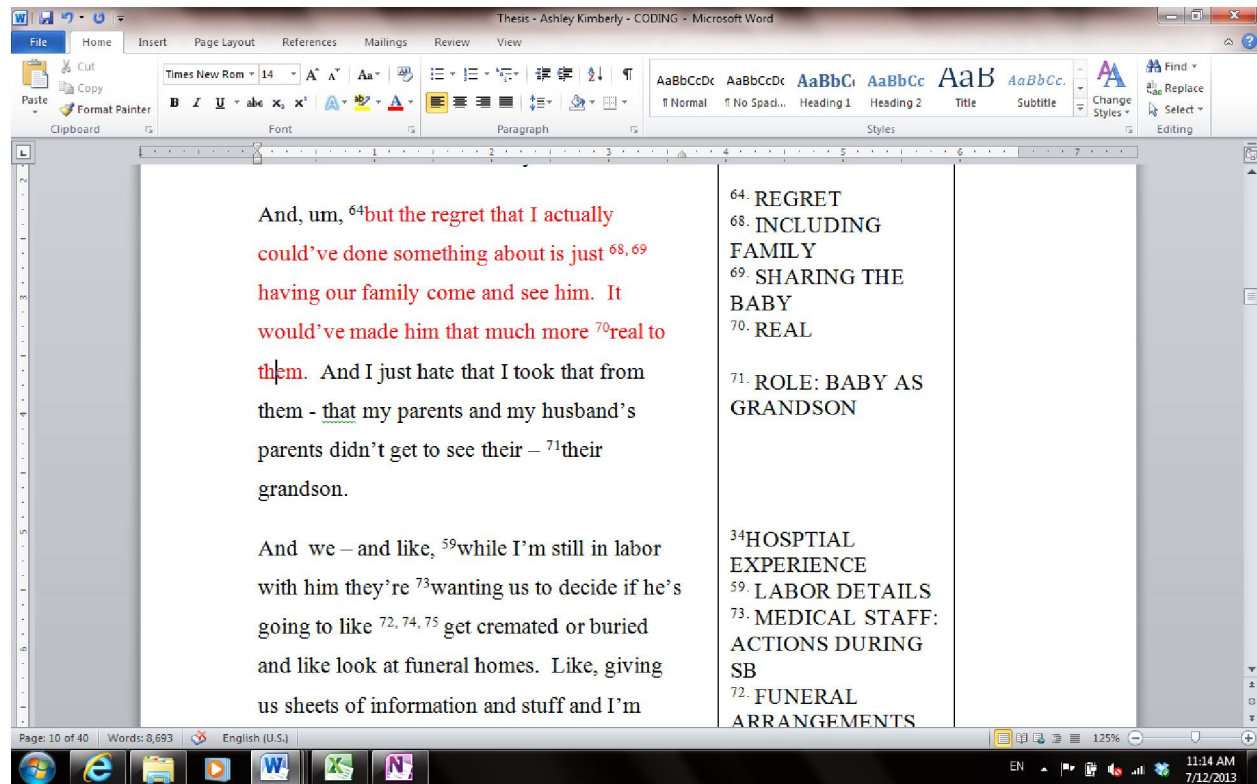


Figure 1 Qualitative codes shown are assigned to interview data. The number corresponding to the code was annotated next to the data and the numbered code was listed in a vertical textbox in the transcription document.

assigned qualitative codes for the first set of data (Ashley's interview) (Saldana, 2013). Each code was assigned an identifying number which I annotated next to the corresponding text of the data. The code itself with the assigned number, I listed in a vertical text box running along the right-hand margin of each page (See Figure 1) (2013). I created a codebook in MS Excel to keep track of all the assigned codes and their definitions. After coding the first interview, I used a table-top method of organizing the codes by writing each on a sticky note and grouping them into initial categories to help maintain focus before further coding (2013). The remaining three interviews, I also coded using the same combination of coding methods.

After a first cycle coding for all of the data was complete, I themed the data in a second cycle of coding using a combination of code mapping, focused coding, table-top organization and assessing major themes (Saldana, 2013; Stringer, 2007). Code mapping helped me group

| Row Labels                         | CAT      | CAT # | AK | AN | KH | TD | Grand Total |
|------------------------------------|----------|-------|----|----|----|----|-------------|
| BEFORE / AFTER - BEFORE            | BEFORE   | 1     |    |    |    |    | 114         |
| NEVER CONSIDERED                   | BEFORE   | 1.1   | 7  | 4  | 4  | 3  | 18          |
| BEFORE                             | BEFORE   | 1.1   | 8  | 5  | 2  | 2  | 17          |
| HAPPY                              | BEFORE   | 1.1   | 6  | 7  |    | 1  | 14          |
| BABY                               | BEFORE   | 1.1   | 6  | 2  | 1  | 3  | 9           |
| PAIN/DISCOMFORT BEFORE BABY DEATH  | BEFORE   | 1.1   | 1  | 5  | 2  |    | 8           |
| PREVIOUS EXPECTATIONS OF PREGNANCY | BEFORE   | 1.1   |    | 4  | 2  | 1  | 7           |
| NOBODY TALKS ABOUT IT              | BEFORE   | 1.1   | 1  | 1  | 1  | 4  | 7           |
| PREVIOUS EXPECTATIONS OF PREGNANCY | BEFORE   | 1.1   |    | 4  | 2  | 1  | 7           |
| PERCEPTIONS: PREGNANCY BEFORE      | BEFORE   | 1.1   | 1  | 6  |    |    | 7           |
| JOY                                | BEFORE / | 1.1   | 1  | 5  |    |    | 6           |
| LACK OF MOVEMENT                   | BEFORE   | 1.1   | 1  | 1  | 1  | 2  | 5           |
| THAT WOMAN                         | BEFORE   | 1.1   | 1  | 2  | 1  | 1  | 5           |
| MINIMIZING OWN CONCERN             | BEFORE   | 1.1   | 1  | 4  | 1  | 1  | 7           |
| DIDN'T CALL WHEN WORRIED           | BEFORE   | 1.1   | 1  | 2  | 1  |    | 4           |
| NOT ADVOCATING FOR SELF            | BEFORE   | 1.1   |    | 2  |    |    | 2           |
| MOM KNEW BABY                      | BEFORE   | 1.1   |    | 1  | 1  |    | 2           |
| PERMISSION TO CALL DOCTOR          | BEFORE   | 1.1   | 1  |    | 1  |    | 2           |
| BEFORE / AFTER - AFTER             | AFTER    | 2     |    |    |    |    | 333         |
| SADNESS                            | AFTER    | 2.2   | 5  | 26 | 12 |    | 43          |
| LIVING V. SB CHILDREN              | AFTER    | 2.2   | 2  | 9  | 3  | 2  | 16          |
| REGRET                             | AFTER    | 2.2   | 4  | 4  | 3  | 2  | 13          |

Abbie & Duane: LINKED TO BEFORE AND THOUGHTS OF BABY, BUT NOT AFTER

Abbie & Duane: Comment from her Born in Silence interview

Figure 2 Focus coding and theming done by transferring all interview codes from transcripts into a spreadsheet then calculated using a pivot table.

codes into categories to reduce the number of codes resulting from combination or deleting redundancies. Focus coding next transferred the lists of codes from each interview data into an Excel spreadsheet. Within the Excel, I used a pivot table to quantify codes and group them into major categories then eliminated less relevant codes and codes which might seem descriptors of major codes and themes (See figure 2) (2007). I used the table-top and focused coding methods again alternately to identify and separate major themes which I then organized into a thesis report.

## The Mothers

When I asked each woman if she would share her story, not one hesitated. Each has come to realize, as I have, that the opportunity to share her story is as rare as the chance to speak her

child's name out loud to someone eager to listen. Each story is precious, valuable, rarely heard in American culture, and for the most part, the stories are all each woman has left of her dead child apart from the few artifacts she treasures. For each mom, telling the story is how she keeps her child's memory alive and honors her child. The stories are also powerful and might be used for instigating change in the ways our culture responds to stillbirth.

### **Ashley**

I first met Ashley at a Parent Support of Puget Sound (PS) meeting held at Seattle Children's Hospital (PS, 2013). It was in the summer of 2009, a few weeks after her son Walker had died, and just over a year after my son, Isaiah, died. As I watched her from my seat in the circled group, she was visibly emotional. Her life had drastically changed. In our first few meetings together, she seemed interested in becoming friends with me. I was farther along in my grief journey, and she looked to me as someone who could provide her with a roadmap to grieving her child. Three months following her child's death, Ashley became pregnant again, and our friendship developed as we shared our grief and also our struggles with our Christian faith.

At the time of the interview, Ashley was 29, a mother to two living children and one stillborn baby. Her daughter, Olive, was four years old; her son, Walker, would have been 17 months old; and her son, George, was five months old. Her interview was the first for this project. Although I came prepared to hear her story and follow up with some carefully considered questions, I quickly found my list of questions was limited (See Appendix A). Her interview became more of a conversation – a narrative inquiry – and as further questions formed from that discussion, I realized I had more to ask her and probably every other mother who shared her story. Eventually, my conversation with Ashley became the framework for the following three conversations.



**Trameela**

Trameela and I met in September 2012 at the Swedish Medical Center in Issaquah. Along with our spouses, we were each asked to participate on a parent panel for a Resolve Through Sharing (RTS) bereavement seminar hosted at the hospital (RTS, 2012). Nurses, social workers and chaplains voluntarily came from the surrounding Seattle area and as far as a Virginia military base to learn how to better care for families experiencing the death of their baby in a hospital setting. Standing in the waiting area outside of the large training room on the second floor, I saw Trameela and her husband, Kendle, waiting nervously in their seats. As my husband and I introduced ourselves, I was shocked to hear that their daughter had died only three months prior and Trameela's proposed due date was the day after the seminar.

While sharing her story on the panel, she strongly emphasized her faith in God and its impact on her experience, as well as her desire to help other people. I invited Trameela and Kendle to the Parent Support memory walk at Coulon Park in Renton the following month, and then had them over to my house for lunch. Again, she found it really helpful to talk through her story with someone who was farther along the grief journey. We are still acquaintances, and we have kept in touch throughout the past year. When I asked by email if she would share her story with me for this project, she instantly scheduled a time. At the time of the interview conversation Trameela was 31 years old and the mother to Kyndle Jazzmyne, stillborn 11 months prior on Father's day 2012.

**Ana**

I met Ana and her husband, Jason, in a PS meeting as well. It was not quite a year after my son, Isaiah's death and very soon after their daughter Lona died. As a couple, they quickly struck me as unique. Each week as we heard from the circle of bereaved parents attending the

meeting, normally it was the woman in a couple who shared their story first. Often the husbands added little or nothing. However, Jason was very verbal and quick to tell their story. Ana spoke afterward, and I assumed she was much younger than she was. She cried as she spoke about the full-term identical twins recently carried in her tiny frame. Maxine lived, yet Lona died. After finding out about Lona's death, Ana carried her for another seventeen days confined to a hospital room to ensure the safe delivery of Maxine. I could not imagine experiencing her trauma.

She and Jason, were so open at each meeting, and made friends easily. They quickly found a connection with Ashley and her husband, then soon afterward with me and my husband. Although we are not close friends, we have a bond unique to our experience. I do not see Ana as often now that we each have subsequent living children, but when we do see each other, our relationship is still very honest and real.

I asked Ana if she would tell her story in 2010, and she agreed. I did not know then if the story of her twins would complicate the project or create more understanding. We did not do the interview at that time, and I had not recently talked to her about it. When I asked her again, it was at a fundraising auction of the Stillborn Still Loved guild (SBSL, 2012a). She was eager to share. She told me that she "needed" to tell Lona's story because it had been too long since she had shared it. Ana was 40 years old the day we did the interview. She is the mother to three children: Maxine, who is four years old; her twin sister, Lona, who was stillborn; and Roman, who, at that time, was seven months old.

### **Keli**

Keli and I met at a luncheon discussion about stillbirth held by the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) (GAPPS, 2013). We had each been invited to share our personal stories with a room of local stakeholders who work in stillbirth research and/or care

for pregnant women. I had invited Ashley to come as well. That same day, a GAPPS team member approached us about possibly starting a stillbirth guild to support GAPPS. Months later, Keli, Ashley and I formed the Stillborn Still Loved Guild together (SBSL, 2012a).

Although we have often worked together in the past two years, I had never heard Keli tell her story of Adam other than in bits and pieces. She is very cautious of opening up to new people. Despite our guild work together, gaining her trust and friendship is yet a slow process. I did not ask her earlier to take part in this project because I was not sure that she would trust me with it, but when I recently asked, she was quick to say yes. Keli was 40 years old at the time of the interview. She is the mother to Adam, stillborn in April 2004, and his younger brother Cole born in 2005.

### **Themes in Personal Narratives**

#### **“Before”**

*“My son’s death is the dividing line in my life, a firm delineation between what I knew and believed about living in the world before we lost him and what life became after his death.” (Williams, 2010, p. 2)*

I arrived at Ashley’s Seattle home on a dreary day in December, 2010. The mocking bright green front door contrasting against its brick Tudor home seemed to belie the sadness and tragedy experienced by the family living within. As she opened the door to greet me, I noticed the “W” necklace encircling her neck. I never saw her without it. On the surface, her attitude was pleasant; covering what seemed to be a slight nervousness, not about having me in her home, but possibly about sharing her story. I crossed the threshold to see holiday decorations displayed across the cozy living room, the Christmas tree in the corner to my left and stockings hung over the fireplace to my right. Just above the stockings sitting on the mantle, was a framed photo of

Walker. Upon first glance, he looked the perfect picture of a sleeping eight and a half pound newborn baby. Except he was not asleep when the photo was taken, he was dead.

As we settled in, Ashley picked a corner of the couch and I sat on a chair across from her, right next to the video camera. I explained to Ashley – as I did with each mom interviewed afterward – that I wanted to hear the story of her stillborn baby in her words, and that I would also ask some questions. In this case I said, “I want you to tell me about Walker.” With her elbow on the arm of the couch and her hand nervously next to her mouth, she smiled as she thought about how to begin. She described herself as the “happiest pregnant woman” and that she was “super happy.” Like the other three mothers, her pregnancy was a happy time in her life.

During much of the conversation, she looked down or away as if she was remembering a different time. She laughed nervously as she mentioned her biggest fear at that time was that he would be late, and then she paused mentioning the date. It was the Fourth of July 2009, and her life was perfect. It used to be her and her husband Tyler’s favorite holiday. She later explained that she felt so lucky in life. During that afternoon in 2009, she and Tyler had a rare conversation that she says had happened only twice during their marriage up to that point, and she told Tyler, “My biggest fear was what God would let me endure... and I didn’t know that Walker was already dead.”

In that moment and even now it makes me cry to hear Ashley talk about her life “Before.” Before she and I knew each other, we were different. Before, we both had strong faith. Before this happened to us, we each had a different relationship with God, and since have been overwhelmed by what God thinks we can endure.

For each of my interview mothers, as for me, the time of their pregnancy was happy and full of expectation. They each described the time before their baby died with words like, “awesome,” “perfect,” “special,” “amazing,” “excited,” and “blessed.”

Ashley continued her story of her perfect day by telling me how in a nonchalant tone she had mentioned to Tyler that she had not felt her baby move that day.

...it was just like a perfect day, and then we got in the car. Tyler had been drinking beers and I – I was driving and I’m – I’m unlocking my Volvo, and I’m just like, ‘You know, I don’t think I felt him move today.’ And it – it never occurred to me that anything was wrong, but I just kind of was making a comment, you know... I didn’t think that anything was really wrong. Of course, you know, of course nothing would really be wrong.

Although she had felt discomfort the night before, and she had not felt him move all day, she never considered that her baby might die. In fact, never considering the possibility of stillbirth was the most common code in the “Before” theme. Three of the four women had moments of discomfort and pain in their abdomen before they found out their baby died, three women were somewhat worried, and all four women noticed a lack of movement. Yet they all mentioned that they never considered something might be fatally wrong.

I assume it might be easy for people looking to question mothers like us to say, “If you felt like something was wrong, why didn’t you call?” These other mothers, like me, all minimized their concerns because they did not want to be “that woman” who calls their obstetrician too much. Ashley commented:

I was always one of those people that erred on the side of not calling and just-everything’s fine and I don’t want to be a pain in the butt. I don’t want to be that like obnoxious pregnant woman that’s always like freaking out about everything.

In Ana's story, she explained how she talked herself out of calling as well:

...I had another appointment on Thursday and we're going every week at that time. I just thought you know, I don't...I don't need to call you know, I've heard other people say, 'I don't want to be *that woman* [emphasis hers] who calls and complains all the time' and I just thought, you know, I will see my doctor on Thursday.

Trameela was the only mother in this project who called her doctor when she was concerned. However, during our conversation in Trameela's living room, she sat on the couch and smiled while telling me about the moments when she had not felt her baby moving, and that she was not concerned at that time. She smiled through telling me that she had waited a couple of days to call after she noticed a lack of movement because despite that she is a Medical Assistant in family practice office at a local hospital, she did not think anything could go wrong. Then she stopped smiling and looked down as she told me her doctor did not find a heartbeat.

Back in Ashley's living room, she paused, and then spoke more about that hot Fourth of July in 2009. After finally calling the doctor, and trying to wait the recommended hour for the baby to move, she and Tyler jumped into the car too concerned to stay home any longer. She mentioned again that in their rush to the hospital, it still never occurred to them that Walker could be dead. Her eyes arched looking straight at me as if to say, "Of course we didn't think that!"

### **Medical Experience and Medical Caregivers**

*"How, you will wonder, can people be so stupid? But then you realize how little you knew, Before, about stillbirth. No book, no article, no well-intentioned word of warning told you that your baby could die days before his due date...No, nothing could have prepared you for this." (Williams, 2010, p. 4)*

I pulled up to Ana and Jason's home in Seattle at 1p.m. on a sunny Sunday afternoon in May, 2013. The last time I visited them was at their previous house located just down the street from Children's Hospital. I awkwardly opened the gate to their yard hoping I had the right home, then walked up and tapped the brass knocker on the front door attached to the old stone house. As a smiling Jason opened the door for me with a seven month old baby Roman in his arms, I realized I had not seen them much in the past couple of years. Between us, three new kids had made safe arrivals into the world, and we were all a bit busy with life.

We talked about the busyness and messy houses that come with having two children at home rather than one. I took a tour of their new place and listened to their renovation plans of what used to be the first club house of the Sandpoint Golf and Country Club. Ana came home a half an hour later. She was out doing some last minute errands before a business trip, and I was not sure at that point whether keeping this appointment had become just a favor to me or still a chance for her to tell Lona's story. Yet, Jason took the kids out to the Fremont market so we could have the quiet house to ourselves.

We sat in the living room where she felt most comfortable – she in a well-worn armchair, and I on the couch facing her. While I was setting up the video camera we laughed about the dead flower bouquet she would have to move out of the background. “Having dead flowers in the shot might be a bit much, huh?!” she joked. The silver heart necklace with Lona's name engraved on it was around Ana's neck. I've never seen her without it. It seems to be part of who she is now. As the video recording began, and she started talking about Lona, her emotions poured through her, clearly showing me that this story was her priority that day.

She talked of the time before Lona's death when she felt “lucky” just as Ashley had felt. She smiled and looked to the side as she described that the amazing feeling of finding out they

would have twins was “like winning the lotto.” I found myself beaming right along with her as she was telling me about it. So much of Ana’s early story was about the joy of being pregnant with twins, and in some ways her and Jason’s concerns about the risks associated with twin pregnancies. Yet, their doctor told them not to worry about those risks. However, Ana had not felt well for a while when she went in for a regular ultrasound appointment at 33 weeks. That day, her husband, Jason, was late for the appointment, stuck on the 520 bridge, when the ultrasound technician carefully told Ana one of her babies had died, then rushed to find a doctor.

Sitting in the armchair with the afternoon sun pouring in the window behind her, Ana started tearing up and sniffing, even though she says she did not cry the moment she first found out. Sitting on her couch I cried along with her. In that moment, her face changed from a picture of light and laughter to seriousness and concern as she reflected on being rushed in a wheelchair through the halls of the Nordstrom Tower, over to Swedish Hospital, and past people who had "fear" on their faces.

For these mothers the medical experiences they had during their pregnancy, delivery and afterward – including their interactions with medical caregivers – played a significant role in the stories of their babies. Their medical experiences had both positive and negative aspects to them.

### **No heartbeat**

All four mothers found out during an ultrasound that their baby had died. None of them expected the news during their exam. When I listened to each woman tell me her story, I clearly remembered lying on the table for my third and final ultrasound in July 2008. I remembered the female technician, Lisa, turning the screen so I could not see it that time. She was the same woman who had shown me my baby’s beautiful sleeping profile eight weeks earlier. I remembered being nervous when she and my doctor started pointing to the screen, and speaking



in what sounded, to me, like a medical code language. I had no idea what was going on, and I was alone. The moment my doctor turned to say my baby had died is a vision still seared into my brain. I was stunned.

### **Shock and disbelief**

Each mother told me about the moment when she found out her baby's heart had stopped beating. Each also explained feelings of shock, disbelief, and an un-real /dream-like state. Combined, the three codes for these feelings make up the largest portion of the medical experience and medical caregivers theme. Ashley told me:

I said to the doctor – you know, they're kind of doing a like real – I don't know – just trying to be really nice and you know, oh shit, you know and I – I said, "He's dead, isn't he?" And- and Tyler just started bawling and I just felt like a statue. You know, I just felt like, I don't know, just shocked and like numb. I can't – I was just shocked.

Trameela works in a medical practice with pregnant women everyday yet it took three ultrasounds for her to start believing her baby girl, Kyndle, had died. She told me about her second ultrasound and stated:

... The doctor showed [my husband and mother] the ultrasound a second time. I still wouldn't look. I- you know, I was just kind of like, "This is unreal. This is not happening. I'm past the 20 week mark. You know, I'm almost, you know 30 weeks. I'm pretty far along. Why is this happening? It doesn't make sense."

After the third ultrasound she finally looked at the screen, but stated that it was still "very unreal".

The shock, disbelief and dream-like feelings actually continued throughout the hospital experience. Because so many women have not heard of stillbirth - and are shocked when it

happens to them - they do not even realize they will have to deliver their baby. This causes further confusion (Kelley & Trinidad, 2012). Trameela explained this saying:

And I was like, “What do you mean I have to deliver this baby?” I mean, all of it was kind of - it didn't make sense to me, so it was very just - it was like a surreal feeling, like I was dreaming almost.

Ana told me of feeling pain pressing in all around her, but also feeling like she was in a dream. Keli, who is an acute care pediatric hospital nurse, was too shocked to want to hold her son, Adam. Ashley and her husband almost left the hospital without telling anyone after delivering Walker because hours after finding out, they were still too shocked to call people.

Back in Ana’s living room she cried as she told me about having to lay in the hospital for 17 days. She had no desire to get out of bed or shower. She swiped at the tears rolling down her face as she told me how Lona’s death was automatically pushed back while medical caregivers gave priority to saving Maxine’s life. Every day that she laid in the hospital, she hoped Lona’s death was a mistake, because the contractions in her uterus made both babies move; and it tricked her into thinking Lona might be born alive. As we both sat there crying I kept wishing I had remembered tissues. She paused to get up saying, “I think I’ve got some tissues, I grabbed some” and after searching them out she sat back down keeping the box to herself. I understood. She would need them. Her mascara was running, her eyes and nose were red, yet she wasn’t even half-way through her story.

### **Hospital experience and caregivers**

The medical experiences and interactions with medical caregivers varied between the mothers. Ana told me that she was so distraught when her daughter Lona died that her hospital experience was a “blessing” because the time there and the medical caregivers helped her and

Jason think about how they would navigate this unexpected tragedy in their life. Unlike Ana, while most mothers are experiencing this sense of shock they will go through labor without time to acclimate themselves to the devastating news. Keli remembered when she was on the maternity floor that she “got moved to another room, I don’t remember where, probably somewhere where I couldn’t scare all the other patients because I was screaming.” Ashley’s tragic ultrasound was done at the hospital, and she described to me emphatically that she would not go home while still carrying a dead baby. She stayed at the hospital to deliver him, and as she was choking back tears she recounted to me:

... While I’m still in labor with him they’re wanting us to decide if he’s going to like get cremated or buried and like look at funeral homes. Like, giving us sheets of information and stuff... as if you have to make that decision [while in labor].

Medical care can be inconsistent during a stillbirth, but the hospital experience is crucial to mothers because this is the only experience they will have with their baby outside of the womb. The time in the hospital for all four mothers included being hooked up to machines, being medicated, having multiple caregivers go in and out of their rooms, waiting for hours, making difficult decisions about autopsy and cremation versus burial, meeting their baby and ultimately leaving without their baby. For some of them, their time also included finding out their baby had died and hazy memories. For Keli, her hospital experience also included having other mothers’ C-sections re-prioritized over her stillbirth induction. The actions of the medical caregivers can help or hinder parents during this shocking surreal time.

### *Medicating mothers*

Three of the mothers talked about being medicated because of their shock and grief. I cringed a little during our conversations when they spoke about being medicated, knowing there

is current debate on whether grief should be labeled as a psychiatric disorder, for the sake of medication, only two weeks after the grief has begun (Cacciatore, 2012). On a Wednesday afternoon in 2008, I had never given thought to medicating grief. I checked in on the maternity floor in the basement of Valley Hospital at 4:30pm just hours after the ultrasound that gave me the devastating news of Isaiah's death. When Duane and I walked in, the charge nurse took one look at our faces then asked if I was Abbie Smith. Pregnant women must not normally look so devastated when going into labor. My contractions had already started just before I left the house, but considering he was my first delivery, my labor was expected to take a couple of days. Not to mention, during contractions, a dead baby does not wiggle into the birth canal like a living baby would. I was distraught. Even though I planned to have a natural childbirth, I remember the doctor and nurse encouraging me to have an epidural so I would not feel any pain, and to take sleeping medication to knock me out. I took their advice and slept hard that night. In hindsight I still feel that preparing my exhausted body to deliver a dead baby was probably a good idea.

However, during our conversations, I had the impression these mothers were medicated for their grief. One mother was told to push the medication button as much as she wanted due to her broken-heart, another was given medication after delivery to sleep through her despair; and in Ana's case, she was given a lot of medication the day she delivered her girls because it was a "really hard day" for her. Sadly, due to medication, she has trouble remembering important parts of that day.

### *Providing choices*

Medical caregivers are often the first people to tell parents what to do during a stillbirth experience and relay possible choices. Nurses or doctors gave each mother choices at various points after these mothers had learned their babies had died, although they were not given the

same choices. Some choices included the option to go home before starting delivery, choices of how to care for their baby after delivery, choices to have a photography service come take pictures, and choices about cremations and burials. Often ignorant about stillbirth experiences, parents find this specific information and its careful presentation crucial. The choices parents make or do not make during this time easily leads to either creating the most cherished memories of their baby, or their largest regrets later on. Keli stated that she really wishes now that she had pictures of herself holding Adam. She had never thought of taking photos with her dead baby, and a photography service was not a choice offered in her situation.

### **Care during pregnancy**

Medical care also included care the mothers received during their pregnancy and after leaving the hospital. When I asked for their perception looking back to the medical care they had received during pregnancy, some of the women felt positive about the care they received before finding out their baby would be stillborn. Nevertheless, in retrospect a couple of mothers thought that certain risks should have been discussed. Keli was considered a high-risk pregnancy, yet no health care person mentioned the risk of stillbirth to her. Ana learned in a twin class given at the hospital that a twin pregnancy was always considered high-risk. She tried to discuss it with her doctor, but her doctor was very “laid back” and treated her concern in a “status quo” manner.

She told me:

It seemed like every week at that class, we learned about something else that we were concerned about and we'd bring it to the doctor... I know she was a good doctor... She had, you know, been many times over named, you know, like “Best OB in Seattle,” but I feel like looking back on it maybe she was too comfortable.

In fact, in Ana's story, she mentioned seven times that she felt different concerns were downplayed during her entire medical experience. Three of the four women experienced medical caregivers downplaying their concerns – some instances include downplaying concern over: (a) not finding a heartbeat in an early ultrasound, (b) telling the doctor the babies were moving in a “weird direction”, (c) having extra amniotic fluid, (d) in response to a phone call about lack of movement, (e) not quickly finding a heartbeat during a non-stress test, or (f) during the moments of the final ultrasound.

### **In compassionate care**

Compassionate care provided by medical caregivers differed in each situation. All four mothers talked about having caring medical caregivers as being a positive experience for them and made constructive comments about their medical care in the hospital. Some of the comments included “awesome,” “well taken care of,” and “handled with care.” The hospital nurses were described as “great,” “sweet,” and “encouraging.” Ana spoke of being grateful for the hospital social worker, and Trameela mentioned that even the food-handling caregiver was kind when the caregiver realized the baby lying in the bassinet was dead. Ana's radiologist came by the hospital on a Saturday to say she had poured through all the ultrasound videos from the entire pregnancy and couldn't see what happened, “She was crying, and it was amazing that she came.” Trameela emphasized that she and Kyndle were both handled with care and that her nurses prayed with her in her hospital room. In some cases: (a) the nurses encouraged them to get showered, (b) explained what the baby might look like after delivery, (c) encouraged moms to hold their baby, (d) took photos, (e) told mothers to phone family, and (f) many other important acts. These interactions were incredibly valuable to the mothers.

Not all of the caregivers extended compassion to the mothers. Three of the mothers also experienced medical caregivers who were uncaring or lacking emotion. Although Ashley stated that the doctor on call who delivered her son was devastated, and that “people are pretty nice to you when you’re in labor with a dead baby,” she also mentioned negative experiences, saying it was “inexcusable and appalling” how she was treated by her own doctor as a patient with a baby who had died. She continued by saying that people expect doctors to be good at dealing with patients emotionally, but they are not. This fact can be especially painful as the doctor will need to explain the baby’s cause of death.

Sitting across from me amidst the Christmas decorations in her living room on that December day in 2010, Ashley let out a sardonic laugh when she talked about how her doctor explained the “fluke” of Walker’s inconclusive cause of death:

She told me that it was kind of like getting in an airplane crash so- or getting struck by lightning, which *does happen* to people *multiple times* [emphasis hers]. But, um, it was just kind of - that was her medical explanation for - yeah. [Laughter].

The experiences mothers have during labor, delivery, and after delivery with their baby’s body as well as the actions of the medical caregivers will mark the most valuable time mothers had with their child. These experiences will set the scene for how they start the next phase of their life after the death of their baby. In fact, if it had not been for one caring nurse, Ashley and Tyler would have left the hospital without telling one person that Walker had just died.

### **Telling others**

Telling other people the baby has died was something each mother talked about as being a difficult part of their medical experience. While they were still in shock, they had to decide whether or not to make phone calls. If they were alone when they found out then the mother had

no choice but to make her own phone calls. As was I, Trameela, Keli and Ana were each alone when they found out their baby died. After my doctor told me the news, and then stated that I was in shock, she helped me back to the regular exam room. The stunned feeling stayed with me. I had recently been commenting to Duane that he needed to make an effort to watch his cell phone at work in case of emergencies. I called his cell phone, and he did not answer. I called his office phone, and again there was no answer. I called the receptionist and she told me he was on a conference call. "It's an emergency," I told her while my heart pounded in my chest. She paged him - twice. He still did not pick up the phone. I was starting to panic by the second time when I heard the receptionist's voice answering the page. I think she could tell I was desperate when she transferred me to an assistant who then offered to pull him out of his meeting. I could not figure out what I should say. After hearing the news he would still have to drive 20 minutes to get to the doctor's office. There was no way for me to know if it was better for him to make the drive to the doctor's office while worrying and wondering what the news might be; or if it would be better for him to drive alone after hearing the devastating news. I chose not to make him wait. I had to tell him on the phone that his baby had died. "The baby died," was all I could say. From the other end, I heard silence.

In our conversations, the four mothers talked about what it was like for them to tell others. Telling others the news of the baby's death was associated with the difficulty of saying it out loud – confirming their baby had died – and also a moment of realization when the shock subsided a bit to the point where it "[sunk] in just a bit, enough..." according to Trameela. It was also an awful repetitive experience where someone, often the spouse, was forced to give the same shocking news over and over. In Ana's case, she remembered her step-mother screaming on the other end of the phone when Jason called simply stating in a somber tone, "Get dad."



While I sat next to the Christmas tree in Ashley's cozy living room, the cheery decorations were a stark contrast to the mood in the room. She looked down, her left hand on her throat, and fidgeted as she recounted how she and Tyler did not tell anyone. She paused then started using her hands while anxiously telling me that saying it out loud would have been too difficult. As she finished the sentence, her words slowed down, she put her right hand up to her cheek, and for the next few seconds she looked down lost in her memories. In addition, they knew it was the night of the Fourth of July and they did not want to "bother anyone." She wondered, "When's it an acceptable time to call your family and tell them your baby's dead?" In order to have much needed support of friends and family each couple will need to navigate those painful phone calls. After all, one of the hardest parts of the medical experience is leaving the hospital without a baby just as these women did.

### **Support**

*"Others will whisper behind your back, hoping that you won't notice, when you long for them to speak to you, face you, ask you how you are and say your child's name-for he had a name, and a face, and he was so close to perfect...."(Williams, 2010, p. 3)*

In Ana's still sunny living room, I was struck by the amount of supportive people she described visiting them during their 17 day hospital stay and attending the memorial service. I have never heard of another stillbirth couple being surrounded by so many caring people right away. In some ways it must speak to their own giving as special people themselves. Ana had just stated she felt like a "failed vessel" when she paused and smiled a bit. She followed her comment with:

And, so many people came to see us. I mean, our room was *full* [emphasis hers] of flowers. I mean, *full* [emphasis hers] of flowers. And, it was amazing how many people

rallied around us. I mean, our family came. All of our family came at some point, either while I was in the hospital or for the birth. All of these people came by.

They accepted the support of their friends and family early on largely due to the hospital social worker encouraging them to invite people to be a part of their experience. The social worker made the important comment to Ana and Jason that their family was also experiencing the death of a loved one. Ana sat in her chair explaining, with help of her hands, how she had previously been trying to control everything. She had planned out what she wanted when it came time to deliver the girls, and she definitely did not want family around until she and Jason had a couple of weeks to settle the babies into their life at home. “So foolish,” she laughed shaking her head at me. Looking down at the tissue in her hands, she said while still in the hospital, they decided to open the doors, and let everyone into their experience.

In terms of the support theme in our conversations, the main aspects in order of prevalence from high to low are:

1. who is supportive,
2. what is supportive, and
3. what lacks support.

The sections below explain: (a) support from family and friends, (b) support from other stillbirth parents, yet sometimes (c) a lack of support.

### **Support from family and friends**

All four mothers appreciated the support they received from family and friends regardless of how much they received. Not one mother told me she would have liked fewer family and friends supporting her. It was nice to have support right away. For three of the women, family and friends came to the hospital. Trameela told me how her extended family, including children,

came to the hospital to meet Kyndle. Keli's parents flew into town, yet with medication she was given, she had difficulty remembering all of the other people who visited her room. Ana, recounted the close friends, acquaintances, family of friends, and out of town family who flooded her room. For each of these women, sharing their baby with other people was a valuable experience.

Early supporters also offered additional help. Ana and Keli had friends offering to help by taking care of pets, picking up things at the store to bring to the hospital, and taking care of flower arrangements; some honored Keli's request to pack up and repaint Adam's newly decorated nursery before she returned home from the hospital. Ana and Keli each had family help with the funeral arrangements, and each were overwhelmed by the numbers of family and friends who came to their baby's service. Ashley as well said they had at least 40 friends and family show up on a remote San Juan island for Walker's service, and she would have loved to have more people come.

As the months and years passed, all four mothers have appreciated the continued long-term support of certain friends and family. They appreciated other people remembering their child at holidays and on the baby's birthday. Some people continued their support by giving the parents room to grieve, saying the baby's name, and acknowledging or validating the parents' experience.

Each mother also mentioned that hearing people talk about their baby was important to them. When I asked Keli about support in her life, she told me that her family talks about Adam. Ashley told me she likes it when friends ask about Walker and say his name. Although Trameela appreciates the support she's received, she still wishes people were more open to talking about Kyndle. Talking about the baby with the parent is healing despite the fact that other people may

not know what to say or may say some things that are not helpful. Ana echoed a sentiment I have heard from many stillbirth mothers when she said it is always okay to talk about her daughter, to say her name, and ask about her. Ana also told me about Hazel.

We were almost 45 minutes into our conversation when Ana started talking of her best friend Hazel whom she has known since nursery school. Hazel flew across the country to be at the hospital in Seattle, and Hazel held Lona after she was born. For Hazel, Lona was very real. Ana started blinking away tears when she spoke about Hazel who still calls every once in a while to say she's been daydreaming about Lona:

It means so much...just that [Hazel would] say, "I was daydreaming about Lona." And, I love her so much for that. And so, sometimes I just ask her to tell me, like daydreams that she's had about Lona because Jason and I daydream about her all the time. I mean, everyday...

Ana continued on in her story, alternating between laughter at Hazel dreaming that maybe Lona would be a black nail polish wearing poet, and wiping rapidly falling tears off her face when she said how much Hazel's daydreaming meant to her. While I listened to her I was crying again and thinking how rare this kind of support is to mothers like us in a culture so unaware of stillbirth. I have one friend like Hazel – my very first friend – and her care for my son, even though she never saw him, has been invaluable to me. Yet, from many other women in support groups, I have heard heartbreaking stories of rejection and isolation by their family and friends.

### **Other stillbirth families**

Outside the support from family and friends, all four mothers spoke of valuable support they received from other parents who have experienced the death of a baby. Ashley commented in our conversation, "I hate that we have that connection but yet, I'm so grateful for it too."

Trameela found encouragement by connecting with other stillbirth moms, and Keli explained that feeling a lack of support was very hard for her until she met another couple whose son was also stillborn. Ana felt supported by other mothers she connected with who seemed to “get it.” Ashley further commented that friends who have experienced a stillbirth “get it” and they know that no one else really does understand. As time goes on, parents realize that their reality of having a stillborn child is not the life their family and friends are living. Although, their family and friends have witnessed an awful tragedy, and possibly grieve that child too, they continue their lives the same normal way they lived before the baby died. For the four mothers I spoke with, their life has been divided into “before” and “after,” where living after a stillbirth means finding a whole new way of feeling like a normal person.

Although these mothers felt supported when (a) other people talked about their baby, (b) considered the baby part of the existing family, (c) validated their current life circumstances, (d) acknowledged the baby, (e) used the baby’s name, (f) allowed the mother room to grieve, and (g) grieved along with them, it is often the support from other parents of stillborn babies who provide the most support because they realize that the parents’ grief is a long journey and that they will never be the person they were before it happened.

The connection these parents may have felt so strongly with other stillbirth parents might also be associated with the importance of talking about their dead baby. As previously discussed, talking about it was very important to these mothers, and in the long run, it is often other parents of stillborn babies who are the most open to talking about the dead baby over a long term period.

### **Lack of support**

Unfortunately, the support from family and friends who have not experienced a stillbirth often tapers off over time. Keli stated:

... The hard thing to is that you got support from your friends and family like in the immediate period, but you have to live with this everyday and they, I feel like forget it happened, you know, or they don't remember... the support tailed of where it was like everybody, and I was very touched by how much it was, and then it was sort of like all there and it was all gone.

Ashley also talked about how being Walker's mom meant not having a lot of support over time.

She told me:

And then from other people, [support was] just hit or miss. I think the people are - I was lucky enough to feel like my family and friends were really supportive at first but it's hard, you know. At some point, you know, we're the only ones that are actually going through it and they're not and they don't have to - they just kind of go back to living their life even though for whatever aspect, they don't have to - they don't get to be *Walker's mom* [emphasis hers] so they don't deal with it every minute.

All four women spoke of loneliness and the fact that people outside the community of stillbirth parents do not really understand their experience. The difficulty of trying to explain stillbirth to uncomprehending people caused mothers to isolate themselves, which perpetuated their feelings of loneliness. Ashley mentioned that not hearing about how common stillbirths were, made her feel lonely and angry. Keli explained in the time that followed her family and friends' support tapering off, she still felt like her heart was "put through a meat grinder", and she had no one to talk with. She tried a support group, but it was not helpful. She also met with multiple counselors lacking experience with stillbirth parents. The counselors were more hurtful than helpful. In her profession as an acute care nurse at Seattle Children's hospital she works with dying kids all the time, but when her son died she felt like she was treated very differently

than other grieving parents, as if she had the “plague”. She told me if Adam had died of cancer she would not have experienced the same kind of alienation. Even now when she tries to talk about stillbirth in conversation, some people just simply choose not respond to her.

Mothers greatly attributed much of the loneliness, isolation, and lack of support due to the silence in our culture surrounding the topic of stillbirth. Whether it was the fact that they never heard of it happening before or the fact that they are unable to talk about it afterward, silence kept mothers in isolation.

The most prevalent aspect of lack of support, following the code loneliness/ isolation/ alienation, was people not knowing what to say. Although people who have not experienced a stillbirth or great loss may not know what to say, it was not the act of someone’s saying something awkwardly that made the mothers feel less supported. Instead, they felt lonely and hurt when people chose to stay away from them for fear of saying something wrong, or when people chose to say something uncaring and hurtful. For example, after Ana delivered one live baby and one dead she was told many times “at least you have one.” That comment invalidated the life and death of her daughter Lona as well as her own grief. Having the support of people who did not know what to say, but chose to come and cry or sit with them was appreciated as was the act of people trying to say something kind even if it felt uncomfortable at the time. In my own experience, the most remarkable thing I heard was from a seemingly gruff man – a former co-worker – who bravely approached me, and simply said, “Abbie, I don’t know what to say. I’m so sorry.” Breaking the silence around stillbirth would help support these stillbirth moms.

### **Social Norms, Customs and Rituals**

*"How do you even start to go about grieving for someone who never lived outside the womb? Who do you call?... It doesn't feel right to us to drop his death into casual*

*conversation. Not in this society, not in this age, so violent and yet so detached from the quotidian reality of death, so unversed in grieving. Telling the simple truth becomes an assault....It wasn't always so. Would that, when asked about her children, a woman were still able to say, as women used to say, simply: 'I have seven, four living.'"* (Hlavasa, 2010, p. 18)

Trameela lives just over a mile from me. As I turned through the streets of her neighborhood, I was astonished that I had never known it existed. It just happened to be around the corner from an office space I rented last summer and the coffee shop where I choose to study when my house is occupied by my family. Unbeknownst to me was the existence of this quiet neighborhood of discreet rambler homes. Like many other small homes on our hill it was probably built for the early factory workers of the Boeing plant seated at the south end of Lake Washington a couple of miles away. I pulled up behind the red car in her driveway promptly at 10am on the third Saturday morning in May. This was my first interview conversation since I spoke with Ashley in her Seattle home over two years earlier. Although I was excited to start the project again, it was turning out to be a beautiful Saturday. I was feeling a little rushed and hoping after she told me her story I would still have a little time to spend with my girls before their afternoon naps.

As she opened the front door her hair was still wet, and her clean face was without make-up. I hesitated when I noticed she was running a little behind. I really wanted to see my girls that day. She smiled excitedly and ushered me across the threshold, through the kitchen, past the table and into the family room in the back of the house. She and her husband Kendle had just moved from a different part of town. They had been living with family before renting their first house together. Belongings were piled in each room looking like they were just taken out of



moving boxes. Picture frames stood on the floor leaned up against the wall, and placed here and there were a few boxes left to be unpacked. I felt fortunate that Trameela prioritized sharing her story with me over further settling into her new home.

Just off the family room was the bathroom where she stood getting ready in the open doorway. The three of us chatted while she finished and I set up the video camera. Draped across the back of their sofa was a large throw blanket embroidered with a bible verse. Thirty minutes later, she settled into the sofa, hair and make-up done, and wearing a cross necklace that sparkled around her neck. I sat on the loveseat kitty corner from her and we started our conversation.

I explained the project to her as I did with each mother, and as she started talking, she smiled and spoke with a very calm and monitored tone. I wondered whether it was because she was uncomfortable telling me her story, if she had not had a lot of experience talking about it, or if there was some other reason that she came across as pleasantly detached from her emotions. She had previously told me that she was not a very emotional person, yet during this conversation she smiled when she said she did not feel her baby move, and she smiled when she said she was not concerned about it. She seemed to be recounting a story where her emotions did not match her words. I hoped she was just getting comfortable with me, but in the early part of our conversation, I could not help but wonder if she would open up. Then as the minutes passed, her smiles were less frequent and a little more awkward. Her façade fell away just enough for me to see her reflect during the retelling of her story. After two years, I was reminded in a new way why this project was so important to me, even if I missed a few minutes of play time with my girls. Like each stillbirth mother I have had the privilege of speaking with in recent years, her story was unique and important.

During our conversation Trameela said how a photographer came to take pictures of them with Kyndle, she held her, slept with her, bonded with her, and the entire family came to see Kyndle the next day. She described those moments as “awesome,” “amazing,” and “helpful.” I had previously found out that when Kyndle died, Trameela had never personally known another woman who had had a stillbirth. On this day, while listening to her describe her time in the hospital, I was a little stunned, if not slightly jealous, that in such a short period of time she knew how she wanted to behave and to include others in her tragedy. She said she had had guidance from the medical caregivers who told her to do whatever she needed to do and to do it however she felt most comfortable. Those words gave her the permission to go through the rituals that helped her bond with Kyndle after delivery. She cocked her head to the side, looked directly at me, and as she spoke her hands found their way up to her heart while she explained:

I really wanted that bonding time. For me personally, I really wanted to have that *bonding time* [emphasis hers] that a mother has with her child after she delivers. I wanted to know what the *feeling* [emphasis hers] was even though I knew I had to eventually let her go. The fact that she was there with me made me feel at ease that I still had a part of her.

### **Customs and rituals**

In a social context that does not have a set of accepted social norms honoring stillborn babies, parents still need to engage in customs or create their own rituals (Kelley & Trinidad, 2012; Cacciatore, 2010). The customs mothers engage in after a stillbirth are very similar to what mothers do after a live birth. Overall, the most spoken about custom was creating artifacts (including photographs), but that was not specific to the time in the hospital. The most common customs these four mothers engaged in post-delivery were:

1. Spending time with the baby.
2. Holding the baby.
3. Including family and friends to come see the baby at the hospital.

Other post-delivery rituals and customs involved (a) bathing the baby, (b) sleeping with the baby, (c) planning for cremation or burial, (d) and making funeral arrangements.

Ana recounted to me that the social worker had come before delivery to encourage her to hold Lona. Lona had been dead in the womb over two weeks. The nurse also came into the room to describe how Lona would look after the delivery since her bones had started collapsing in on each other. Ana took their advice, and now her most cherished photo was one that was taken in the hospital while she held her two girls together. Ashley remembered holding Walker right away and seeing his “perfect little face.” His body was still warm, and he looked like he was sleeping. She said the love she felt for him was “the same feeling” as the love she felt when she first held each of her living children.

Ana, Keli, and Trameela were all grateful that they had family and friends come to the hospital to see their baby. Ana told me how she felt very “raw” around other people while she was living this experience and that it was “good,” but also “bad and hard.” The benefit of including others in her experience was that, rather than being invisible to others like so many stillborn babies, Lona was more real to some of the people who came to see her.

### **Artifacts**

Creating artifacts – specifically pictures – was the most talked about ritual or custom. Some of the artifacts these mothers took from the hospital include (a) photos, (b) memory boxes offered by the hospital, (c) locks of hair, (d) handprints, (e) footprints, and (f) the gown the baby wore. Artifacts mothers acquired after leaving the hospital included (a) an urn of the baby’s

ashes, (b) framed photography and photo albums, (c) necklaces with their child's name or initials, (d) letters to their baby, (e) Christmas ornaments, (f) a Christmas stocking, (g) a letter written to the baby, (h) a memory box hand-painted with writings from the parents, (i) a memorial bench, (j) and tattoos. The tattoos serve as both an artifact and a means to share their baby's story.

Now I Lay Me Down to Sleep is a non-profit photography service, started in 2005, that creates remembrance photographs for parents when a baby dies (NILMDTS, 2013). Three of the mothers learned of this service and used it to photograph their baby. Ashley said she does not know what she would do if she did not have photos of Walker. Keli was sad that they did not have better pictures of Adam. Ana explained that a very important picture captures the beauty of her daughters' births:

But, in the picture I'm holding both of them, and I'm looking at Lona and smiling. You know, and it was an awful day, but it was a beautiful day, you know. We had Maxine.

But, I love that picture because you know there was happiness having [Lona] too.

Trameela stated that having photos of Kyndle is how they keep her a part of their life.

As I turned off the camera in Trameela's family room, her cheerful polished demeanor changed. Instead of sitting bolt upright, her whole body relaxed, and we continued to talk for another 30 minutes. I later wished that I had left the camera on because what followed was just as important, yet much more heartfelt than the words she spoke to me while the camera was on. It was less an interview and more a narrative inquiry. At one point, she quickly went to find her photo album of Kyndle. While she was out of the room, her husband Kendle (whom her daughter is named after) proudly showed me the photos of his daughter he kept on his phone. Trameela

returned with the photo album, and as I slowly looked at each photo, her eyes lit up while she told me how much that one pound, eight ounce baby girl looked just like her.

### **Lack of social norms, customs and rituals**

Despite the fact that many of the customs and rituals remain the same in both a live birth and stillbirth (e.g. holding the baby, taking pictures, bathing the baby, getting their hand and footprints etc.), the fact that stillbirth is so unheard of means that mothers do not immediately realize that they will want to take care of their precious time with their deceased babies. Like these four women, many mothers do not know what to do because they are unaware of social norms and rituals surrounding a stillbirth. Just as all four mothers experienced, the medical caregivers often guide parents and give them permission to engage in rituals for their baby. Ashley was the only mother who knew of a small portion of another mom's experience. She told me that she would not have pictures of Walker except for the faint memory of that acquaintance's cherished photos. While listening to the mothers tell me about a confusion that I was all too familiar with, I was saddened. I find it interesting that as a culture we are so unversed with stillbirth, that mothers' would defy maternal instincts to hold their baby out of a fear of the unknown.

Even with the guidance of medical caregivers, it was still a bewildering time, that some of these mothers look back on, unsatisfied with the decisions they made. I sat in Keli's Seattle living room and listened to her rattle off Adams stats and to me; she sounded just like a nurse:

Adam was born just before midnight on my parents' anniversary, April 24th, 2004. He was 6 pounds, 4 ounces, 19 1/2 inches long and um blond hair. I don't know what color his eyes were and I must have been pushing for a while because his head was distorted, but 10 fingers, 10 toes.

She was trying not to cry while telling me how he looked; about his memory box of artifacts containing a lock of hair, handprints, footprints, and the gown he wore; and also telling me of their “crappy” Polaroid pictures of Adam. Nobody thought to have a photographer come to her room. Now *I Lay Me Down to Sleep* did not exist in 2004. Even the nurses did not offer to photograph them with Adam. Keli had no idea that she would cherish her pictures more than anything else. Then she finally let herself cry while telling me she wished she had known that she would have wanted to bathe him herself, would have wanted a picture of her holding Adam, and would have wanted to spend more time with him. She said, “These are things you shouldn’t even have to think about.” This mother, who almost chose not to hold her baby before the nurses encouraged her to do so, now wishes she had known to do much more than hold him.

Listening to the recording again later, I heard us both sniffing; and while she was talking, I remembered thinking how much I wished I had a lock of Isaiah’s hair, a better handprint, had known about *Now I Lay Me Down to Sleep*, and had known I would have wanted my family to come in to see my son. Maybe if they had seen him, he would seem more real to them. My husband and I also had no idea what to do, we had never heard what other people did when their baby died, and we felt so confused by wondering what we *should* have been doing. Out of this confusion, I chose not to let anyone else see my son, and I chose not to spend nearly enough time seeing him myself. I heavily regret both of those choices.

During our conversation Ashley wished that she had had permission right away to embrace Walker as her son rather than worrying herself about what other people thought about her stillborn son. She wished she had known more about stillbirth and had been witness to someone else’s experience before it happened to her. She told me of still being uneasy about the decisions they made in the hospital:

And we decided to have him cremated... I mean, your first decision when you have a baby boy is supposed to be do you want them to get circumcised or not and you know... I don't know if I made the wrong decision or not.

She later went on to describe that the lack of social norms is not only an issue in the hospital.

After parents leave the hospital they still have to navigate their way through a life without their baby. She stated:

But it was, I remember so many times, especially those first couple weeks where you're just like, "How do we do this?" There's not – like, this is a big deal. And there's a way, generally speaking that, you know, you get married. Or if your parent dies or if like, even if a child dies, it's horrible. But your – your baby or your stillborn baby and it's like who do you invite? What's the right way to do it? Are you supposed to – I mean- it just like – on top of the grief, the stress of trying to figure out what the right way to do something that's so unimaginable...

In Trameela's family room she sat up straight and leaned forward on her couch then looked me straight in the eyes. Her pleasant look turned serious when she spoke of the silence around stillbirths and not knowing how to handle it. Then she stated, "... I felt like a lot of people were in the same situation that I was, in where they had no idea and then it kind of - it happens to them and they're like, 'Well, what do I do now?'" Even though Trameela felt her time in the hospital was awesome because she was able to do exactly what she felt was needed to bond with her daughter, she also felt lost trying to navigate life after a stillbirth.

These mothers did not know of social norms surrounding stillbirths and encountered a lack of awareness in the greater social context. They worried about bothering other people. Some of their worry kept them from including people in their experience, which will only perpetuate a

lack of awareness. When they did try to talk about their baby with other people, they found those people were not familiar with stillbirth so they said “stupid” and hurtful things. Ana told me that some people sounded like they did not believe that Lona was as real or as valuable as Maxine, and their hurtful comments invalidated Ana’s grief following Lona’s death. Keli’s perspective as an acute care nurse at Seattle Children’s hospital is valuable. On a regular basis, she is witness to the socially accepted way that children are grieved. At the end of our conversation when I asked her if there was one last thing she wanted to say, she became very emotional and wanted people to know that stillbirth is the death of a child. She said:

It's, to me, no different than if you lose a child to cancer or [lose] a parent. It's a death, and it should be treated like that rather than this life that didn't really exist. So, [people act like] you really shouldn't be upset [if a stillborn baby dies] because well, you didn't know him or you could have more kids. Yeah, that's my child, I want that child, and he died, and I am grieving, and just because you didn't see him or feel him or hold him doesn't mean he didn't exist, just because it was a short period that he was in our lives. It's all the same, absolutely the same, and I just wish that people knew that and would treat women and families that have gone through it that way rather than, I feel sort of, that they treat us like we have a plague or something .

### **Knowledge and Awareness**

*“Stillbirth, the culprit that destroys more than one in every two hundred pregnancies in this country, was glaringly absent from these books that are specifically intended to guide couples through their pregnancies, to prepare them for every possible twist or turn.”*

*(Goldenbach, 2010, p. 8)*



It was a gorgeous Friday morning in May. Keli's story was the last I needed to record for this project, and I pulled up to her home on a quiet side street, just blocks from Seattle Children's hospital. Most of the homes on her street were older, but Keli's large home had been recently built. I'd been to her house a few times, but had only been inside once a couple of years before. I slowly climbed the steep steps of her wide front porch with my heavy computer bag. When she swung the door open to greet me, holding her excited black lab Rosie by the collar, she said she saw me coming through the office window while sitting in her desk chair working on Stillborn Still Loved tax letters from our recent auction. She was wearing running clothes, and as she turned around to lead me into the back of the house, I saw the large tattoo on her right calf. It was a picture of two actual-sized baby footprints with the names "Adam" and "Cole" – the names of her sons. She and her husband got tattoos last year for Adam's eighth birthday, but I think I had only seen it in pictures. She was a little distant while we made casual conversation about her house, yet when I saw her at our auction less than two weeks earlier she had acted like a close friend. I never know how she will be feeling when I see her.

After a few minutes, we set up in the front room of her house opposite of the office, where the sound of her story would pick up better on the recording. It was not a cozy room, but rather the pretty room – the room that people probably do not sit in. In fact, as she settled in to a chair opposite of the light coming in from the front window over the porch, she casually mentioned that she could not remember when she last sat in those chairs. I set up the camera and the memory card was not in it. I had remembered to charge every battery and back-up, but somehow forgotten to put the card in the camera. It was my third interview within seven days and I already felt a little bedraggled coming into it, so in that moment I felt super frustrated. Also, Keli had this slight air of superiority or formality that is off-putting at times, and it made

me slightly uneasy. I usually assume it is a self-protection mechanism, but that day I considered that it is possibly intended to make people uneasy whether she realizes it consciously or not.

Nevertheless, I set up my i-phone to make an audio recording instead of a video, and her story began. She hesitated at the beginning, paused in reflection after her first few words, then decided to start her story with her first pregnancy, a miscarriage in 2003. Like many other women I have met in support groups, it is hard for her to tell her story of stillbirth without talking about her experiences before and after her baby died. She told me that before she had Adam she had a high-risk pregnancy, was sad but not shocked that it ended in miscarriage, and had never heard of the risk of stillbirth. After Adam, she went through a terrifying subsequent pregnancy with Cole the following year. Without knowing why stillbirth happens, she spent her entire pregnancy with Cole unsure of how it would end.

Keli's voice wavered as she described being put in a room at the end of the hallway away from the other women on the maternity floor. She said that she remembered being in that room alone with her husband Ryan and saying, "Why? Why us? Why does this happen?" She literally had no idea that stillbirth happens in pregnancy. When I later asked her what she knew of stillbirth before Adam died, she said this:

Nothing, absolutely nothing. I don't even think I'd heard the word until it happened. And it's sad because I'm in the medical profession, and I'd not heard of it, knew nothing about it. I've felt uninformed and unaware and really thought that if something like that was going to happen, it was going to happen in a third world country, not in Seattle to somebody who was in the medical profession and took really good care of themselves in their pregnancy, like bent over backwards pretty much to have that healthy baby... And I felt like I went through a lot to get there and knew nothing that stillbirth could happen. I

knew that, you know, miscarriage like my first pregnancy could happen. It's very common, but nothing about stillbirth, um, that it could happen and your baby is kicking and fine one day and not alive the next and that they're going to be born and – oh wait, you actually have to give birth to them.

When I asked how her previous knowledge or lack of knowledge affected her, she said she was “blindsided.” Finally when I asked if there was something she wished she had known before Adam died she said, “Stillbirth happens,” and knowing the risk is better than being blindsided.

I listened to her recount her lack of knowledge and thought to myself, if the medical community has not heard of something as common as stillbirth, then who will advocate for the pregnant women when they voice concern during their pregnancies? It angered me, yet I was not surprised.

### **Lack of stillbirth knowledge**

#### ***Mothers do not know about stillbirth***

As each of the four mothers recounted their story uninterrupted by my additional questions, all four mentioned aspects of experiencing a lack of knowledge, lack of understanding, or a questioning about why stillbirth happened to them. Three of the four mothers also volunteered that they felt that having more knowledge would have been helpful. After asking them more questions, I found that these four mothers further indicated that their knowledge of stillbirth was lacking, their knowledge was inaccurate, or that having knowledge about stillbirths would have been helpful during pregnancy.

Sitting with each mother, I asked what they knew of stillbirth before their pregnancy. They either (a) did not know anything of stillbirth, (b) thought it was related only to traumatic events, (c) thought it was a rare occurrence, (d) thought it only happened in a 3<sup>rd</sup> world country,

or (e) thought of stillbirth as antiquated. Two of the mothers, Keli and Ana, told me they knew nothing. Ana used her hands for emphasis and said:

Nothing. Nothing... I think the only time I have ever heard that phrase, and I will just be totally honest, was like "A Little House on the Prairie" episode or something... Anything I knew about it was like associated with like settler times or like hundreds of years ago people had stillborn babies. It--I never heard of anybody having a stillborn baby. Never.

When I started asking Trameela my additional questions about her story, her polished smile initially faded to a serious look. I wondered if she had told her story enough that she learned to smile through it; and maybe that was why she seemed pleasantly detached. However, she had not practiced the answers to the questions I asked her to think through. She wrapped her arms across her body in a hug as we continued our conversation. Even though Trameela is a medical assistant in a family practice, and has worked in a hospital, she stated she knew "not much at all." What she heard before were "horror stories" she deemed the "worst of the worst." Each story she previously heard of stillbirth was related to an awful cause like a car accident, a fall down the stairs, or an extreme illness. She later stated that, "...People that are healthy, like me I was healthy, you don't really hear about them delivering still- stillborns [sic]."

Ashley, raised her eyebrows, opened her eyes wide, and focused her attention directly at me when she explained that she thought it was something that used to happen:

I mean, I think it's something I thought that happened more in the past which may be that is the case, but it was something that I knew happened, but it seemed very, very rare and unusual... and so before Walker died, I just had a couple of the experiences that I'd heard about, and I just thought it sounded like the most heartbreaking thing, but I didn't know really, you know, how often it happened or the reasons why - I just hadn't thought about

it that much. I had a friend, and her baby was stillborn I think at about 24 weeks, and she wasn't like a really close friend...

Regardless that stillbirth is a common occurrence in the U.S. these four mothers did not know about it.

Each mother thought that part of the reason for their ignorance about stillbirth was due to a silence in society. They each said that when stillbirths do occur, nobody talks about it. They also thought that it was talked about only after it happened to them. Then family and neighbors shared with them previously untold stories of stillbirths. The mothers commented, "I never heard of anybody," "nobody really talks about it," "it's not like a fun topic...after it happened to me then I hear every story," and "I felt like I really just wanted, I don't know, someone that I knew to come up and say that it had happened to them...but I didn't ever have that."

Unfortunately, for these mothers, not knowing about stillbirths before their babies died caused fear, confusion, anger, self-doubt, blame, and the feeling of being blindsided. They also felt a strong lack of understanding and questioned why this loss could have happened. They used phrases like, "Why is this happening", "it doesn't make sense", "out of my understanding", "didn't even understand it," "we didn't know what happened," "what did I do?" "outside my realm of possibility," and "how is it that I don't have a live baby inside of me?" In Ana's case, she still had to wait over two weeks to deliver Lona's twin sister Maxine alive. She described her experience:

I was really scared, you know, that her heart was gonna [sic] stop beating. You know, there was no answer. You know, there was no explanation. So, it felt like, anything terrible could happen at any minute, you know. There was just no control. It didn't matter what you did, anything could happen...

Doctors did not have any answers that could help ease Ana's mind while she waited out the days until Maxine and Lona were born.

*Doctors do not know why stillbirths happen*

After Lona was born, the doctors did not suggest an autopsy because, as Ana told me, they said "with a lot of authority and certainty it was something with the umbilical cord."

However, doctors did not provide the answer as to why there was a problem with the umbilical cord in the first place. Every OB and perinatologist Ana has seen since Lona died has told her medical science knows very little about umbilical cords. She further said:

What I've learned from this experience is that doctors don't know, you know? There's a lot that they know and a lot that they are great at and -- but there's -- I mean, it's foolish to put all of your trust that your doctor knows everything.

The remaining three mothers' babies had autopsies, yet the women still had the impression that the doctors did not have answers.

In speaking about Walker's autopsy, Ashley explained that even with an official cause of death, they still said it was inconclusive. She laughed as if to emphasize that it is both silly and mystifying that the medical community seemed not to have answers. She laughed ironically about Walker's premature closure of the ductus venosus, then shook her head and stated the perinatologists do not normally see these occurrences. The ductus venosus is a valve in the liver that normally closes a week after birth, but if it closes in utero, it will cause death (Meyer, 1996). It is rare. Doctors do not know why it happens, and they cannot predict it. They told Ashley there was no existing research on the issue. As I listened to her, I sensed that shaking her head and laughing helped her avoid total anger and frustration. She recounted her doctor's explanation of Walker's death as comparable to getting hit by lightning; she said she felt "jaded and cynical"

towards her doctor for her lack of knowledge which seemed to provide an excuse to be distant and uncaring.

Even after receiving an official cause of death, the mothers found their questions unanswered. Adam's autopsy was "sort of inconclusive," Keli explained although there were some clots in the cord. She told me her doctors do not know why he died. Doctors told Trameela her daughter was wrapped in her umbilical cord, yet there was an unexplained thinning in the umbilical cord as well. I greatly admired these mothers' ability to have an autopsy performed. Within hours after delivering my son Isaiah, nurses asked if we wanted to have an autopsy performed. I had just given birth to my beautiful baby boy, and I had not spent nearly enough time holding him. Yet, they wanted to know if we were fine with having him cut into pieces – not to mention we would have to foot the bill for the few hundred dollar autopsy fee. As much as I wanted to know why he died, it was too soon to make that decision, so we declined. My doctor later told me that my placenta was "as large as the largest" she had seen in her 20 year career, but according to pathology studies, it seemed to have functioned normally. She also said unconvincingly that they thought Isaiah's death was a cord accident. Perhaps in providing me with a reason for his death my doctor intended to give me peace, but it did not. She also assured me it was rare, that cord accidents are a fluke and that statistically it would never happen again. Later, I found out that most undetermined stillbirths are ruled a "cord accident" for the fetal death certificate. However, I have also heard some women tell me about their disproportionate amount of bad statistics during their pregnancies, including stories of multiple cord accidents. Being provided a probable cause of death as a consolation does not answer the hard, specific questions.

Doctors may not have those hard fast answers. Many doctors are still not fully educated about stillbirths. In fall, 2012 a practicing OB, also a professor at the University of Washington, School of Medicine (UWSOM), explained that stillbirth has never been a part of the UWSOM obstetrician and family practice medical training. He added that the students receive no training in scientific, physiological, or psychosocial support facts of stillbirth, yet as physicians in their field, it is the “worst thing” they encounter. Fortunately, with the collaboration of GAPPS and parents from SBSL, he hopes to implement more training in all aspects of stillbirth (SBSL, 2012b, p. 3).

Furthermore, the silence surrounding stillbirths does not encourage doctors and researchers to advocate for stillbirth research funding. Yet, recently available research does exist, and there are answers available to roughly 50% of stillbirths, proving that when funding was made available, stillbirth researchers leapt at the chance to study its root causes (GAPPS, 2013). Keli mentioned that doctors have researched and currently test for multiple congenital diseases in case the mother would like to terminate a pregnancy, “and [doctors] tell you about all these risks, like you can have a, you know, baby with all of these diseases, but they don’t tell you, ‘But you might not have a baby that's alive,’ and that's not right.” Although it apparently remains an uncomfortable topic for doctors, further investing in research to find answers may reduce the stigma for physicians and families of stillborn babies while finding preventative measures (Kelley & Trinidad, 2012).

### **Existence of knowledge and awareness**

Mothers who talked about feeling blindsided and the silence surrounding the topic of stillbirth also said that previous knowledge of stillbirth may have been helpful. Three of the women wished they had known about the potential for stillbirth before, and Ana looked at it



from both sides. She thought it would have scared her, yet it would not have prepared her for its shock. Still, knowing would have been helpful when it came to making decisions in the hospital, and navigating customs and rituals. The mothers considered having previous knowledge as beneficial in three general ways:

- To possibly prevent a stillbirth from happening.
- To provide knowledge on how to navigate social norms and rituals.
- To reduce stigma for stillbirth families.

Ana explained that knowing the risks might have helped her pay closer attention to the “weird movement” she felt. She also wondered if a specialist who knew more about twin pregnancy risks might have realized early on that she was contracting, and one of her babies had stopped moving. Trameela approached the topic like a medical professional; and stated that previous knowledge of stillbirth and existing protocols would have helped her pay attention to changes in her pregnancy and also would have helped her decide what actions to take if she was concerned.

Even if previous knowledge does not lead to prevention, hearing about stillbirth, including the stories of other stillbirth mothers, would help all pregnant women know what to do after their baby dies. In terms of ritual, an existing social knowledge of stillbirth would have helped some mothers feel they had “permission” to parent their stillborn baby. They thought hearing about the rituals of others would have reduced their regrets and minimized the struggle with decisions about (a) photographing their dead baby; (b) holding their baby in the hospital; (c) inviting family to see the baby; (d) deciding whether to have the baby cremated or buried; (e) deciding whether or not to hold a memorial service and whom to invite; (f) and giving

themselves permission to engage in grieving rituals. Ana explained that without previously knowing of stillbirth, the social worker and nurses did help her think through possible actions:

You might want to have pictures with your baby. You might – you're going to want to hold your baby. You might want your friends and family to meet your baby. You might want to plan a memorial. It's okay to plan a memorial service. You know, we didn't know any of those things.

Knowledge would also create general societal awareness and social norms surrounding stillbirths. For the mothers, knowing about stillbirth beforehand would have helped them navigate their life after a stillbirth. They felt that other people should be more aware. Mothers wanted people to know it is always acceptable to talk about their baby, and to say the baby's name. Ana said she "trained" people to talk about Lona even though Lona is still not real to them. Keli felt societal awareness would prevent others from thinking stillbirth such a "weird" thing to happen. Mothers need to mourn their baby, but a common lack of awareness around stillbirth caused others to invalidate their experience and push these moms to heal or get "over it."

These four mothers agree that general stillbirth knowledge and awareness as well as sharing personal stories are important to reduce stigma of "fault", "guilt" or of stillbirth as an anomalous pregnancy outcome. Keli wished she had known that stillbirth can happen even if the mother does everything right, and that it is not her fault. Also, general awareness might reduce isolation and loneliness by helping people in society better care for their friends, family, and neighbors when it does happen rather than treat them like they have "the plague" as Keli explained.

Ashley paused before her eyes darted down and away to explain that stillbirth was something she “could *not* [emphasis hers] imagine happening” to her. She put her hand on her chin, took an even longer pause, then distantly looked across the room while she spoke, “I don’t understand how anybody ever survives it. And then, there you are... you just don’t have a choice.” Her face changed, and her back straightened in her seat as she looked me in the eyes saying how people tell her she is so strong. The look in her eyes actually showed that strength, as did her touch of anger: “And it makes me want to smack them and it’s like, I would not – I don’t want to be this strong. I- It’s not about being strong. You just – you just, you know, time just keeps passing.” She later said that hearing of her church friend’s experiencing a stillbirth helped her in the “teeniest way” because she remembered that the woman had survived it. To have watched other women walk through a stillbirth can provide hope. Additionally, removing the shroud of silence surrounding stillbirth will increase supporting conversation, help relate women’s stories, plus increase awareness, and further knowledge.

#### **“After”**

*“In life After, none of the books you read during that time you now call Before will matter. No words written down in black and white could have readied you for the moment you discovered that your child died before he took his first breath. There is no way to prepare someone for the long months of bottomless sorrow that will fill every moment of every day. No one can describe or explain the emptiness that follows the death of your baby.” (Williams, 2010, p. 3)*

As I sat at my desk piled high with research texts and coffee cups to write about life after a stillbirth, it was difficult to decide which mother I wanted to present first. Some of Keli’s words about creating awareness were powerful, but Ana spoke a lot of sadness which was, by

far, the most common code in life after stillbirth. More than the other mothers, Trameela easily focused on moving forward, and helping other women cope when their baby dies. However, the fact is that I am simply having a hard time writing today. I cannot seem to pull myself together. Tomorrow my son would be five years old.

Every year I see July barreling down on me like a freight train. Except that first year, of course, I never did see that coming. But each year after, July looms ahead of me, intimidating me, and I fear it. I get anxious and scared. I worry that it will come, but then I worry that it will go too soon. I worry that it will hurt me more than I can handle, and I worry that I will not hurt enough. I stress about celebrating, and I stress about celebrating wrongly. I let myself completely freak out in July. I am irrational, I cry, I weep even. I sulk, I am difficult, I am pensive, and I am selfish. Then, each year when it comes, it is gentler than I expected; and when it is gone, I am sad to see it go.

This year, however, I kept my head down. I knew the train would come, but I had to keep my head down to survive everything else pulling at my attention. I am a wife and a mother to two living little girls, the oldest of whom just turned two years old. I am a board member of the Stillborn Still Loved guild, and I am a student. My son is missing in our family, but my life after his death is still full. I do not have time to freak out, do not have time to be selfish, and do not have time to be sad that I cannot be selfish. I will undoubtedly feel like I have done it wrong this year.

This year, with my head down, I easily lived through the beginning of July. Last year it was uncharted territory, and I could not fathom creating space to celebrate Isaiah ten days after Paige's first birthday. I wondered if other people would care about him after we celebrated her, and I worried that the joy of celebrating her would leave no space for my loving him which is all

tangled up in grieving him. However, after all the stress I found out I still had time to be selfish, and I still had time to celebrate my son. This year I knew we could do both and still come out ok, so I kept my clarity through it all, sailed through Paige's second birthday party, and even added in Quinn's baby dedication at church.

This year, as July came around, I had buried my head in the stories of four other beautiful babies and their mothers who miss them like I miss mine. I have spent my days picking apart each facet of their stories, and retelling each detail in a way that honors their lives while speaking of the need to honor other "still" lives. I wrote of their children, and I wrote about my son. As I wrote about Isaiah in light of Walker, Lona, Adam, and Kyndle, I remembered feelings and details put away in a journal in the drawer of my nightstand to be taken out, maybe, one day, when I write a book. I typed up moments of pain, sorrow and confusion; all the while I kept it in the compartment of my life I call my "Thesis."

I looked up last night. The full moon shining brilliantly into my bedroom window shined brightly like the light of a train. Suddenly, the train hit me hard and late. In a second I became anxious, and felt like I was about to throw up. I became irrational and worried. I woke my husband from a near sleep and tried to chat it out, but then hid myself under the covers while my tears streamed down my face. When that did not help, I asked for a hug and wept with sudden wracking sobs. July is here, and July is almost over. Five years ago today I found out he was dead. Almost exactly 5 years ago – it was this hour of the day. How do I get up and climb back in my thesis box after feeling like I have been hit by a train?

Now two days later, I realize that my life after is much like those of the women who shared their stories. They told me of overwhelming sadness; guilt and self-doubt; trying to remember and honor their child; and life moving forward. Every year they have their own

version of this train wreck. Holidays, anniversaries and birthdays are difficult for mothers like us, and most significant, the baby's birthday is extremely difficult. We do not have the luxury of going through the year as we once had, celebrating in the same way as we had "before." The calendar looks different to someone whose baby is missing from every event, and we, ourselves, are different as well.

The Christmas decorations in Ashley's house were a poignant reminder that life keeps moving after the death of a baby. Life does not stop when someone you love dies, and the world keeps celebrating even when you do not feel up to it. When I had arrived, Ashley pointed out the Walker's hand-sewn stocking over the mantle; it matched the others. Her beautiful tree in the corner covered with antique glass ornaments, was very well suited to my artist friend, Ashley. She dabbed at her eyes, looked down, and told me that she had everything in life except her baby. Then, all of a sudden, we looked up to see her Christmas tree come crashing down from my left side onto the camera before it landed on the coffee table directly between us.

We propped the tree back up in the corner for Tyler to secure later and swept the glass into a corner. As the camera started rolling again, Ashley laughed saying, "Where were we?!" The tree falling brought a brief levity to our conversation, and even though we could not laugh with most people, we easily laughed together because we each knew that the other person would not assume that our ability to laugh was a sign that we had gotten over our sons' deaths. Despite our laughter, the sincerity in her story remained, and just as quickly as the tree fell, she described how she felt looking backwards:

I think the main thing is feeling almost – uh, what's the word? Almost betrayed or just disillusioned, I think. I don't know if I'll ever be - I know I'll never be like that again, like that's my old self, you know. And so, I see pictures of myself, you know, knowing that it

was just before, like Walker dying is like that marker in the time before and after where everything changed. So, I think I - when I see a picture of myself and I know it was you know, June of 2009, just sort of takes my breath away that makes me feel a little - I don't know, betrayed, but also like I miss that person, kind of this longing for that, and this longing for when I still had him, when he was still alive, so just kind of - so very much a bitter-sweetness.

When she spoke of missing herself, she half-smiled with bittersweet nostalgia matching her words.

In my conversations with Ashley, Ana, Keli, and Trameela, I learned how their lives after their babies' deaths were marked in many ways. Some of the more dominant codes in the theme of "After", I have grouped into sub-themes, and have listed in descending order of frequency:

1. Sadness and grief
2. Distance from former self
3. Regret, guilt, and self-doubt
4. Living v. stillborn children
5. Missing, remembering and honoring their baby
6. Reaching out / awareness.

### **Sadness and grief**

Sadness and grief were the most common codes in life "After." Each of the four women demonstrated sadness to varying degrees. However, they also verbalized the sadness they had experienced immediately, then as the shock wore off, next in the months and years of early grieving, and the continued ongoing sadness. Some of their early sadness related to the moments they found out their babies had died, their labor and delivery, and telling others about their

babies' deaths. Ana said that in the early days after Lona's death, it was awful to think about being unaware of the moment when Lona died. She added, "... and I didn't know it... that she might have had pain, [Ana crying] or that she may have needed me, and I was selfishly trying to sleep, you know, and to get in a comfortable [position]." She said she experienced so much sadness with Lona's death that she does not have room in her life to be sad about other things:

... After this happened to me, I don't have a lot of capacity for pain. I feel like I'm kind of full. And, I mean, like I can't bother to go to a movie that's going to be sad if I know that it's going to be sad. I don't have any extra space for sad.

The mothers also talked about the continued effects of sadness. While some of the mothers still had a hard time talking about their babies without crying, others worried about the effect their sadness might have on living children.

Ashley told me that "loving [Walker] means grieving him." She also stated that, "People want grief to be this linear process where it gets easier and easier and easier... and that's not how it is...some days it feels like just as bad as it felt that first week." The grief caused by a stillbirth is a "disenfranchised grief" stemming from an "ambiguous loss" (Bergman, 1999; Cacciatore, DeFrain & Jones, 2008). Mothers found they were grieving their babies and the loss of the hopes they had for life with them. They grieved the person they had been before their stillbirths occurred, and the lives they had lived before. In some cases, the mother grieved that she was the only person who knew the baby while he or she was alive. Like Ashley, mothers also struggled with letting go of sadness when it came to being a parent of a dead baby. People encouraged them to "get back to normal" or "heal." Yet, because the love of their babies was so closely tied to their sadness, they could not let go of the sadness without feeling that they loved their babies less or that they were less than a good parent to those babies.



Ana spoke of the role that sadness plays in changing the suffering parents:

Well [Lona's death] definitely changed who Jason and I are. I mean, we're definitely not, I mean, we're not the same people for sure. And I think... I don't want to say we're not as happy, but we're not as innocent, or maybe, I don't know... I mean, there's a mark of sadness, I think in our life for sure, and there's something missing.

### **Distance from former self**

Three of the four moms mentioned in a number of ways that they were different now, and that life was different now since their babies had died. Ashley explained that people try to find the "old me" in her, but her whole life has been affected. She said, "I mean it's impacted my life completely... I just feel different about everything. I don't feel like I'm the same person, and I'm not waiting for myself to go back to being that same person." Ashley further explained that she felt she "should be different" after Walker died. She said that being different was the only thing that felt right. She stated, "I want to be different. I mean, I want Walker's life to be impactful enough, to matter enough." Keli told me she realized that in life after a stillbirth she "could not be fixed." She also explained how her son Adam's death changed her:

[His death] completely turned [my life] upside down, sideways. I'm not the same person.

I would say, before, I was more outgoing, you know, more - I don't know, out there.

Now, I'm not as outgoing and more closed off...- it's too much work to, you know, explain what's happened [to new people].

Although Trameela did not speak of being different, she mentioned how she was not back to normal yet. Hearing her, I wondered if the facts that she had so few people in her life who shared their story of stillbirth with her, that she did not participate in a support group, and that her daughter's death was relatively recent, all played a part in her uncommon expectation of

getting back to normal. She did not consider when we spoke that she would probably never be “back to normal.” Much of the literature written about baby-loss discusses parents finding a “new normal.” Mothers and fathers learn to accept that they are now parents of a dead child while they also create a life that feels normal to them within that reality (Ash, 2004; Atlas, 2010). I have found this “new normal” true. The person I am now after my son died is different from the person I was before he died, and it has taken five years to start to feel like I fit in my skin again - to start feeling “normal” in a way that fits my life now.

### **Regret, guilt and self-doubt**

Each of the four mothers mentioned regret, guilt and self-doubt; and each of the feelings emerged with equal frequency throughout the four stories. Some of the mother’s regrets related to their pregnancy. They felt they should have advocated better for themselves during pregnancy, should have listened better during informative classes, should have been more vocal, should have seen a specialist, or should have taken better precautions while pregnant. Ana stated that she had “a lot of regrets of not standing up when I felt like something was wrong.” Other regrets related to the customs and rituals after the baby was delivered. Although these regrets pertain to life and activities that occurred soon after the baby was delivered, some hold lasting repercussions.

Ashley said:

The regret I actually could’ve done something about is just having our family come and see him. It would’ve made him that much more real to them. And I just hate that I took that from them - that my parents and my husband’s parents didn’t get to see their – their grandson.

Other mothers regretted later trying to rush their grief and trying to ignore the initial feelings, ones that persist to this day.

Each mother still experienced guilt. For three of the four mothers, the stillbirth occurred during their first pregnancy, or the first time they passed the first trimester in a pregnancy, and they felt guilty for not knowing the signs of an abnormal pregnancy. Some of the other things they felt guilty about during pregnancy included: (a) eating potentially harmful foods unknowingly, (b) taking hot baths, (c) drinking a daily cup of coffee, (d) walking stairs every day, (e) working too hard, and (f) not helping their baby when he or she was in distress. They also felt guilty for not calling the doctor sooner when they were concerned. Mothers' guilt stems from being the baby's lifeline and caretaker. They did not knowingly cause harm to their babies, and the causes of death given to each mother did not indicate the mothers' actions causes their babies' deaths. However, each continued to feel somewhat responsible for their baby's death.

The four mothers still feel responsible as a parent to their babies even in death, and they continue to feel guilt for some of their current actions. Ana told me that she felt like she does not "do enough to remember [Lona]." She had been feeling guilty lately about not being a better parent to Lona by honoring her memory. She also spoke to the guilt associated with answering a question that is extremely difficult for most stillbirth parents, "Answering the question of how many kids you have is really hard. And, sometimes I answer it right; and sometimes I take an easy way and say I'm not going to upset people."

Guilt and self-doubt were often spoken of together. The mothers assumed fault and wondered if something they did caused their babies deaths. The mothers' used questions such as "What did I do?" "Why didn't I know?" "What could I have done differently?" and "What-ifs and if-onlys?" Keli commented, "I beat myself up for a long time. What did I do? What could I have done differently?" Trameela told me, "...Looking back, I wonder if I could have done something different. I question... I question like the fact that my pregnancy was so good, and it

was so just awesome and amazing, like is that the reason? You know, like I'm looking for reasons why this happened.” For the three mothers who had subsequent children, anxiety and worry reigned throughout those later pregnancies.

It is possible that knowing more about stillbirth, the causes and preventions, as well as customs parents generally engage in when their baby is stillborn, could have prevented much of the constant guilt and self-doubt mothers experienced. If the stillbirth were prevented in the first place, obviously, they would not have their babies' death to feel guilt about, and even if they had been more aware about stillbirth in the eventuality of it's happening, they would not automatically assume fault for the death. Also, they would not face the stigma of other people who sometimes act as if it was possibly the mother's fault. I have encountered numerous women in support groups who heard other people in their lives tell them that they did not rest enough, did not eat well enough, and they did not pray enough to prevent their babies' stillbirths. A general awareness debunking the mystique of stillbirth, the fact that it is common, and the causes are rarely a mother's fault would guard mothers against such negative, inaccurate and possibly superstitious comments.

### **Living children v. stillborn babies**

After their babies were stillborn, the mothers compared their dead babies with living children. Often this comparison defended their babies who had died. Keli cannot talk about Adam with some people she knows because in their minds, he was not a real baby. She added, “He came into the world, but he didn't take his first breath. So somehow to other people, that doesn't count as much.” Trameela commented that Kyndle was still her first child, and “she was loved, she was wanted.” Ashley and Ana both had their own living children to compare with. Ashley told me how her love of Walker was just like loving her other children and followed

with, “I mean, I’m so grateful that I’m his mom.” In Ana’s unique case, the child whom people often compare to Lona is Lona’s twin Maxine. She said, “I don’t like always, the association of Maxine equals happy, and Lona equals sad because Lona brought us a lot of joy—a lot of joy!”

### **Missing, parenting, remembering and honoring**

All four mothers talked of their babies as real girls and boys who lived before birth and died, rather than thinking of their babies as fetuses. They also talked about missing their babies. While I was with Ana, her husband Jason stopped at home along with the kids, Maxine and Roman, to grab some presents before heading off to another child’s birthday party. Coincidentally, Maxine happened to be weaving in and out of the video hovering close to her mother’s chair while Ana told me that Lona was as real as Maxine. Jason stood behind me on the opposite side of the room as Ana, intently watching her face while he listened. Maxine settled on the right arm of the chair as Ana told me how she missed Lona now:

I feel like that’s what we’re missing, you know, that person in our life, that actual person at the table who says something funny or, tells us about her day, or you know. We’re missing all of that life. We’re missing her in our life.

Maxine and Lona were identical twins. At that moment, with vivid clarity, I saw the absence of an identical girl who should be leaning on the left arm of the chair. Instead there was a void in my video shot to Ana’s side where Lona would have been. Jason could not keep quiet. He jumped into our conversation to mention a recent instance when Maxine had been playing with a friend. He said:

... That should be our night every night is [sic] the two of them just giggling, laughing, inseparable, just reading each other’s minds and thoughts and laughing and just

absolutely, like just hearing that all the whole time. And then instead, you know, we – she just plays by herself and, you know, we play with her, but it’s just – yeah.

In their house, even the sounds of Lona are missing from their family life.

The mothers described feelings of longing for their babies, wishing they were here, wishing things were different, wishing that they were mothers to the correct number of living kids and also imagining the baby were alive. Three of the moms talked about imagining the living babies by either pretending to shop for clothes in the size they might be had they lived, pretending that their babies rode in the backseat while they were driving down the road, and, in Ana’s case, imagining that her living child’s friend was actually the twin who had died. Ana said, “I had an awful lot of games like that I would play with myself and let myself be happy for a minute before I came back to the truth.” Some of the imagined parenting might stem from the real need these mothers still felt to parent their deceased children.

Finding ways to include the stillborn baby into their family life was very important. The mothers try to remember and honor their babies in different ways, and perhaps the greatest way has been in openly talking about them.

### **Increasing awareness and reaching out**

A positive byproduct of their losses is that each mother has now sincerely endeavored to increase awareness about stillbirth and reach out to other people experiencing a similar grief. I did not specifically ask each mother if she wanted to increase stillbirth awareness or help others, but at the end of each conversation, I asked if there was anything else they would like to say. Each mother felt it important to say they wanted to increase stillbirth awareness and/or outreach.

Earlier in our conversation, Keli stated that she knew the frequency of stillbirth because she had already worked in creating awareness. She did not want other people to say they didn’t

know it could happen to them, and she wanted better treatment of women who have experienced a stillbirth. As our conversation was ending, I asked Keli if there was anything else she would like to people to know; she said she wanted people to know that stillbirth is a “crappy” thing to have happen, but that there are other people who have experienced it. She emphasized that by saying, “You are not alone. If this happens to you, you’re not alone...” She reiterated that she wanted to create awareness to reduce the stigma of stillbirth in our society.

Trameela said that after her daughter’s stillbirth she was more aware of others, and she wanted to reach out to help other people experiencing the silence and isolation of a stillbirth. She said:

I just really want to reach out and do more for others because it's not talked about, and I felt like a lot of people were in the same situation that I was in where they had no idea and then it kind of - it happens to them.

Trameela also expressed her interest to provide other people hope that life will move on and to demonstrate to them through her relationship with God that life can move forward.

At one point, Ana said she was more sensitive to other people’s grief now, and was more willing and equipped to support friends. Then at the end of the conversation, she reminded me of the laminated flower signs posted on hospital doors for mothers of dead babies; the signs are a warning that a baby has died, there for hospital staff members who enter a maternity floor room. She said, “I kind of wish I could wear that all the time...” so she could tell everyone her baby died and then ended by saying:

I wish people – I wish everybody knew and would be sensitive to it. I don’t know. I mean, I guess that’s part of, you know, the objective with everything that is being done at

Stillborn Still Loved, but I don't know. I just kind of wish that, every time I meet somebody that doesn't know, I want them to know.

She also wanted other people to know it is alright to talk about a stillborn baby, to ask questions, and to say his or her name. Ana wanted people to be aware of the words they say to women about their children. Someone told Ana her family was "perfect" because she now has a girl, Maxine, and a boy, Roman. It was an awful thing to say. In her opinion, her family would be perfect only with Lona in it, too.

Ashley said the least about outreach and awareness. However, her final thoughts were that she wanted Walker's life to have impact. In 2010, at the time of our conversation, neither of us knew that she, Keli, and I would later found the Stillborn Still Loved guild together whose mission is to "Honor the lives of stillborn babies through advocacy, awareness, and support" (SBSL, 2012a). We three also participated in the SBSL funded, collaborative video project created with GAPPS, called "Born in Silence" (Silverstein and Associates, 2012). It is a video made for the sole purpose of creating awareness and starting a conversation about stillbirth. It has already been used in multiple women's health conferences, used by the National Institute of Health, and was chosen as Cinema Corner finalist at the 2013 Women Deliver global conference to be shared with a global audience. As guild president, Ashley currently spends much time working to create stillbirth awareness and outreach opportunities.

All four women decided that the status quo of silence surrounding stillbirths in American culture today was not acceptable. Continued silence about stillbirth perpetuates a lack of knowledge that may further allow stillbirths to occur to unsuspecting mothers. Silence also creates painful scenarios for grieving mothers.



## Sharing Stories

*“But that’s the thing about losing a child to stillbirth: our stories are all more similar than they are different... Those of us who have lost children at birth or just before or just after are a more closely related family, I think, both because of the nature of the loss, and how little the loss is spoken of by people who haven’t been through it... You can’t do anything for a stillborn child except know and acknowledge that he or she existed. We have nothing to give each other but our stories.” (McCracken, 2010, p. xv)*

### Stories as healing

The purpose of this research project was to glean information from stillbirth mothers through their stories and also to assess how story sharing could further awareness and advocacy efforts. Thus, the final theme discovered in these four conversations is that of story sharing. Although I did not ask the mothers specifically about story sharing, they spoke of the aspect of shared stories of stillbirths. Story sharing was seen as beneficial in terms of helping grief and helping women through a subsequent pregnancy after a stillbirth. However, not sharing was seen as difficult. Some mothers even felt there were times when they had to withhold their stories, and not being able to share stories made grieving hard. Overall, not hearing other stories was harmful to the mothers. Sharing stories means sharing awareness.

Ashley was the only mother who had heard part of someone’s stillbirth story, a church friend, and she appreciated the memory of that story when Walker’s stillbirth occurred. Keli looked for people to talk to after her son Adam died. She wanted someone she really knew well to tell her of their own stillbirth experience, but that never happened. The only people who “came out of the woodwork” were people she did not know well enough to share her story.

Trameela wished that people were more open to telling and listening to stories of stillbirth. She also said that learning through other people's stories gave her hope.

The other stories helped the new stillbirth moms to learn from mothers who had grieved before them and who still loved their children. Stories helped them see what life might be like during a subsequent and fear-filled pregnancy. Keli was "stunned" by her friends Charlie and Amy when she met them at a Parent Support memorial walk. Their son, Aiden, was stillborn exactly one year before Adam. They already had a new baby, Dylan. Keli could not imagine having another baby after Adam, and she was "scared as hell" her entire next pregnancy, but it was the act of sharing stories with Charlie and Amy that helped her through. She was able to talk with them through that pregnancy and ask if they had experienced similar worries with Dylan.

At Lona's memorial service, Ana and Jason shared a letter they had written about Lona. Ana explained, "We wanted her life that she had, even if it was just in our dreams, to be shared with our friends and family. And, we wanted her to be real - as she was to us - to other people." Yet, after settling back into regular life, she found over time, she did not go anywhere that people did not know her story. After joining a Program for Early Parenting Support (PEPS) group, she was obligated to introduce herself:

I burst into tears because at that point I had not told my story to anybody because everybody I knew, knew my story. And, I didn't go to the grocery store, I didn't go any place where people didn't already know my story because I didn't want to have to see the lady at the grocery store who knew I was having twins, because we told everybody, we couldn't keep anything to our self [sic]. I couldn't go to the grocery store; I didn't want to go to get coffee. I mean, I didn't leave the house. I didn't go anywhere. So, I was really in a cocoon. I mean, the only people I saw were people who knew my story.

Four years later, Ana does not isolate herself from people who do not know her story of Lona. She chooses when she will share with new people in her life, yet she admitted that even if it is a double-standard, she is “wholly injured and angry” if someone else omits Lona from the story of her family.

Mothers expressed discomfort, even fear, that they should not share their story with others. They did not know if it was “appropriate” to talk about their babies and thought that their stillborn babies did not really “count” to other people. They thought they would upset people with their story yet then felt silenced when they did not share. Sometimes they still wanted to share, but felt it was “too much work” to go through the difficulty of sharing with people who may not understand, care, or even remember it later. Keli reflected that she felt she does not tell her story because some people act as if Adam does not count, so she feels that she can talk only about her living son. Ana said:

I don't know how to tell them, and I don't know that it's appropriate to tell them, you know, but I just want – as much as anybody knows that I have two kids -- I want them to know that I have three.

Three of the mothers connected their loneliness and isolation to not hearing and not sharing stories. Even if hearing someone else's story could not have prevented a stillbirth, they still might not have felt as alone, blind-sided, and angry when it happened to them.

### **Badges**

Before the writing portion of this project began, while the transcriptions were still in progress, I spent hours one day in a local coffee shop watching and listening to the interviews again to write down final field notes and thoughts of our talks together. As each mother shared what was on her heart, powerful words poured from her vulnerability. While I was watching

Ana's video, I found myself crying through it again, but not nearly as much as the first time we spoke. I heard my daughter Paige's favorite song 'Ho Hey' come on the speakers in the coffee shop, and it made me smile through my tears. I paused the video and removed my headphones to listen. I was sorrowful for the sadness in their stories, but I wanted to remember, to appreciate the beauty and joy of each child. I found myself so drained that as the song ended, I closed my computer a little early to go home and hug my girls.

Later that evening I happened to be meeting with the Dead Babies Club. We are a group of six mothers who met through our support group, and that is what we call ourselves. We used to get together every month, and now it happens a few times a year. We are all so busy. I miss those ladies. I do not think I have had dinner with them since we went to one of Tom Douglas' restaurants, Lola, in downtown Seattle about a year and a half ago. I have not even seen a couple of them since then. Even as we sat in the dining room of the Rainier Club, 75 floors above a gorgeous Seattle summer skyline, it was so grounding to talk to them. It did not matter where we were; our time together was real life. Not dining in a fancy restaurant. Not the work for advocacy through Stillborn Still Loved. Not the trying to be my new self in life with the people who knew the old me, but *that*, spending time with these women who get it all. I felt a complete sense of belonging and relaxation. Every story we told about our living children did not seem like a sacrifice of not mentioning the dead child, and every time we laughed did not feel like betrayal of our truest selves. When we talked about our dead children, we had no need to explain, qualify, defend, or feel misunderstood. It was easy. We already knew and cherished each other's stories.

At one point Katy mentioned that she felt so emotional when she recently connected, on two separate occasions, with two separate parents of two different dead babies. One of those connections came about because of her tattoo showing AJ's and Hazel's footprints, all four feet.

I was so jealous. Her nurses had captured great footprints of her twins. It hit me in that moment that tattoos are the badges Ana spoke of at the end of her story. I had just finished listening to her story again that afternoon in the coffee shop, and she had said she wanted to wear a badge that gave her permission to talk about Lona. Our tattoos are our badges. My tattoo is my badge.

Later I asked the four mothers in this project about having tattoos of their babies.

Ashley's skin was unmarked at the time of our conversation, but she now has a beautiful, lightly etched profile of Walker's face surrounded by an angel wing on her right forearm. His name is scripted underneath. She chose that part of her body because that is where his head lay when she held him. When I asked her why she got her tattoo and what it meant to her, she said it meant she is a changed person, that Walker is her son, and he is always with her. Keli's tattoo on her calf means that she has been marked and forever changed by Adam. Trameela still wants a tattoo for Kyndle, but she has waited because she felt a friend of hers hijacked her grief and her story by tattooing Kyndle's name on her own body. In time, she hopes to have a tattoo of either Kyndle's handprints or footprints. Ana told me she chose not to get a tattoo; instead, she wears her Lona necklace. However, her husband Jason now has a tattoo on his arm of the last line in an untitled poem by Gregory Orr which was read at Lona's memorial service, "Turn me into song, sing me awake." He is glad to talk about Lona to anyone who asks him about it.

Mothers are forever marked by their babies' lives and deaths. Their tattoos are badges that tell everybody they have been changed, and the tattoos give them opportunities to share their stories. In Katy's case, it brought much needed connection to isolated parents, early in their grief, who needed to make a connection with another stillbirth family. For me, and mothers in this project who have tattoos, it creates opportunity to reach out to others and for others to reach out to us. Story sharing is healing for the mothers and could be powerfully used to create awareness.

## Literature Review

### Stillbirth as an Epidemic

Stillbirth as an epidemic is finally catching the attention of scientists, physicians, international health advocates and organizations. I find it unbelievable that for so long stillbirth was ignored as a global maternal fetal health issue. However, recently, a group of 69 authors from over 18 different countries and 50 organizations finally collaborated to analyze the problem of stillbirth worldwide; and to create an international call to action to help reduce the number of annual stillbirths (Lawn & Kinney, 2011, p. 2). An estimated 3.2 million babies worldwide are stillborn every year, which equals an average of 8,760 daily stillbirths, and approximately 25,000 annual stillbirths occur in the US alone equaling an average of 70 daily stillbirths (CDC, 2009; Kelley & Trinidad, 2012; Lawn et al., 2009; Stanton, Lawn, Rahman, Wilczynska-Ketende & Hill, 2006). Some sources quote the US annual number as high as 30,000. Regardless, at minimum, one baby every 21 minutes is stillborn in the US (Silverstein and Associates, 2012).

Nevertheless, current estimations are assumed to be low. Global data is low partially because fewer than 5% of the world's births occur in countries that use vital registration (Lawn et al., 2010, p.2), but also because the collected stillbirth data is inconsistent (Lawn et al., 2011). Only 2% of the world's stillbirths are actually counted through vital statistics (Lawn et al., 2010, p.1). Even in the US, stillbirth counting varies from state to state.

Stillbirth as an epidemic has been invisible in global policy; and was never included in the Millennium Development Goals (MGD) despite the fact that stillbirth greatly impacts worldwide efforts to reduce the rates of child mortality under 5 years old and maternal mortality counted in MGD's 4 & 5 (Bhutta et al., 2011; Lawn et al., 2010, p.2; Stanton et al., 2006). In the US alone, stillbirth affects almost ten times the number of babies each year as SIDS, yet due to

grassroots parent advocacy organizations, SIDS is commonly recognized as a health issue, whereas stillbirth is not (CDC, 2009). If roughly 3 million babies are dying before birth every year, why does it not gain more attention? Why are people not talking about it? Improper counting may be a root cause of the silence around stillbirth.

First, there is no firm definition of what constitutes a stillbirth. Stunned a few years back, I learned that the definition of stillbirth varies around the world and across the US. In Washington State where I live, stillbirth is considered the death of a fetus after 20 weeks gestation, whereas other states may have chosen a later gestation time to define stillbirth. Some countries define a stillbirth as a fetus who is born dead at 20 weeks, others define it at 22 weeks, and according to the World Health Organization (WHO), a stillbirth has occurred when a fetus is born dead after 28 weeks gestation (Lawn et al., 2010, p. 9, Lawn et al., 2011).

My son was born dead at 29.5 weeks gestation; and by that time, I had known for weeks – if not months – exactly what time he woke up every day, what music made him kick, and what music made him wiggle. To learn that had he been delivered a week and a half earlier, the WHO would have considered him a miscarriage made me feel sick. We would not have been allowed to bury him. I emailed the author in a journal article about the shocking disparity. According to Cynthia Stanton, a professor at John's Hopkins in the Bloomberg School of Public Health and a stillbirth researcher, the WHO determined that in some countries, a baby is viable from 20 weeks, and in other parts of the world, a baby is viable after 28 weeks (C. Stanton, November 15, 2010, personal communication). The differences in counting vary due to the population's accessibility to interventions in the event that a baby is born prematurely (Lawn et al., 2010, Lawn et al., 2011, Bhutta et al., 2011). Our ability as humankind to intervene with medical care

does not determine the natural developmental growth rate of a fetus, yet it determines how a baby's life is counted.

Second, overall, little is understood about what causes stillbirths. Many stillbirths go unexplained due to under-investigation and “inadequate attempts to determine the cause of death” (Flenady et al., 2011b; Silver, 2007, p. 161). After so many years of figuratively sweeping the issue of stillbirth under the rug, and literally whisking away newly stillborn babies unseen by their mothers, as was common practice in the US up until the past few decades, and in order to gain a better knowledge, doctors and health officials cannot ignore stillborn babies any longer. Gaining knowledge will require validation of the babies' deaths. It will also require improvements to be made in systematic perinatal audits and investigations, as well as post-mortem investigative protocols – including placental histopathology and high-quality autopsy (Flenady et al., 2011b). These exams are not currently performed on a regular basis, and when they are, unfortunately, parents may be asked to bear the burden of post-mortem investigation costs.

Finally, where data has been tracked, there is little comparability between data sets because even when stillbirth has been defined by a standard gestation period, there are still over 30 different classification systems encompassing 37 different causes (Lawn et al., 2010, p.12; C. Rubens, personal communication, March 5, 2012). The variety of classifications can seem “baffling,” and they hinder progress when scientists and physicians try to compare causes for the sake of finding prevention measures (Mullan & Horton, 2011).

According to Cacciatore et al. (2008), all of these factors contribute to a sense of “ambiguity” since many stillbirths, even after autopsy, have undetermined causes. Even within the US medical community, stillbirth as a clinical issue is “cloaked in obscurities” and is not



discussed as an epidemic due to the pervading sentiment that stillbirths are unavoidable (Cacciatore et al., 2008, p. 5). As a result, according to Silver et al. (2007), in the article titled, *Workup of stillbirth: review of the evidence*, stillbirth “remains an important, largely unstudied, and poignant problem in obstetrics” (p. 433). Seemingly intimidated by what they do not understand, the medical community rarely legitimizes the babies’ deaths, there is a “sense of invisibility,” and parents are left with “no tangible signs of parenthood” (Cacciatore et al., 2008, p. 5). Yet, mothers who have experienced the death of a baby are often isolated while plagued with shame and chronic guilt (Barr & Cacciatore, 2007). Similar to the mothers in this project who previously thought stillbirths were antiquated, in this day of routine medical miracles, the continued existence of stillbirth seems like an anachronism.

### **Medical Experience and Medical Caregivers**

Ashley, Ana, Trameela and Keli all felt shocked and blind-sided when their babies died. According to Kelley and Trinidad (2012) in *Silence loss and the clinical encounter: Parents’ and physicians’ experiences of stillbirth – a qualitative analysis*, despite the prevalence of stillbirth it commonly remains an unexpected event. Parent participants in multiple focus groups believed it was a rare event that happened to other people. Like Keli, women who experienced a high-risk pregnancy were not warned of the risk of stillbirth. Physicians in a separate focus group also stated stillbirth was an “unexpected outcome,” and they were surprised when presented with current stillbirth rates in the US. The physicians also mistakenly believed that “stillbirth primarily affects women in developing countries” (2012, p. 3).

Despite that mothers of stillborn infants refer to them as dead babies, physicians commonly refer to stillbirth as “fetal demise” which shows a disconnect between the patient and physician experience (Kelley & Trinidad, 2012). Physicians stated they are uncomfortable

talking about stillbirth (2012; Silver, 2007). They commented that they choose not to use the word “stillbirth” with patients because it “scares people” (2012, p.4). However, when physicians choose not to talk about stillbirth beforehand, it leaves pregnant mothers unaware of risks, and using terms like “fetal demise” after a stillbirth only invalidates the mothers’ strong feelings that her baby just died. Consequently, the women in Dr. Kelley’s focus group study felt the entire medical experience from beginning to end was generally “confusing and shocking,” and they felt caregivers were uncomfortable and uncommunicative (p.4). The physicians felt ill-equipped to handle the patients, and were perceived by mothers as having a “code of silence,” while the nurses were seen as a “saving grace” (2012, p.4). Physicians thought that their medical training did not cover stillbirth well and that more information on the prevalence and causes would help them better interact with patients (2012). Delivering a stillborn baby is a relatively common occurrence for physicians in the US, and it necessitates further training (2012; Gold, Kuznia, & Hayward, 2008; Silver, 2007).

In this project five women in all, myself included, each delivered a stillborn baby at a total of four different hospitals, yet each experienced a unique type of care. Their experiences, whether good or bad, are then too reliant on the specific people who cared for them. Some hospitals provide training in neonatal death, but protocols vary from one hospital to another. Improved curriculum in medical schools and obstetric training programs could have a profound impact on parents’ experiences (Kelley & Trinidad, 2012).

In addition, physicians’ continued education on current research findings is imperative. Just as the four mothers in this project explained, accurately assigning a cause of death is seen as extremely important to mothers. An accurate cause of death is known to aid in counseling parents of stillborn babies, and it might ease some of the mother’s guilt surrounding the baby’s

death (Dudley et al., 2010; Silver, 2007). When women go through a subsequent pregnancy following a stillbirth, they feel anxious, emotional, and sometimes crazy. Their physician having accurately explained why their baby died will help them provide the mother with sound medical and emotional care during that time (Silver, 2007). Furthermore, as medical caregivers openly brave the topic of stillbirth, they have an amazing opportunity to help reverse its stigma in our society, and when parents continue to share their stories they will help caregivers understand what interventions are most helpful during pregnancies (2012).

### **Stillbirth within the US Culture**

Silence, stigma, and social taboo are words that pervade literature about the effects of stillbirth on mothers in Western culture (Cacciatore, 2009; DeFrain, 1986; Godel, 2007; Kelley & Trinidad, 2012; St. John, Cooke & Goopy, 2006). In many cultures women are alienated after a stillbirth, but in U.S. culture specifically, women feel like stillbirth is treated as a non-event (Cacciatore, 2010; DeFrain, 1986; Kelley, personal communication, May 20, 2012). The experience of the four mothers in this project is not unique. Like many other women, each of them crave caring, compassionate support, acknowledgement of their grief, and validation; but instead they face a lack of support, invalidation of their babies' identities, a rush to get over their grief, and intense feelings of regret and guilt (Cacciatore, 2010; Cacciatore et al., 2008; DeFrain, 1986; Kelley & Trinidad, 2012). A lack of support and validation by society is a common experience stretching beyond the bounds of the four conversations with Ashley, Keli, Trameela and Ana. Cacciatore (2007) stated, symptoms of grieving mothers are "exacerbated by a lack of responsiveness from society at large" (p. 72).

In terms of grief, according to Bregman (1999) in *Beyond silence and denial*, naming a death as a loss and allowing mourning as a personal coming to terms with loss, is not linked to

the presence of actual bereavement practices. Instead allowing people to mourn a loss is linked to culturally sanctioned public meanings for that loss (1999, p. 104). Yet stillbirth still has no public meaning. Bregman described grief for this type of loss as a “disenfranchised grief” where the grief is not legitimized by society, family or possibly the mourner (p. 111). Stillbirth mothers often feel their experience is invalidated by society, and in some cases, mothers in turn downplay their own experience trying to minimize their grief. Cacciatore, Schnebley and Froen (2009) argued that there is a “social discrepancy” for legitimizing grief of a live-born versus a stillborn child (p. 168). If their child were born and took one breath, society would validate him or her regardless his/her untimely death.

Government systems reinforce this fact. In many states, stillborn babies, regardless of their gestation, do not receive a birth certificate because they were born dead. This invalidation is difficult for the parents. The parents hear the conflicting message that they must bury or cremate their baby – which requires a death certificate, but a birth certificate of any kind, validating the delivery of their baby, will not be issued. Their child’s birth is not counted; thus, their child does not count. For example, a baby born dead at 42 weeks gestation in the state of Washington will never receive a birth certificate, while a baby delivered at 20 weeks gestation, which took one breath and died, will receive a birth certificate. One baby counts while the other does not. While it may seem trivial to outsiders, it plays a part in how society validates the life of that baby and the experience of the mother. Mothers want their babies’ lives to count. They want a certificate stating the baby’s name, birthdate, time of birth, weight and length. They do not want a state issued certificate, similar to the one I received in the mail, stating “fetal demise,” which I have stuffed away in a file never to see again. According to Jutel, as quoted in Cacciatore and Bushfield (2008), for the mother who wanted and loved her stillborn baby “denying fetal

personhood simultaneously denies maternity by creating the childless mother” (p. 385). The identity of her baby and her identity as a mother are both invalidated. Fortunately, due to recent grassroots activism efforts, in the past few years a number of states have started issuing, upon a mother’s request, a Certificate of Birth Resulting in Stillbirth (CBRS) (MISS, n.d.).

At some point stillbirth mothers will realize that they have given birth to death, and American culture stigmatizes women for the babies’ deaths rather than validating them for giving birth. After my son died, I kept a journal to write out his story. At one point in the weeks after he died on September 3, 2008, I wrote:

*“It messes with your head for everyone to be so somber when you’re in the hospital birth center... for the lights to be low, silence in the room, sad visitors...it’s not supposed to be that way. Getting dressed in the hospital bed and sitting in the bed – getting ready for the long haul of giving birth to death... I GAVE BIRTH TO DEATH.”*

On one hand, the act of giving birth to any baby feels like the most natural thing a woman might do, yet on the other hand, it feels completely unnatural for that baby to be born dead (Jones, 2001). Mothers need inclusion and comfort rather than isolation.

The fact that mothers have given birth to death also causes physical and emotional difficulties that go unrecognized (Cacciatore, 2007; Cacciatore & Bushfield, 2008; DeFrain, 1986; Cacciatore et al., 2008). Many mothers feel (a) like time has stopped, (b) they feel out of body sensations, (c) insomnia, (d) hypersomnia, (e) gastro-intestinal disorders, (f) headaches, (g) changes in brain chemistry, (h) memory impairment, (i) aching arms, and (j) hallucinations like “phantom crying”; in addition, amongst many emotions they experience shame, guilt, sadness, and anger (Cacciatore et al., 2008). While mothers’ bodies recover from childbirth acting as if it

would have a baby to nurture, the absence of a baby leads others to invalidate her experience by treating the mother as if she has not delivered a baby at all (Cacciatore, 2010).

Rather than receiving much needed support and compassionate care, mothers who were recently given regular attention in society for being pregnant, soon after delivery experience feelings of disenfranchisement and social isolation (Cacciatore, 2010; Cacciatore et al., 2008; St. John et al., 2006). Consequently, once mothers feel stigmatized, they will often isolate themselves because they sense other people do not understand (Cacciatore et al., 2008). Ashley, Ana and Keli spoke of the same thing many mothers experience either initially or over time, which was the absence of support from friends and “deterioration” of relationships when they reach out (Cacciatore et al., 2009, p. 169). In some cases, family support is lacking because the baby goes unrecognized as a family member (Cacciatore et al., 2008; Cacciatore et al., 2009). Worse still, are people who hear of a stillborn child and may think that child was not real or hold the opinion that the child did not really count (Cacciatore et al., 2008). Sadly, this was a concern of all four women in this project.

These attitudes of confusion, ambiguity, obscurity, invisibility, and silence extend into the greater society. On February 29, 2012, Anne Kingston, wrote an online magazine article titled, “Are we over-sharing lost pregnancies? Devastated by perinatal deaths, parents reach out in sometimes disturbingly public ways.” Kingston (2012), wrote of one family’s black and white photo of their 25 week stillborn daughter posted on their personal blog as “fetus fetishization” (para. 4). Kingston explained how she saw a societal trend moving from “stigma and silence to over-sharing” and further stated that sending a birth announcement for a full-term stillborn would be “confusing and disturbing” since an actual birth hadn’t occurred’ (2012, Para 6). To her I would say that, contrary to her opinion, not enough stories have been shared for her to

understand that a baby was born, loved, and wanted; that the parents must be proud to share their child with others. Kingston's perspective in society perpetuates a sense of taboo and stigma which hinders awareness. Lack of awareness hinders advocacy efforts for research into the causes of stillbirth, and it prevents society in general from learning to comfort others after a loss. It also prevents the establishment of social norms which make it acceptable for mothers to share their stories and receive much needed support.

Research shows there are benefits to mothers sharing their stories, and I have currently found no research stating that over-sharing is a negative issue. In fact, the benefits of support provided by either individuals or a group help mitigate negative feelings when people are free to share their stories (Cacciatore, 2007). One study showed that every participant (47 total) stated their identity had significantly changed because of their baby's stillbirth (Cacciatore, 2007). The same study indicated that time did not improve the mothers' abilities to cope with their grief and stress; however, mothers who were "well-connected to others sharing their experiences" developed coping skills as they learned to live each as a different person (Cacciatore, 2007, p. 84). The mothers in this project all described being a different person from who they had been before the stillbirth and, in some ways, finding their new normal; they also talked about sharing their stories as beneficial as life moved forward. However, not only does the act of sharing their personal stories help the mothers in their grief, it also helps their family units function as a whole (Cacciatore, 2012; Cacciatore et al., 2009). Furthermore, sharing benefits physicians as they process their own grief of losing a baby in their care (Gold et al., 2008).

Even though knowing what to do in the hospital can be very confusing, rituals and artifacts are extremely important to stillbirth mothers and a means to further story-sharing. Mothers who spend time holding their baby after birth see lower levels of anxiety and depression

later on, and many wish they had engaged in “more ritualistic contact” with their babies (Cacciatore, 2010; Cacciatore & Bushfield, 2008; Cacciatore, Radestad, & Froen, 2008). In addition, after the delivery, they cherish the few artifacts that validate their babies once existed (Cacciatore, 2010; Cacciatore & Bushfield, 2008).

Godel (2007) explained in her article titled, “Images of stillbirth: memory, mourning, memorial,” that although few rites for stillborn babies exist, perhaps a cause of long-standing social denial of stillbirth, some practices may be changing, and mothers are encouraged in hospitals to gather mementos and artifacts because images, artifacts and narratives help keep a family from disintegration (2007). By validating the baby’s existence, artifacts may give the baby status in the family and a place in society, in turn giving parents permission to share their stories; sometimes the pictures and stories also give the parents a place in society as the parent of a stillborn child (2007). So, while stillbirth taboo still exists, Godel states that efforts are being made to change rituals surrounding stillbirths (2007).

### **Stillbirth Prevention**

Until recently, invisibility has led to inaction, and the stillbirth rate has remained unacceptably high (SCRN, 2012; Stanton et al., 2006). New global research efforts will hopefully determine effective interventions to prevent them from occurring (Dudley et al., 2010; GAPPS, 2013). Initial research showed that of the estimated 3.2 million annual stillbirths worldwide, one million babies die after the onset of labor, and up to 62% of these late stillbirths – 620,000 stillbirths –are avoidable with better maternal care, quicker responses to complications, and reducing the time it takes women to seek care (Lawn et al., 2010, p.13). Also, many of the stillbirths that occur in the US are preventable (Flenady et al. 2011b). In a wealthy country like the US, where advanced medical care and sophisticated medical technologies are



prevalent, access to healthcare should not determine whether women experience an avoidable stillbirth (Sen, 1999). Unfortunately, when women are unaware that it could happen to them, they will not seek access to superior medical care when they have concerns in pregnancy. Fully addressing the issue of stillbirth advocacy requires our attention through increasing risk-factor awareness at the “community, health-care provider, and policy levels” and through ensuring women access to the best medical resources in their community (Flenady et al., 2011b, p. 11; Flenady et al., 2011a).

### **Discussion**

This information cannot reach to global experiences in stillbirth, but it can influence research and action in the US and in the western world. Still, I am aware of ongoing research gathering in African cultures which also assesses the cultural and personal impact of stillbirths in their communities (GAPPS, 2013). Thus far, from that research, women’s stories also emerged about the love they have for their stillborn children, and the cultural stigma of stillbirth they suffer in their communities (Kelley, personal communication, May 20, 2012). Primarily in this project, the stories of four mothers, one researcher/mother, and recent research all speak to the current suffering and marginalization experienced by mothers of stillborn babies. Similar to the trauma parents experience with SIDS, and in terms of social justice, the issue of stillbirth prevention and compassionate care for grieving mothers is decidedly a woman’s health issue physically, mentally, and emotionally (Cacciatore & Bushfield, 2008). A focus on stillbirth awareness will help alleviate suffering.

### **A Christian Response to Stillbirth**

As a researcher, my bias is that unborn babies have value and that their mothers’ suffering is valid. While all do not hold my belief, I encourage and support advocating for

stillbirth research, awareness, and social change. Some people may believe that the primary importance of stillbirth advocacy is the desire to spare the parents pain, but that would be short-sighted. Ultimately, I fully believe the parents of stillborn children grieve deeply because they know their children had value. As a Christian, I am certain these children have value because they are “fearfully and wonderfully” made by God in his image, and He has known them since conception (Psalm 139, NIV). He also loves his children which, in turn, gives them an inherent worth from conception onward (Wolterstorff, 2008). Ultimately, only God is the author of all life, yet is it just to passively allow preventable death and the suffering that ensues? Is it just to invalidate the worth of God-given life by disregarding the suffering of mothers whose babies are stillborn? Is it just to care more about alleviating the deaths of babies after they leave the womb? Put bluntly, babies die stillborn, and others are suffering because of it. What is the Christian response to stillbirth as a public health concern?

After my son Isaiah died, my husband and I experienced an outpouring of compassion through cards and flowers. In the first few weeks, we felt cared for by friends, family, and a previous church community. Unfortunately, it seemed that was the greatest extent of their compassion, and we noticed many friends were not comfortable offering any compassion at all. Our American culture does not have a lot of room for mourning and grieving rituals for any death, even less for the stillborn.

Most painful for me was realizing that our church community did not differ from our secular community in their response to our child’s death. In fact, feeling compelled by their faith to say something “helpful,” some church members often seemed to offer us hopeful platitudes about seeing Isaiah in heaven, or prayers that left us feeling misunderstood and even uncared for. They referred us to a real hope in eternity that was not really helpful in caring for us as newly

bereaved parents who wanted our baby here on earth. There was a disconnect between our pain and their response. After Isaiah was stillborn, we changed our church “home” three times in as many years. Each time we left knowing real relationships with our church family were too difficult once they heard we were parents of a dead baby. We tried to communicate openly with others around us, but often experienced a total lack of response, leading us to feel isolated even from our church community. Inside church and out, our life’s reality was a relationship killer.

For years, I struggled with this kind of response and wondered why it made me so angry. I felt detached from God, church, and most Christians I knew. I wondered if I was missing something completely in my faith and felt disappointed by other Christians. I am not the only one. Although one of the mothers in my research found comfort in God, two of the other mothers have stopped going to church since their baby died, and the fourth mother, as a non-Christian, has not found the advice of Christian believers helpful. Compassionate Christian friends made up such a small percentage of the Christians who “cared” for me. They differed so little from my non-Christian compassionate friends in the way they cared for me that I felt their faith must not be the determiner of their caring hearts.

I knew the Christians offering me simple platitudes were absolutely affected by the American culture around them and that their comments of hope in God were biblically true. Yet through much reading, I concurred that what they were offering as a compassionate response came from a focus on the not-yet kingdom of God, so extreme in fact that it left no room for mourning or suffering in the wake of tragedy. They were not offering compassion in the already, every day, human kingdom of God. Not only that, but they cared very little about the fact that many babies are stillborn every day.

L. Serene Jones, theologian and author of “Hope deferred: Theological reflections on reproductive loss” (2001) noted that in North American culture reproductive loss is still addressed in clinical terms, and that this is particularly true in mainline Protestant churches where “one might expect there to be powerful resources for reflecting on the character of such loss in the lives of women...” (p. 228). Jones was struck by the absence of these reflections and from her perspective; Christians have not offered a cultural response that differs at all from that of secular society. While Jones (2001) stated that “eschatology has often been used (wrongly so) as a facile palliative for those who mourn” she also wondered if “it [is] faithful or even helpful for infertile women to imagine they have children in heaven?” (p. 240). Their identity has been shattered, yet Christian responses even to that loss are incongruent.

For many years, there has been a Christian emphasis on hope and victory in which Bregman (1999) noted, “the church seemed to conspire with American society as a whole to deny both death and a space for grief” (p. 121). Although hope and victory in death are theologically true, it’s not wrong to mourn. Bregman also stated, “The dead person may be on track for the resurrection, but if so, those who survive still face a real loss” (p. 121). Maybe it is because of this long-term focus on our personal death and eternal life that Christians have not considered how to care for the grieving. There is a place for mourners at the foot of the cross; and according to Bregman, it’s a Christian “responsibility... to contribute to our society’s fragile yet emergent ability to say something real about dying and loss... no message that negates the reality of loss, that avoids rather than encompasses pain, can really work in the long run” (1999, p. 176).

Again, pointing towards an eschatological hope when someone is in desperate need of compassionate (meaning “to suffer with”) care, can be like trying to pass out tracts to starving

people in Africa. The person's physical needs are not being met. Suffering and grief are very real for Christians regardless of the eternal hope they know to be true. In the book, *A grief observed*, C.S. Lewis (1963) noted:

If a mother is mourning not for what she has lost but for what her dead child has lost, it is a comfort to believe that the child has not lost the end for which it was created. And it is a comfort to believe that she herself, in losing her chief or only natural happiness, has not lost a greater thing, that she may still hope to "glorify God and enjoy Him forever." A comfort to the God-aimed spirit within her. But not to her motherhood. (p. 29)

Even Christian mothers of deceased children sense a tension of knowing their children are in heaven, yet still wanting to care for them. In the case of stillbirth mothers, suffering is also very physical and emotional with the added burdens of stigma, guilt, and incessant questions of "what if?"

The not-yet kingdom of God calls for hope in spending eternity with our child, yet the already-kingdom of God allows for pain and human suffering where others have an opportunity to extend the compassion of Christ (see Appendix B). Many Christians do not want to acknowledge today that suffering and joy, grief and hope can all co-exist (Smith, 2010). Just like the four women in this research experienced, one of the most difficult displays of love and compassion is walking with someone else in their suffering, yet that is also how we may best show the love of God to them (Palmer, 2000). God has a heart of compassion plus the unique ability to identify with a mother's pain when her child has died (See Appendix B). When people are suffering, they may not seek God, but desperately need His compassionate love which He entrusts us to extend.

God can use suffering, grief and pain to refine us and grow us in ways that would have been unlikely beforehand. Joy and hope may even break into our lives to point to the not-yet kingdom where there will be no more suffering. Wolterstorff (1987) commented that as “aching visionaries,” it is the mourners who ache for others in their pain because they realize more keenly that the already-kingdom of God is not complete (p. 86). In these four women’s experiences, it was other suffering parents of stillborn babies who were the greatest comfort, and now, in turn, the four mothers seek to help others. Christians who identify with suffering, who can genuinely listen and offer support have a unique opportunity to extend God’s compassion.

However, as caring Christians, what should we do while we wait and hope? We should neither live our entire life mourning for ourselves and others in the already kingdom of God, biding our time until eternity, nor put on a cheery face to focus on the eternal joy that is yet to come while denying real pain. The better choice is to live our lives balancing genuine grief and sorrow with authentic joy and hope, as aching visionaries seeking the shalom of God’s people in the cities where he has placed us (Jeremiah 29:7, HNV).

This is a call to an active posture of offering even more than sympathy and encouragement. The meaning of shalom is much more than peace, but also “completeness, soundness, welfare, in good health” (Shalom, 2001). Advocacy and research efforts fall under the umbrella of seeking the shalom of the God’s people. The gospel of Christ is unlimited. It is holistic and relevant when we choose to apply it to all different situations (Perkins, 1982, p. 21, 27). In *Encounter God in the city: Onramps to personal and community transformation*, White (2006) claimed Christian leaders in the West were rediscovering that “we can wholeheartedly commit ourselves to Christ-motivated social action combined with the proclamation of the gospel without feeling we are somehow abandoning the ‘real’ gospel for a ‘social’ gospel”

(p.119). White (2006) also stated that transformation in a community “means development of shalom” (p. 126). What will shalom look like when transforming a community’s culture of silence around stillbirth and replacing it with awareness that causes prevention and compassionate care for families?

In seeking the well-being, peace and wholeness of shalom for mothers in a relevant way, we are not resigning ourselves to help after the fact – one very large aspect of a compassionate response – but also to proactively prevent suffering in the first place. After investigating the intense pain, isolation, silence, and suffering that stillbirth parents commonly experience, our society must develop a more compassionate shalom-seeking response to help find ways to stop preventable stillbirths so that fewer parents would suffer the loss of their children. Seeking the shalom of God’s people regarding stillbirths is two-fold: compassionate care for suffering as well as advocacy and research efforts towards prevention.

In terms of compassion care for the suffering, Bregman (1999) discussed that focusing on the whole person provides meaning-making for the dying patient, family, and culture. But when one of those persons is a stillborn baby, families and sometimes parents do not even acknowledge the whole person. However, the strength of Christians who believe, in general, is that the lives of babies living in the womb have value. They can provide a Godly compassion, speak of the whole person, and validate the child’s life. Mothers want their babies' lives to count, and they want their baby’s name to be spoken. They want the life, brief as it is, of their children to be valued. It doesn’t eradicate suffering, but validating the life of the baby makes their death more “natural” in society; natural deaths lead to receiving recognition and support; and it helps alleviate much of the depression and anxiety mothers suffer due to isolation (Bregman, 1999; Cacciatore et al., 2009). Many mothers, like Ashley, Ana, Trameela and Keli want to speak out

in compassion themselves to tell others that “it happens” so that others gain awareness, help, and support to help prevent a similar death. A key word in caring for the whole person, as Bregman stated, is prevention.

In terms of prevention, the mother and baby are two separate people, so it is important to look at what medical science and others can do to prevent the death or suffering of both. This means investing in medical research and technologies that improve maternal healthcare. We work to cure or treat chronic diseases such as AIDS, malaria and TB, so why not stillbirth? Jesus did not come to bring programs as a solution; he brought comfort and healing (White, 2011). Healing is for both the body and soul which means working towards prevention while also talking to people about the not-yet kingdom of God. It is an opportunity to care for people in His name, to comfort sufferers in His name, to speak to them about an eternal hope and to prevent further suffering. When we do so, we demonstrate the compassion and love of Christ, who restored Lazarus from death to life because he understood the suffering of Mary and Martha (see Appendix B). This concept shows living in the tension between the already and not yet. Christians have a unique opportunity to lead the way towards such relevant, cultural change.

### **Moving forward**

To change the hearts of a culture that remains passive and unconcerned about the issue of stillbirth, people must break the silence. Most stillbirths happen where awareness is low, so increased awareness is the “catalyst” for personal change (Mehendra et al., n.d.; Miles & Wright, 2003, p. 87). Edwards and Sen (2000) argued that inner-personal change and outer-social change are intrinsically linked, adding that, “It is rarely possible to generate sustainable changes in human behavior simply by altering the rules and institutions that govern our lives. The missing ingredient is personal change which acts as the wellspring of change in all other areas” (p. 609).



In the case of stillbirth, inner personal transformation is essential to inspire compassion, as well as motivation towards the outer-social change that will impact cultural responses and prevention work.

Speaking the stories of stillbirth puts faces to the unseen stillborn babies. Mothers' stories are powerful, influential, and telling of a tragedy so commonly cloaked in silence. Sharing these narratives will create awareness that will call for a culture change which validates the stillborn babies' lives and deaths as well as the suffering experienced by mothers, fathers, families, friends, and medical caregivers. Giving mothers a voice will remove them from the margins of society, de-stigmatize them, help them to engage in rituals, and further establish more widely accepted social norms.

Sharing personal stories helps when others come to value the mother and the baby, thereby creating space for true dialogue. According to Harris and Wasilewski (2004), when we interact with each other in true dialogue, we come to a better understanding of each other – it allows people to be heard equally. “It’s not enough to simply give voice.... One has to actually be listened to and heard” (2004, p. 10). Mothers in this project experienced times when they have tried to share their story, but felt that people did not hear them, understand, think their baby was real, or at times even choose to respond. However, a true exchange where mothers are free to speak openly and people are truly hearing what they say will create opportunity for awareness and culture change. Engaging in what Martin Buber (1966) calls “genuine dialogue” will foster deeper relationship because it affirms personhood – in the case of stillbirth for both the mother and the baby (p. 122, 105). Sharing personal stories and engaging in true dialogue with others will provide opportunities for relational politics (2004). Thus, sharing stories through advocacy efforts has a strong chance to lead to viable prevention.

Advocacy is not merely for the political platforms any longer. In reality, “advocacy” is as simple as the act of supporting a cause (Advocacy, 2012). Now, it is also often practiced on a relational and social platform. Freidman (2007) stated, “This kind of activism is now so easy, so cheap, so readily available to even the smallest player...the Web provides a global platform and global audience (p. 492). This new kind of social advocacy connects with people in seemingly personal ways and shared stories. If we want to change hearts and motivate those hearts to change policy for funding and prevention, then an advocate does not need to be in politics. An advocate merely needs to be aware of the issues, interested in the issues, and willing to talk about them with others. Advocates seek change-making.

According to Cacciatore (2009), to break the silence around stillbirth, we need to “help women find their voices” and help them share their stories (p. 93; Cacciatore, 2007). Sharing statistics will take the issue only so far. Numbers and facts do not convey personal value. Personal stories add value to the statistics. Identifying and valuing the uniqueness of babies who were born still is essential to creating an “ethos of care” required in leadership for change-making (Harris & Wasilewski, 2004). Valuing the babies’ lives will place more value on the mother’s loss which in turn will validate spending resources on prevention and compassionate care.

Changing our culture around stillbirth by legitimizing the experience will ultimately give momentum to prevention efforts. Change will take radical means. We must challenge the status quo of assuming stillbirths are unavoidable, unpreventable, and invisible. Like Paul Farmer trying to give a voice to the voiceless of Haiti through relational medicine and boldly challenging a deeply entrenched status quo, I seek transformation through relational medicine and stillbirth advocacy (Kidder, p. 73, 44).

In 2009, according to Melinda Gates, one of the greatest challenges in the way of achieving Millennium Development Goals 4 & 5 is that too little is known about the causes and prevention of stillbirth (The Gates Foundation, 2009). If the work of international development goals focusing on reducing child mortality and increasing maternal health fails to value three million babies and nearly as many mothers each year, then caring, effective dialogue has not been taking place. Someday, I hope not to hear the words, “Nobody ever talks about it.”

### **Conclusion**

A focus on stillbirth awareness told through shared stories – and aimed at both prevention and compassionate care – could help alleviate the suffering that families endure after bearing a stillborn child. Moreover, Christians, as well as the medical community have a unique opportunity to lead the way in culture change by offering appropriate responses to women who suffer stillbirth, by recognizing the stillborn child as God’s precious son or daughter, and also by advocating for stillbirth prevention. Advocacy, Christian or secular, medical or social, opens hearts and minds to the stories of the stillborn; it builds knowledge and understanding and recognizes compassion; ultimately, it has the power to create inner personal change which will lead to societal and policy changes.

To develop this thesis project, I present the personal narratives of four brave mothers, one researcher/mother, and current literature both medical and professional to argue that the silence of stillbirth is unacceptable. Themes from the personal narratives prove that a mother’s entire identity as a mother is shaken when her baby is stillborn, and the life she had “Before” her baby died will never be the same: she may have held no prior knowledge of the fact of stillbirth, she loses a “future” built and bonded in her heart as well as in her body, she may receive only mediocre psychological care from medical professionals, and she and her family bear the silence

that accompanies such a tragedy, This silence surrounding stillbirth creates painful and possibly avoidable pregnancy outcomes as well as ongoing stigma after the death of a baby. Regardless of the pain involved, each mother still cherishes her stillborn baby plus the reality of his or her short life. Each mother has a voice to tell her child's story and strive to create awareness.

The numbers of stillbirths worldwide are inconceivably high, and so far, statistics have not created a strong reaction to fund more research efforts, to change medical education curricula, to inform medical protocols, and to create an informed, compassionate cultural response which respects the life and death of stillborn babies as well as the mothers' trauma. As Bateson (1994) astutely reminds us, "Our species thinks in metaphors and learns through stories." The personal narratives, the faces and families of those involved, will help add the required research value to the flat statistics: it is people who suffer, who can learn to alleviate this suffering, and who also fund and take on the research necessary in this case.

As Christians, we have a challenge to act in humility, follow the Holy Spirit, and emulate the compassionate heart of Jesus Christ and the God who stands in solidarity with women after the loss of their children. We can help alleviate some of their pain by simply listening to their stories, by caring about their suffering and about the real lives of their babies. We can choose to stand in the gap for the stillborn, to communicate their stories, to say we are not okay with allowing preventable deaths of precious babies. We can break the silence. Thus, as aching visionaries, we can share the compassion of a loving God. Even more, we point others to the not-yet kingdom of God in which will exist no more suffering the death of a child.

It is time to remove the burden of stillbirth prevention, guilt, stigma, suffering and continued silence from stillbirth mothers. In compassion and advocacy, it is time to give voices to the mothers grieving in silence. It is time to give voices to their motherhood, and it is time to

tell the stories of their babies – to say we care about the lives and deaths of their children, we care about their motherhood, and we will no longer accept the often unexplained, silent, yearly death of nearly 4 million babies. It is time to learn through their stories. Let the stories begin.

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### **Appendix A: Thesis Interview Questions**

1. What is your story?
2. How did you feel about your pregnancy before the stillbirth?
3. How do you feel about your pregnancy after the stillbirth?
4. What did you know about stillbirth before your pregnancy?
5. Did you know of people who have had stillborn children?
6. Do you know to what extent stillbirths occur in the world?
7. How has your previous knowledge of stillbirth affected your experience?
8. Is there anything you wish you had known before that you know now?
9. How do you feel about the medical care you received?
10. Do you know why your baby died?
11. Do you know if anything could be done to prevent it from happening?
12. Have you gotten support and how do you feel about the support you have/have not been given?  

Do you feel they were able to understand?

How do they feel about your child?
13. Did you make funeral arrangements?
14. Do you have any regrets?
15. How do you feel about your fetus/child now?
16. Do you see yourself as a mother?
17. How has this impacted your life?
18. Is there anything else you want other people to know?

### **Appendix B: Theological Perspectives for Stillbirth**

In my struggle through grieving the death of Isaiah, living in North American culture, and spending time in Christian circles, I was often confused by some of the messages I received from others or from the lack of response that felt contrary to the heart of God in the Bible. I found it difficult to separate the actions of God's people from the His own heart. Although I rationally know that God and His people don't always reflect the same heart, it does feel like an affront when His people so poorly reflect His heart. How does His body of believers so grossly miss the mark sometimes? It is clear to me now through the journey of this project that apart from directly reading the Bible, I gained a deeper understanding of God's presence in the midst of the grief experienced by stillbirth parents like me, when I looked at theological ideas about God which are based on Scriptures, rather than looking at the actions of his imperfect people.

Christian theology surrounding death doesn't support the all too common silence and pithy statements stillbirth mothers often receive in the midst of grief. Just as Angie Smith (2010) found the ability to balance both sorrow and joy, it is a fact that both feelings are appropriate in the grieving Christian. Death is part of God's plan, but nothing can separate us from his love. Bregman (1999) offered:

The choice is not between mourning or resurrection, sorrow or joy, Good Friday or Easter. Christian faith is complex, rich and realistic enough to encompass a lot of these dimensions. I am sure that Christians intuitively recognize this, yet I believe it needs to be affirmed clearly. There is a time to mourn, there is also a time to rejoice. (p. 184)

Several theological perspectives below helped shape my understanding of God's possible responses to the pain and suffering of stillbirth in his already-kingdom. These perspectives include Angie Smith's study on the understanding and compassion of Christ, L. Serene Jone's

thoughts on the Trinitarian view of God's solidarity with a mother in the death of a child, and Nicholas Wolterstorff's ideas on suffering as pointing to the not-yet kingdom of God.

### **The Understanding and Compassion of Jesus**

During the months following her daughter's death, Angie Smith (2010) delved into the Bible to find indications of God's compassion for grievers. John 11 provides an insight into God's truly compassionate heart for the mourners suffering death of a loved one. This Scripture demonstrates that even Jesus, knowing the hope that was to come, became angry after the death of his friend Lazarus (Smith, 2010). The emotion he felt was described in the Greek as "embrimaomai" which can be translated as his being angry in his spirit and deeply troubled (2010, p. 91). Scholars suggest that he was angry at death itself (2010, p. 91).

In addition, when reading that Lazarus' sisters Mary and Martha are crying, it may seem that Jesus is crying along with the women, yet Jesus was weeping while Mary and Martha were wailing. Smith (2010) suggested that in John 11:34 when Jesus wept ("dakyro" in the Greek), that he was weeping out of empathy for Mary and Martha who were wailing ("klaio") over the death of their brother (p. 91-92). He knew there was hope for Lazarus after death and even that he would restore Lazarus from death to life, but Jesus felt anger and deep sadness at death and the pain it caused others. Smith (2010) stated it is a "conscious, daily choice to experience dakyro, the sadness that allows one to grieve with the expectation of redemption" (p. 92). In Jesus' example, we see that anger and sadness are valid responses to death, even a death with hope of eternity, and also that compassion for others is the willingness to suffer with them rather than invalidating their sorrow. As God in human form, Jesus lived in the already and felt the sting of death rather than pretending the not-yet kingdom had already come. According to Bregman (1999), Christians ought to recognize grief and invest in compassion care. Our



Christian witness to death's meaning can speak to salvation, redemption, and hope in the transition into eternity with Jesus; yet all of these responses ought to come from a place of compassion.

### **Trinitarian View on Solidarity**

Jones (2001) offered a unique theological perspective by suggesting the trinity as a view of God that could comfort and provide understanding to a mother in her grief. It is an "image of God 'standing with' the woman ravaged by grief at the loss of hoped-for children" (p. 240). This story of God shows His redemptive love for creation extending to all persons – even women deeply grieving reproductive loss – and Jones showed a perspective on the classical view of the Trinity that indicates "solidarity" with women specifically grieving this loss (p. 241-2). God in Trinitarian form held death within himself when Jesus died on the cross, and it is reminiscent of the image of a woman who has held death within her body without dying herself. One of the aspects of reproductive loss and specifically stillbirth that can be so painful is the idea of giving birth to death. Jones commented, it is a "portrait of suffering that is painfully unique," that while the mother's womb is a deathbed to her child, she lives (p. 236).

In Jones' Trinitarian perspective of God's solidarity, when Jesus is crucified, God's own child dies (2001). God sent his child bearing the hope of eternal love, and it becomes a death of hope that people who see Jesus will believe. "It is the death of a possibility that has never been, the possibility of true human community" (p. 242). God in Trinitarian form not only experiences a death within himself but also the death of hope that this child would bring community on earth. Jones (2001) wrote:

The poetic move here is not to identify these women with God or vice versa, but rather to suggest a morphological space within which they might imagine God's solidarity... [it] won't stop their sorrow but it might lessen their sense of isolation. (p. 242)

It is rare to find theological perspectives on reproductive loss and Jones' thoughts on God's understanding of the unique suffering that comes with giving birth to death serve to remind us that God's understanding truly has no limit (Psalm 147:5, NIV).

### **Suffering as Pointing to the Not-Yet**

The suffering brought by death and grief is incredibly painful, yet one with hope. It is a human experience in which humans in the already-kingdom of God rightly experience the pain, anger and sorrow over the death of their loved one; yet it also serves to create desire for the God-promised kingdom that is to come. After the death of his son, theologian and author, Nicholas Wolterstorff (1987) wondered why Jesus would list mourners as those who are blessed in the Kingdom of God (Matt 5, NIV), yet in Wolterstorff's personal experience, he became keenly aware that as a mourner, he better understood hoping for the not-yet kingdom of God than he had understood in the past. In *Lament for a Son*, he stated (1987), "Mourners are those who have caught a glimpse of God's new day, who ache with all their being for that day's coming" (p. 85). In Matthew 5, Jesus acknowledged mourners by validating a quality in their character which allows them to identify with the sorrow and wounds of humanity (1987). Suffering can draw us closer to the heart of God arousing compassion and leading to acts of mercy (Lewis, 1962). Wolterstorff (1987) commented that as "aching visionaries," it is the mourners who ache for others in their pain because they realize more keenly that the already-kingdom of God is not complete (p. 86).

Nicholas Wolterstorff's observation on mourners as "aching visionaries" speaks to an observation made by other Christians. In *Mere Christianity* (1943), C.S. Lewis stated, "If I find in myself a desire which no experience in this world can satisfy, the most probable explanation is that I was made for another world" (p. 121). Angie Smith (2010) also observed that life on earth isn't going to satisfy us and it wasn't designed to give us answers "but rather [we should] let the question penetrate our lives daily" (p. 54-55). The death of a child is an unspeakable loss to grieve. However, this suffering reminds us that although God's kingdom on earth isn't complete, His ultimate and compassionate desire for all people is *shalom*.

**Appendix C: “*The Almost-Fives*”**

There are two kids who always remind me how big my boy should be. I see them so rarely – only a few times a year. So what are the odds that within one painful week, they both accosted my eyes, attention and heart?

The first encounter was at my best friend Cristen’s house on a Sunday afternoon in April. I’m still in the foyer holding the hand of my 21 month old daughter as she greets the birthday girl when, I turn around to see a familiar woman walk up the sunlit path and through the open door behind me. Suddenly, I am nauseous, well aware that the young girl holding the woman’s hand is the one I never want to see.

She was due to enter the world just weeks before my boy. Her mother is Cristen’s other “best friend”. The three of us were so excited to have these two babies due at the same time. Cristen already had a son who would be just over a year when the new ones arrived. We lived with this idealistic notion that two new babies would be the perfect additions to friendly visits; and that they would, in time, make the perfect playmates. How naïve were we to live with so much hope and certainty?

The tall blond girl with bouncy curls distracts me, hurts me and pulls at my curiosity in ways I would much rather ignore. I see her mother and her only at birthday parties like this one or other functions occasionally hosted by our mutual friend. The possibility of us three women enjoying each other’s company together has long been shattered.

Inside Cristen’s house, the mother feels awkward, as do I. She acts as if she doesn’t see me standing right in front of her as she walks in and chats with the little children gathering around us. In the first few years it only seemed to be *awkward* and now it seems to be something else. Is

it disdain? Disrespect? Misunderstanding? In her mind should I be different? Do I come across as a bitch? I'm sure I will never know exactly. She doesn't look me in the eye as I muster a pathetic "hi" in their direction with what must certainly be a blank look on my face. "*Don't look at the girl. Look at the mom. Be friendly. Smile. Act NORMAL. Breathe.*" I tell myself in that frozen moment.

I doubt she knows what her presence and the presence of her daughter do to my inner being as the day goes on. How it rattles my core. My eyes try to dodge that child when the cake is being cut, but then I seek her out with sick painful curiosity during present opening. How tall would he be? At least her tall. The mom and her husband are not as tall as my husband and me and my subsequent children are tall for their age. He would be, at least, her tall. Would he be her friend? Would he be laughing? Would he be running with her? Would he be blond haired?

He would be— maybe be brown-eyed to her blue. He *would* be joy and laughter. He would unite us in a common motherhood where we are now driven apart by drastically different experiences. We would have a bond. In reality I don't often care about that bond, but I am keenly aware of its absence when I'm in the presence of that child and her mother. I can't touch the child. Hug her. Say hi to her. Acknowledge her much. It hurts. It rips at my heart in ways that make it hard to speak. Those two friends don't know that. They don't know what that child does to me... and let's not forget her mother who has, for nearly five years, gone on to enjoy what I have lost. No, not lost. He is not lost. My little boy did not wander off. He died.

The second encounter happened the following Wednesday. It was a beautiful spring evening. My husband made it home early, so we rush our two little girls out of the house in the double stroller to wander over and watch the end of a baseball game at the nearby high school. An hour later,

we happily make our way back down our street with a grinning infant in the stroller and our “big girl” walking on her own. It is one of those rare times when our family life seemed perfect and it is a perfect night for a walk, that is, until I see the neighbor and her child.

Nearly five years ago, my unfortunate new neighbor was out for a stroll when she spotted me outside my house. She eagerly came up our driveway to introduce herself and her brand-new baby. It was the first afternoon that I left my house alone after Isaiah died. I had just returned from approving the final drawings at the cemetery for his headstone. I was shattered. I was a wreck and there was Jill with her brand-new baby.

“Do you have kids?” she asked.

“I was just pregnant but my baby died.”

How’s that for a conversation killer? It was the first time I was ever asked that awful question. I hadn’t practiced my responses. I didn’t have the arsenal of statements I now choose from when asked. She couldn’t possibly know how to respond, so she rushed off with an awkward goodbye, mumbling something about her contented grinning child seeming hungry.

Since then, I’ve chatted with Jill at another neighbor’s jewelry party and tried to explain my story of Isaiah to some extent, until she used the word “miscarriage” in her misunderstanding of what I was saying. Sadly, I don’t think it is possible to break into her mental construct of what my dead child meant to me when she ran into me that first sunny summer day. Like most people, she has no reference for the word “stillbirth.”

On this sunny Wednesday evening, Jill and her children are out playing. I don’t see them often and the times I have, I’ve tried not to look at that girl. Of course, I fail in my attempt to avert my

gaze. I don't want to catch Jill's attention because I don't want to be forced to smile in such close proximity to that little girl; The "should be Isaiah's age" little girl. Instead, I walk down the opposite sidewalk quickly with a cursory sideways smile to dodge her mother while staring at that girl from across the street. She's Asian and, I assume, is smaller than my little boy would be, but she seems SO BIG! Is that what almost-five looks like? She rides a big girl bike down the road and looks after her little brother.

Isaiah should be watching after Paige and Quinn. Isaiah is invisible on our family walk as we pass the people I try to avoid. He's with us, but invisible. On our perfect family walk, I see him on his bike laughing with his toddling sister, Paige, who is looking oh-so-sassy in her shades, bright-colored clothes and curly pigtails; just as I saw him at the birthday party last Saturday excitedly hovering over the gifts right next to that tall blond girl with bouncy curls.

He's not lost; he's just invisible. Since they – Jill and Cristen's friend – can't see him, I don't feel like talking to them and their children. As I duck into the garage away from an always friendly, but somewhat confused, Jill I think that she will never see him walking with me.

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*Abbie Smith is the mother of Isaiah, born still in July 2008, and his two spunky little sisters. She is a founding member of Stillborn Still Loved, a strong advocate for the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) and a Seattle local leader for the Return to Zero movie project.*

**Appendix D: “*Little Boy Not Lost*”**

For years, I’ve needed to get something out in the open instead of simply scolding people in my head. I want to get up high on my soapbox with a formal statement that: STILLBORN BABIES ARE NOT LOST; THEY ARE DEAD. Face it, people. The baby died.

Whenever someone refers to a dead baby as “lost,” I just want to scream. I correct them each time in my head that they are not “lost;” they are “dead.” Isaiah did not fall out during delivery and disappear under a gurney somewhere. Nor, was he transported to the morgue only to be misplaced and never found. We did not just happen to *lose* our firstborn son.

If you really want to test the “lost baby” euphemism for ridiculousness factor, run it past a young child.

*Mom: "Well you see, sweetie, we lost your brother Isaiah when he was a baby."*

*Note the child's really confused and possibly concerned look.*

*Child: "Where did you lose him? Like at Target? Can we go back and get him?"*

*As she wonders, "Will you lose me too?"*

Tell a 2-year-old that you lost your baby and you just might find them looking behind the furniture. Tell them that your baby died and they'll probably just say "oh."

Maybe they'll mull it over. Maybe they'll try to work through it in their own mind. Maybe questions will come up down the road. This is how it should be.

There's no need for me to tell someone I “lost” a baby to ease the blow when telling someone my baby has died. In return, they shouldn't feel compelled to have some quick pre-packaged



response other than "oh". Maybe they'll mull it over. Maybe they'll try to work through it in their own mind. Maybe questions will come up down the road. This is how it should be.

No need to have a quick and confident "Now you have an angel in heaven" waiting in your back pocket to be offered in plucky response. No need to have special words of any kind. "I'm so sorry" is one of the best answers I've yet to hear. This shouldn't be a "Thank you" / "You're welcome" kind of exchange, or in this case, a "We lost our baby" / "Now you have an angel in heaven" kind of chit chat.

When I tell you my son died, follow the child's lead and mull it over. Come back with questions down the road. Let me know you've thought about what having a dead baby actually means to someone like me. Hell, feel free to think about what it would mean to you.

Most of our friends and family still find themselves quite uncomfortable and at a loss for words whenever the conversation turns toward our "lost" baby. His name is often whispered, eyes awkwardly averted by the brave person who dares say his name.

Yet I will never forget the moment my 5-year-old nephew turned to me out of the blue on a camping trip just after Isaiah's first birthday and said with such frank authenticity, "Aunt Abbie, I'm sorry your baby died," before turning back to play without missing a beat.

That's how we think of our baby. He died. He is not missing. Thoughts of his death run through the rhythm of my day from one moment to the next. In between eating lunch and loading the dishwasher, Isaiah is on my mind. Pick up dish... *Would he have liked a Buzz Lightyear plate or maybe Lightning McQueen?*... load dish. Between putting in a load of whites and folding the darks, he is on my mind. Turn on washer... *How tall would he be? What size pants would he wear?*... grab his sisters' tiny girl clothes out of the clean basket.

I don't need a euphemism to ease the blow as if the thought of him dead will put my mood into a flat spin. I don't ever forget him although others may have. I can't stand the idea that “losing” him makes it easier for other people to handle. Can we really find solace in the idea that misplacing a child forever is somehow more acceptable than acknowledging the reality of their death? One day I'll ask a parent whose child is truly missing. I'd like to know how they feel.

And so... this is my formal statement on the issue in hopes that maybe just one person will have the courage to speak the uncomfortable truth to the next person they may (God forbid) come across with a dead (not lost) baby. And maybe their first exchange will be like a breath of clean mountain air to a parent suffocating in platitudes and awkward superficiality who did not, in fact, just misplace their beloved child.

*You can BREAK THE SILENCE.*

*Every 21 minutes in the U.S. a baby is stillborn. That is 26,000 babies a year.*

*Stillbirth is 10 times more common than SIDS.*

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