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Stillbirth: A Phenomenological Exploration of the Clinical Encounter for Couples

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STILLBIRTH: A PHENOMENOLOGICAL EXPLORATION OF THE
CLINICAL ENCOUNTER FOR COUPLES

by

Michael Q. King

A thesis submitted in partial fulfillment
of the requirements for the degree

of

MASTER OF SCIENCE

in

Family, Consumer, and Human Development
(Marriage and Family Therapy)

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ABSTRACT

Stillbirth: A Phenomenological Exploration of the Clinical Encounter for Couples

by

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Utah State University, 2017

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Approximately 65 pregnancies end in stillbirth each day in the United States. For parents, stillbirth poses a risk of marital dissolution. In what's been called the "ultimate paradox", parents are left to replace preparations for welcoming life with arrangements for mourning death. The aim of this project was to describe the phenomenon of stillbirth, specifically the clinical encounter. Using a phenomenological approach, 8 couples were recruited to take part in a semi-structured interview. Participants described the influence hospital staff had on the clinical encounter. For some, hospital staff were "gems" or "angels". For others, hospital staff were seen as the source of invalidating comments. Allowing for personal grieving style combined with open communication is described as bringing couples closer together following the experience. A holistic and collaborative approach should be taken with parents of a stillborn as it has the potential to impact multiple areas of health. Continued studies should examine the period immediately following a stillbirth and what practices help individuals and couples grieve.

(72 pages)

PUBLIC ABSTRACT

Stillbirth: A Phenomenological Exploration of the Clinical Encounter for Couples

Michael Q. King

With approximately 65 stillbirths occurring each day in the United States, a significant number of parents are left to navigate a difficult grieving process. An event like stillbirth presents many individual and relational challenges. For this study, researchers focused on the hospital experience for couples following notification of stillbirth. Interviews were held with 8 couples that had experienced stillbirth within the past 10 years. Researchers wanted to know what similarities and differences existed in how mothers and fathers described the clinical encounter.

The data for this study were collected through interviews. Couples were encouraged to share as much or as little as they'd like about the hospital experience. Couples were also asked to describe how they experienced the clinical encounter as individuals and as a couple. Participants in this study were also given the opportunity to provide feedback on what doctors and other hospital staff could do to assist individuals and couples during this difficult time.

Participants discussed how hospital staff helped to shape the experience. This was done both in their interactions with staff and the accommodations that were made. Some parents described hospital staff as “gems” or their “angels” while others reported the pain of hospital staff invalidating their experience. While similarities existed in how parents experienced the clinical encounter, each participant’s experience was unique. Studies should continue to be conducted in an effort to further develop evidence-based practices in hospitals meant to help parents navigate this difficult experience.

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Thank you Sam, Roger, and Jack for helping me remember what's really important.

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Thank you to the many others that have assisted this project in a variety of ways. Whether it was spreading the word about this project or tending our boys when writing and coding needed to be done, thank you for making this possible.

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Michael Q. King

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CHAPTER 1

INTRODUCTION

In 2013, there were 23,595 recorded stillbirths in the United States, representing 6 per 1000 deliveries (Centers for Disease Control and Prevention, 2015a; Centers for Disease Control and Prevention, 2015b). This equates to approximately 65 stillbirths each day in the United States. The result is 65 families left to grieve the loss on a daily basis. Stillbirth is defined as pregnancy loss after 20 weeks of gestation (Silver, 2007). For many parents, stillbirth is a devastating and life-changing event (Burden et al., 2016; Cacciatore, 2013). Individually, parents often experience overwhelming psychological, physical, social, and spiritual consequences (Burden et al., 2016; Campbell-Jackson & Horsch, 2014). In addition, parents also report feeling shell-shocked, overwhelmed, numb, angry, and empty (Lindgren, Malm, & Rådestad, 2014; Kelley & Trinidad, 2012; Stinson, Lasker, Lohmann, & Toedter, 1992). As a couple, parents are at an increased risk for marital dissolution (Cacciatore, 2013).

In many cases, the cause of stillbirth cannot be determined and occurs regardless of the level of risk to the pregnancy (Silver, 2007). Parents do not anticipate their pregnancy ending in stillbirth, leaving parents grief-stricken and in disbelief (Kelley & Trinidad, 2012). Parents are left to experience a number of paradoxes in this unique loss where life and death converge (Cacciatore, 2013). Arrangements for welcoming life are now replaced by arrangements for mourning a death. Stillbirth has appropriately been conceptualized as the “ultimate paradox,” death taking place where life was meant to be begin (Cacciatore, 2013).

Stillbirth has been found to have an impact on every area of health (i.e. psychological, physical, social, spiritual). Psychologically, high rates of depression, anxiety, and symptoms of

post-traumatic stress disorder were reported by parents who experience stillbirth (Burden et al., 2016; Campbell-Jackson & Horsch, 2014). With regards to their identity, women report a sense that they are no longer a “whole” person (Burden et al., 2016). Physically, women are tormented and embarrassed for having “post pregnancy bodies” yet not having a baby to show for it (Burden et al., 2016). Social consequences of stillbirth for parents include feelings of isolation, lack of support from friends or family, and not having parenthood recognized as part of their identity (Burden et al., 2016; Kelley & Trinidad, 2012; Lindgren et al., 2014). The experience of stillbirth has also been found to have an impact on spirituality, producing a weakened sense of spirituality or an anger towards a higher power (Bakker & Paris, 2013; DeFrain, 1986).

Within a sample of hundreds of obstetricians, virtually all had provided care for women experiencing a stillbirth (Farrow, Goldenberg, Fretts & Schulkin, 2013). When treating stillbirth and interacting with parents, physicians have reported feeling uncomfortable taking on the role of “grief counselor” and are unsure of how to approach frank conversations with patients about their loss (Kelley & Trinidad 2012; Silver, 2007). Parents reported the stillbirth became more difficult to bear when they were on the receiving end of disoriented care or a lack of communication (Kelley & Trinidad, 2012). Parents have also reported the clinical encounter was a time where they were unsure of how involved they were allowed to be in medical decisions or what they were allowed to do during their time in the hospital (Burden et al., 2016).

As a student of Marriage and Family Therapy, I am interested in these findings and how they might benefit clinical work when working with those that experience stillbirth. For this project, I am interested in what contribution can be made to better understand how mothers and fathers experience stillbirth within the context of their relationship. In addition, I perceive there being a gap in the understanding we have of how the clinical encounter is experienced

differently, as well as similarly, between mothers and fathers. To address this gap, I sought to meet with couples and *better understand how they experienced the clinical encounter as a couple*. In conjunction, I would like to gain insight into *how mothers and fathers experienced the clinical encounter differently*.

CHAPTER 2

REVIEW OF LITERATURE

Introduction

In preparation for discussing the methods of my project, I will devote this section to a review of the relevant theories, models, and extant research surrounding stillbirth. I begin this literature review with a discussion of the theory that helped bring the need of a review of the relational experience to my attention, family systems theory. I will then include a discussion on the preliminary theoretical orientation of this project, specifically the bio-psycho-social-spiritual (BPSS) model. Using that model as a lens for understanding the impact of stillbirth, what is known about the impact of stillbirth in these different areas of health will be reviewed. A model for understanding this grief experience will then be discussed. To conclude the literature review, what is known about the clinical encounter following a stillbirth will be reviewed. My hope is that the literature review has been constructed in such a way that the reader will be able to see the value of better understanding the relational experience of the clinical encounter.

Family Systems Theory

Within family systems theory, the family is more than simply a collection of individuals (Smith & Hamon, 2012). Each family, or system, has its own set of rules, characteristics, and power structure. To understand the individual members of a system, you need to understand the context of the whole system (Smith & Hamon, 2012). Family systems theory provides a lens to view stillbirth as a systemic issue. For this project, it will be important to consider how different “parts” of the family system affect each other. This project will specifically look at the

relationship between the parental dyad. This is significant as extant research often focuses on the mother. While important to understand individual experiences, it is also important to recognize stillbirth as a *family* loss and a family experience.

Family Systems theory emphasizes the importance of roles in the family relationship. When a stillbirth occurs, there is a potential for confusion or a sense of failure in carrying out these roles. Following a stillbirth, women have reported feeling as if they had failed as a mother and wife (Burden et al., 2016). Fathers report feeling a sense of failure as a provider (Burden et al., 2016). Additional or pilot research would be valuable in better understanding the experience of grandparents and experiences within this role.

Cacciatore (2013) provides research on the impact on surviving siblings. In her work, she describes how siblings are able to pick up on the sober moods following a stillbirth. These children, while not completely understanding the situation, took the mood around them as a sign to not engage in their usual fun activities. Younger children that are not aware of what is happening are still aware that something is different due to the changes in routine. Indeed, stillbirth is a family experience and needs to begin being better understood within that context.

Bio-psycho-social and Bio-psycho-social-spiritual Models

Just as the experience of one, or multiple, family members will have an impact on the remaining system, different areas of health will impact each other. Said simply, the Bio-psycho-social-spiritual Model is an approach to assess one's experience holistically. Based on general systems theory, Engel (1977) introduced the Bio-psycho-social Model as a way to better account for the holistic human experience. Engle's argument was that the previously relied on biomedical

model of health was unscientific, lacking complexity, and did not account for the larger systems the client was involved in (McDaniel, Doherty, & Hepworth, 2014). Many drawbacks Engel (1977) pointed out with the biomedical model (e.g. physicians lacking interest or understanding, preoccupation with procedures, and insensitivity with difficult situations) have also been found within the context of medical care for stillbirth (Erlandsson, Säflund, Wredling, & Rådestad, 2011). The bio-psycho-social-spiritual (BPSS) model is an extension of Engel's (1977) model that provides a tool to examine the interaction and contribution between these different systems (Prest & Robinson, 2006). In the upcoming sections, I will review what is known about how stillbirth impacts these different areas.



Figure 1. The Bio-psycho-social-spiritual Model.

Biological Impact of Stillbirth

Among the most important reminders to those not familiar with stillbirth is that the birthing process, whether vaginal or caesarean section, still needs to be endured by the mother. Even for parents, there is an unexpected realization that their baby will still need to be delivered (Kelley & Trinidad, 2012). Up to early second trimester (13–28 weeks gestation), “evacuation” of the uterus can be performed just as safely as a medical induction of labor (Silver, 2007). With losses later in the second trimester and into the third, labor induction becomes the safer option (Silver, 2007). The actual experience of delivery will vary from patient to patient. While some woman experienced a relatively short delivery, other women report the process of induction, labor and delivery taking multiple days (DeFrain, 1986). In addition to recovering from the

physical toll of labor and delivery, many parents reported chronic pain and fatigue following the stillbirth (Burden et al., 2016). Mothers have also described the experience of having breasts that are producing milk for the baby that is not there. These physical reminders of their loss surely contribute to the psychological experience.

Psychological Impact of Stillbirth

For both mothers and fathers, many psychological issues can arise as a result of a stillbirth. For parents that have experienced a stillbirth, rates of depression, feelings of failure, guilt, and post-traumatic stress disorder symptoms have been found to be significantly high (Badenhorst, Riches, Turton, & Hughes, 2006; Burden et al., 2016). In one sample, 28% of mothers and 17% percent of fathers “seriously considered” suicide following the stillbirth (DeFrain, 1986). Cacciatore (2013) described how mothers of a stillborn report twice as many cases of anxiety than the mothers of live babies.

While there is a significant list of negative impacts related to stillbirth, a number of positives were found by Burden and colleagues (2016). As a result of the stillbirth, some parents came away with a different approach to life including an attitude that life should not be taken for granted. This change in attitude brought changes in behavior including being more caring, thoughtful, and compassionate. The authors saw this as the attempts of some parents to change their approach to life.

Social Impact of Stillbirth

Parents report a stillbirth having an impact within their circle of family and friends. Parents of a stillborn report feelings of being disconnected from their social environment and

feeling these relationships have been changed irrevocably (Burden et al., 2016). Parents, women especially, often feel a social pressure to prove their reproductive capabilities and soon attempt to have another child (Burden et al., 2016). From the same study, parents reported engaging in voluntary social isolation in an effort to avoid activities where they could potentially come in contact with babies or be reminded of their loss.

When making attempts to engage in social interactions, parents have reported others become uncomfortable when they bring up their stillborn in conversations (Kelley & Trinidad, 2012). Parents often experience this same type of avoidance from hospital staff during the clinical encounter (Cacciatore, 2013). This is perhaps why many parents have turned to online support groups to connect with those that can empathize and are willing to speak openly about the experience (Bakker & Paris, 2013; Burden et al., 2016).

Impact of stillbirth on the marital relationship. The marital relationship sits firmly within the social section of the BPSS model. Cacciatore, DeFrain, Jones, and Jones (2008b) described a couple's relationship having "both risk and great opportunity" following a stillbirth. In addition, the time following the stillbirth is often described as a struggle to find a new normal (Cacciatore et al., 2008b; DeFrain, 1986). Difficulties within all aspects of the relationship have been frequently reported following a stillbirth (Burden et al., 2016; Cacciatore et al., 2008b). Tensions can be deepened by the stresses of hospital bills and funeral expenses following a stillbirth (Burden et al., 2016). In addition, some parents reported a lack of interest in sexual activity following the stillbirth. Women, more often than men, have their sexual experiences impacted by feelings of guilt associated with the stillbirth and disturbing thoughts and images (Burden et al., 2016).

A significant area that poses “risk” but also “great opportunity” is differing grieving styles (Burden et al., 2016; Cacciatore et al., 2008b). When relational problems arise after a stillbirth, these are often seen as the result of incongruent grieving styles (Burden et al., 2016). Parents report a great deal of strength coming from being allowed, and giving the other partner permission, to grieve in a way comfortable to them (Cacciatore et al., 2008b). For many couples, the experience of stillbirth brought them closer together and created a new special bond (Cacciatore et al., 2008b; Burden et al., 2016). For couples that came closer together, this was often the result of respect for grieving style, emotional connection, and tolerance for their partner through the process of grief (Cacciatore et al., 2008b).

Spiritual Impact of Stillbirth

For many parents, spirituality played an important role in coping with a stillbirth and increased faith in a God (Bakker & Paris, 2013; DeFrain, 1986). For several parents, religious or spiritual activities helped to reduce pain and allowed them to be more accepting of the tragedy (Burden et al., 2016). After stillbirth, many parents have been found to reevaluate their religious beliefs (Bakker & Paris, 2013).

For some, the experience weakened their faith in God or a higher power (Cacciatore, DeFrain, & Jones, 2008a; DeFrain, 1986). When there was a spiritual struggle, it was often manifested through anger towards God or a higher power for what has been done to an innocent child (Burden et al., 2016; DeFrain, 1986). Others felt the stillbirth was the result of punishment for sins committed (Bakker & Paris, 2013; Cacciatore et al., 2008a; DeFrain, 1986). For others, the stillbirth experience neither strengthened or weakened the faith they had. For this group, the stillbirth was not connected to a higher power and simply “just happened” (DeFrain, 1986).

Grief

Grief that parents of a stillborn experience may not be legitimized by surrounding family, social circles, medical professionals, or society (Burden et al., 2016). Fathers especially felt their grief was unacknowledged (Bonnette & Broom, 2012; Burden et al., 2016). Fathers reported feeling anger towards those who do not understand the depth of their grief (Kelley & Trinidad 2012). Many mothers felt grief was dealt with privately and alone (Burden et al., 2016). Women have been found to react more intensely to pregnancy loss (Stinson et al., 1992). While attempting to grieve, parents reported being hurt by comments that somehow suggested the child was “replaceable” or not a real person (Burden et al., 2016). Some parents even feel that the mourning of the stillbirth was somehow not acceptable within their culture (Burden et al., 2016). In an attempt to be emotionally available and supportive of their spouse, some fathers have suppressed their grief so that they can focus on helping their wife (Burden et al., 2016). For these fathers, there was a reported feeling of needing to provide emotional support, rather than be the one that received it (Burden et al., 2016; Kelley & Trinidad, 2012).

Many parents have found it beneficial to take part in research projects, provide support and mentorship to others, and work with hospitals to improve service (Burden et al., 2016; Kelley & Trinidad, 2012). Opportunities to see, hold, and make memories with their baby along with a postmortem evaluation brought a sense of finality and helped in the healing process and decreased negative symptoms and better cope with the grief (Burden et al., 2016). Social taboos, stigma, and overall silence were experienced as significant sources of distress. Disenfranchised grief has been found prevalent across many countries and is reported as a source of distress for

parents (Burden et al., 2016; Kelley & Trinidad, 2012). The grieving process for parents gets complicated by the fact that it is somewhat ambiguous, or less clear-cut.

Ambiguous Loss

Ambiguous loss differs from a clear-cut loss in a few key ways. For example, a clear cut loss allows for a death certificate, the opportunity to dispose and honor remains and engage in other mourning rituals (Boss, 2004). Developed by Pauline Boss, the theoretical premise behind ambiguous loss is that it is the most stressful type of loss, as it defies resolution and leaves the family confused about who is in and out of a family (Boss, 2004). Examples include those who grieve soldiers missing in action or individuals lost in natural disasters. Family roles, rules, and boundaries are often left in ambiguity as a major piece of the family is now missing (Boss, 2004). Where the tendency might be to treat such cases as post-traumatic stress disorder (PTSD), Boss (2004) suggests this might not be the best approach. Treatment for PTSD is often non-systemic and may not address the need of individuals and families to return to their daily lives (Boss, 2004).

Cacciatore and her colleagues (2008) found ambiguity to be a dominant theme among those experiencing the loss of a child. The experience of stillbirth often leaves parents with more questions than answers and does not necessarily allow for closure. In addition, stillbirth is rarely legitimized as a real loss (Cacciatore et al., 2008a). Like other families experiencing an ambiguous loss, families that experience a stillbirth are left asking questions that are often unanswerable (Cacciatore et al., 2008a; DeFrain, 1986). For example, medical professionals often are not able to answer why the baby died (Cacciatore et al., 2008a). In many ways, the child's death is "invisible" to those surrounding the parents (Cacciatore et al., 2008a). Many

family and friends do not have the opportunity to meet a stillborn, and thus have a more difficult time recognizing the loss and having it be a tangible one.

Hospital Experience

When a stillbirth occurs, physicians are hesitant to make a transition from “physician” to a “grief counselor” (Kelley & Trinidad, 2012). Beginning when the news that their baby has died is delivered, parents have reported a lack of connection and that their needs were not met (Erlandsson et al., 2011). For medical professionals, there is sometimes a fear that talking about the loss will make the parents feel worse (Kelley & Trinidad, 2012). Now that care is for a stillbirth, rather than a live birth, parents are unaware of what procedures the hospital will need to follow and unsure of what decisions they are allowed to make (Burden et al., 2016). In these difficult moments, physicians often defer to social workers or nurses to provide emotional support to patients (Kelley & Trinidad, 2012).

This literature review was prepared to bring attention to the relevant theories, models, and extant research surrounding stillbirth. Models and how they can be used to better understand stillbirth were discussed. The importance of treating stillbirth as a family experience was discussed. Grief and a relevant model for understanding grief following a stillbirth was introduced. Key experiences relating the clinical encounter and how they were experienced by the parents was discussed. With this project, I hope to add knowledge to the existing literature about how stillbirth is experienced with the context of mother-father dyads. I will also seek to highlight differences in how fathers and mothers grieve. This will ideally be helpful to medical professionals, clinicians, family members, and the parents themselves in assisting the navigation

of a difficult grieving process. With the review complete, the reader is prepared for a discussion of the methods for carrying out this project.

CHAPTER 3

METHODS

As the goal of my project was to gain a *depth* of understanding about the clinical encounter for couples, the most appropriate methodological approach was found within a qualitative design (McWey, James, & Smock, 2005). More specifically, I chose to utilize phenomenology as its use in research is to describe the meaning placed on a lived experience by several individuals (Creswell, 2007). With this approach, I sought the reality, or truth, that couples place on this experience.

Data was collected from interviews with couples that have experienced a stillbirth. Interview questions focused on the period from notification of death to discharge from the hospital. In interviews, parents were encouraged to include as much or as little detail as they would like. In the interviews, couples were asked about their overall experience, their interactions with medical staff, and the differences and similarities in their grieving process. Parents were also asked about the impact the clinical encounter had on their relationship, recommendations they have for medical professionals, and advice they would give to parents who experience stillbirth. Parents were also given the opportunity to share as much or as little about other experiences relating to stillbirth that were not covered in one of the questions.

Researcher's Experience with Phenomenon

As a researcher, it is important to recognize that I cannot consider myself as completely separate from the phenomenon that I study. As such, my beliefs and overall worldview will impact and influence this work (Dahl & Boss, 2005). My role is to consistently and explicitly

review the impact my worldview is having on the project and what changes, if any, should be made to the project to make the methods more productive and ethical (Dahl & Boss, 2005).

As a parent, I have never experienced a pregnancy loss. My wife and I have two sons and no significant complications took place during pregnancy. The experience I do have with stillbirth is as a brother. My earliest memory is the funeral for my younger brother that had been alive on his due date but was found to be stillborn at the following appointment. I have witnessed the lasting impact this loss has had on my parents. As a therapist, I have helped individuals and couples that experienced pregnancy loss work through many of the issues highlighted in the literature review. Naturally, I am sympathetic to parents in these situations. I willingly support improved care, empathy, and understanding for parents experiencing pregnancy loss. My intention through therapy and this research project is to improve care for individuals and couples that have experienced a stillbirth.

Research Design

For this project, I utilized a phenomenological approach. Phenomenology seeks to explore and describe the meaning placed by several individuals on a lived experience (Creswell, 2007). Within phenomenology, the sacred, mundane, ordinary, and extraordinary are equally intriguing (Dahl & Boss, 2005). The focus of this approach is to be able to describe the essence of what participants have in common in that experience (Creswell, 2007).

Traditionally used in the health and social sciences, phenomenology is strongly philosophical and draws heavily from the works of German mathematician Edmund Husserl (Creswell, 2007). The philosophical assumptions behind phenomenology include: (1) phenomenology is the study of lived experiences of persons, (2) experiences are conscious ones,

and the goal is (3) the development of the essence of the experience rather than an explanation of it (Creswell, 2007). As such, the goal of the interviews was to allow these couples to tell their story and I attempted to capture the essence of their experience. Within phenomenology, knowledge is seen as something that is constructed by individuals. Being something we construct, a common experience will mean different things to different people (Dahl & Boss, 2005).

I chose a phenomenological approach for this study as I seek to be able to describe the essence of the couple's experience of the clinical encounter following a stillbirth. In addition, I felt it was appropriate to rely on the responses participants provided to help us better understand the reality as they perceived it. With this approach, I am interested in the truth provided by participants, not necessarily pursue absolute truth. In asking what was true for the couple in this experience, I will learn how stillbirth and the clinical encounter was experienced by the couple but also the individuals.

Recruitment and Sample

With approval from the University's Institutional Review Board, couples that met inclusion criteria were recruited through social media, local support groups, and national support groups (e.g., Facebook, Share Parents). Inclusion criteria for this study included: (1) participants were an intact couple, both partners needing to be 18 years or older at the time of stillbirth, (2) couples have been married for at least 6 months at the time of stillbirth, (3) participants are the biological parents of the stillborn, (4) couples spoke English, (5) the stillbirth took place in the last 10 years, (6) the couple was able to take part in the interview together. The purpose such criteria was to recruit a homogeneous sample and allow for an examination of the phenomenon.

Interviews were conducted until the research team reached *saturation*, or when new themes no longer emerged. Creswell (2007) provided the recommendation that a phenomenological study would be able to reach saturation between 5 and 25 participants. My study included 16 individuals, or eight couples.

Procedure

Interviews were held in person at Utah State University's Family Life Center in Logan, Utah, at participant's homes, and through video conferencing software (e.g. FaceTime). Prior to the interview, participants were given the opportunity to complete and give informed consent to participation. Participants also provided demographic information and completed the following assessments: The Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder 7-item (GAD-7), and the Couple Satisfaction Index (CSI). Every attempt was made to make the interview a safe environment for couples to share their experience. This included meeting in a private room and ensuring participants that their identity would be protected in the study. Following a brief introduction to the research project and giving the couple an opportunity to ask any questions they may have, the interviewer began audio recording the interview. These interviews were recorded using a digital voice recorder. These interviews were recorded using a digital voice recorder. The interviewer used a semi-structured interview approach and started the interview by asking the couple to describe their overall experience with stillbirth, adding as much of as little detail as they would like. Follow-up and clarifying questions were also commonly used. The questions were designed to allow for the sharing of an experience, and not to lead the participants toward positive or negative reports of their clinical encounter. The following questions were used as part of the interview. This list is also located in Appendix C.

1. To start, I'd love to hear about your overall experience related to stillbirth.
 - a. What memories do you have of that day?
2. Tell me about your interactions with medical the staff?
3. How did you both grieve during your time in the hospital?
 - a. What similarities and differences were there?
4. What impact would you say the hospital experience had on your relationship?
5. If you had the opportunity to meet with a couple that had just experienced a stillbirth, what advice would you give or what would you want them to know?
6. If you had the opportunity to meet with medical professionals, what advice would you give them with regards of how to care for couples that have experienced a stillbirth?
7. Is there anything else you'd like to share with regards to your experience with stillbirth?

After the couple felt they had shared everything they felt was relevant to the interview, the audio recording was stopped. The interviewer then spent approximately 10 minutes with the couple to debrief, discuss their experience in the interview, and answer any additional questions the couple may have had. The couple was then offered the option for referrals to therapy/counseling services. Couples that participated in this study qualified for compensation in the amount of \$30.

Sample and Measures

As shown in Appendix A, which describes the demographics of the sample, eight males and eight females participated in this study. The average age of participants was 30.75. 15 of the participants were White/Caucasian (93.75%) and one participant was Bolivian (6.25%). The average length of the relationship was 9 years. One participant reported being in the \$20,000 -

\$24,999 range for combined income, two participants reported being in the \$30,000 - \$34,999 range, and the remaining 13 reported being in the \$35,000 and over range for income.

As stated previously, the couple took part in a number of assessments. The average PHQ-9 score was 4.68 (minimal depression). Ten participants scored in the minimal range for depression. Four participants scored in the mild range for depression. One participant scored in the moderate range for depression. One participant scored in the range for moderately severe depression. Also as part of the interview, any suicidal ideation was discussed to ensure safety and provide any referrals that may be needed for treatment. One participant out of the 16 reported suicidal ideation. These thoughts were discussed during the interview and the participant reported having a current therapist that they felt was a good fit. The average GAD-7 score was 4.12, which is just below the cutoff for scoring in the “mild” range. Thirteen participants scored in the mild range for anxiety. Two scored in the moderate range of anxiety. One scored within the severe range for anxiety. The average Couple Satisfaction Inventory Score was 68.69. With this scale, scores under 51 are seen as indicative of clinical relationship distress. In one sample, the mean score among couples was 61 ($SD = 17$) (Funk & Rogge, 2007).

The amount of time spent in the hospital ranged from 15 to 96 hours ($M = 37.75$). Hours spent in labor ranged from two to 24 ($M = 9.43$). Range of total pregnancies (including previous pregnancy loss) before the stillbirth was from 0 to 4 ($M = 1.38$). Among the stillborns, six were female and two were male. The vast majority ($n = 7$ couples) delivered their stillborn vaginally. One couple had their stillborn delivered by cesarean section.

Coding and Interpretation

The coding process and analysis of data was performed by a team of four coders. Once the research team was assembled, they participated in a 2-hour training with a faculty member from Utah State University. In this training, coders were instructed on their responsibilities for the project as well as the coding process for a phenomenological study. All four members of the research team coded each of the interviews that had been transcribed verbatim.

Based on Creswell's (2007) simplified version of the Stevick-Colaizzi-Keen method, as discussed by Moustakas (1994), researchers first reviewed their experiences with the phenomenon. This was done as a best effort to set our experiences with phenomenon aside and focus on what is being said by the participants. Coders were encouraged to read through the transcribed interviews the first time without making any markings or notes. Upon returning to re-read interviews, coders created a list of significant statements. Upon additional reviews of the transcript, coders then marked significant statements and grouped them into larger groups called themes or "meaning units." Each statement was seen as equal worth and coders attempted to make these lists non-repetitive. Coders wanted the themes to reflect and provide insight into both *what* participants experienced related to the phenomenon as well as the *context* in which they experienced it. Upon conducting the individual review of the interview transcripts, the research team met together. In these meetings, the research team discussed their individual list of themes and quotes from participants to illustrate these themes. The goal of the research team was to be able to describe what was experienced by participants, referred to as the *textural description*, and provided verbatim examples. It was also important for the research team to represent the context of the experienced phenomenon, referred to as the *structural description*. Equipped with these descriptions, the coders wrote a composite description of the phenomenon incorporating both

textural and structural descriptions. This became the essence of the experience and provided an explanation of the experience and how it was experienced (Moustakas, 1994).

CHAPTER 4

RESULTS

Data for this study were collected by holding interviews with couples that had experienced stillbirth. Interviews were held with eight couples ($N = 16$ total participants) that had experienced stillbirth within the past 10 years. Participants were asked questions about the overall experience of the clinical encounter, how they experienced this encounter similarly or differently, how this experience changed their relationship, recommendations for medical professionals, and any advice for couples that experience a stillbirth. Before addressing the results of the study, I will discuss the trustworthiness of our results.

Trustworthiness

To ensure trustworthiness, or that the researchers' interpretations aligned with the perspectives of the participants, measures were taken to ensure this result. The process of having four independent coders review all transcripts helped in this pursuit. In addition, participants were given an opportunity to review the themes our research team had established. Giving participants a chance to review and make comments on the list of themes is referred to as a *member check* (Cohen & Crabtree, 2006). Out of the eight that were contacted by email and given the opportunity to take part in this process, four couples participated. Each received a list of the themes that had been developed by the research team and were given the opportunity to express how well the list of themes captured their experience. They were encouraged to provide any corrections or additions they would make to the list. Vital to the ability to claim trustworthiness is that all four couples felt the list of themes captured the experience. One

participant made the comment that the list of themes was “spot on” with their experience. Another participant remarked that the list of themes had actually reminded her of items she had forgotten to mention in her interview but had took place in her experience. One participant desired to add some thoughts regarding the experience. These thoughts are included in Appendix D. Besides this addition, no other change to the list of themes was seen as needful by the participants. With the coding process performed by the research team along with the positive response from the member checking, I confidently present these results as an accurate representation of the interviews that took place.

Themes

With this being a phenomenological approach, the goal was never to capture everything there is to be known about the experience. This simply is not possible and the true intention of this analysis was to simply better understand experiences (Boss, Dahl, & Kaplan, 1996). In this attempt to better understand the experience of the clinical encounter following a stillbirth, a number of themes emerged. After extensive review of the interviews, the following codes emerged as the major themes: *the clinical encounter*, *grief and loss*, *relationship with spouse and family*, and *long-term impacts*. Illustrative quotes, that align with the themes, provided by the participants will be used throughout this section.

The clinical encounter. Couples reported that the hospital staff, policies, and accommodations played a large role in shaping how the clinical encounter was experienced. A variety of positive and negative experiences associated with the clinical encounter were reported by couples. This theme will be described in a chronological order and will include events ranging from when the couple was informed their baby was stillborn to discharge from the hospital. As

many couples began describing their experience by discussing the already existing relationship with their unborn baby, this will be reviewed first.

Anticipation and excitement for baby. Each of the couples expressed some sort of anticipation or excitement for the arrival of their baby. Couples discussed how their pregnancy was an experience that they shared with family and friends. Sharing the experience of pregnancy added to the excitement. One father noted:

Lots of our friends have had their babies. My best friend, they got pregnant right away when they started trying. Another...really close friend, they got pregnant at the same time as us essentially. And my brother did as well... And my best cousin. So we had a group of babies that we're all going to be born at the same time. So, we were very excited.

Some couples reported there had been complications and setbacks in attempting to become pregnant, making the pregnancy especially meaningful. One couple mentioned they had been trying for 2 years to get pregnant. Other couples described the preparations, such as purchasing cribs, that had already been done. One couple described how they purchased a fetal Doppler so that they could hear the baby's heartbeat on a nightly basis:

(male partner)...early on, we had decided it would be cool to listen to the baby's heartbeat every night. So we...bought a fetal Doppler. And so we would listen to your heartbeat every night. (female partner) I remember we started doing that, probably at like nine weeks...And looking back on it, we say, we're so thankful for that, because we felt bonded to her. Like, we listened to her heart beat pretty much every night before we go to sleep.

Like this couple, other participants reported pregnancy being a time of anticipation and excitement for the arrival of the baby. For one couple that had not planned on becoming pregnant at that point in their relationship, they described the pregnancy as a “happy accident.”

Notification of loss. Many parents reported the news that their baby was stillborn was completely unexpected. For two couples, they had been informed that their pregnancy was at risk, but hoped or assumed they baby would be okay. One parent described this hope as, “We’re

going to be in the percentage that our baby (is) small, but she makes it.” Some mothers reported a sense that something might be wrong when they felt decreased movement from the baby. For parents in this study, stillborn was confirmed with an ultrasound. Also common was the individual attempting to find the heartbeat deferring to a doctor to notify the couple of death. When they were given the news that their baby had passed, parents reported feeling numb or being in a state of shock and disbelief. One mother reported what took place during the ultrasound:

I could see the picture, but I couldn't hear anything... (the doctor) actually checked the volume... I remember he kind of stepped back and said, “Well, as you can see your baby's heart is not beating. So, it's dead.” And, at that point, I was...in disbelief.... I just remember covering my face with my hands and I started to cry.... I was like, “I was just here two days ago, and she was alive”.... And so, at that point I just kind of melted on the table.... I just remember sitting there again, in shock.... It wasn't...sinking in really.

One father described the experience of being informed by saying:

The lady was doing the ultrasound, she just pauses, she's like, “who's your doctor?” ...we told her, and she just runs out, she didn't say where. And then the doctor came, and he's like, “so if you look here and here you can see swelling.” Then he explained that he had somehow passed away, so from that point it was really really tough. For one, when you're expecting something to come, and then, next thing you know, it's not coming.

The mother in this same experience provided additional detail by saying:

And then the lady went through the ultrasound...“oh the spine looks good, the circumference of the head is good” and then she asked who the doctor was. And then she went out, and didn't say anything, just went to get the doctor. While she was gone, (husband) was trying to be like, “it's OK, everything's OK.” But this is not OK. Something's got to be wrong. I don't think they just leave. So the doctor came back, and he saw the swelling. It was in his abdomen, but he said, more concerning, is there is no heartbeat. It had been a week since our last appointment. So sometime in that week, he had died. The doctor just helped me get cleaned up. I sat up, I just couldn't stop crying.

Among the difficult tasks, couples reported it being especially difficult to inform family members. One mother described the situation of informing her mother:

So, I called and said, “Are you at home?”...And she said, “sure.” So, I came in, and I think she already knew. Cause I walked in and I was like, “ugh, she’s gone.” And my mom made me cry more, because it’s hard to see somebody else feeling pain for you. That’s was the hard part. But then she started crying, she patted my belly and said, oh, (baby name). Cause we’d named her already. She was like, “oh, (baby name).” She was just so sad, and I was like kind of crying too, but trying to have a stiff upper lip.

Some mothers received this news on their own, as they were attending what they thought was a routine appointment. One father was a full hour commute away when he received the news that their baby was stillborn.

Mothers described other impacts of this routine appointment. Some mothers reported feeling caught off-guard or unprepared for the physical exams and the delivery that followed the news of the stillbirth. One mother reported:

I hadn’t showered that morning. Because I didn’t think anything was wrong, I was going to come home and clean up, and so I was just like humiliated that this person, this emotional rag, who, you know, shows up and I felt unhygienic and dirty, like because I hadn’t prepared for any examination. And I remember being so embarrassed in so many ways.

Just as parents reported a difficulty in not being able to make physical preparations, other parents described the difficulty of being able to emotionally prepare. One mother, who was moved directly for a cesarean section, described the rush of thoughts and difficult decisions that needed to be made:

And the anesthesiologist kept reminding me you need to breath. Because, I was just so nervous the whole time, I kept thinking. Ok, so, do we still name her? Is she still (baby name)? Do I want to hold her? What is she going to look like? All that was running through my head.

Mothers and fathers reported many similar emotions and initial reactions to the loss. For fathers, the initial reactions of shock and disbelief largely mirrored what was happening for the mothers. The key difference, as reported earlier, was that it was not uncommon for the father to not be at the appointment.

Labor and delivery. Despite the grief from losing the baby, some discussed a peace or a sense of joy that came from the thought of getting to meet their baby. One mother described this experience by saying:

I felt...her moving down the canal, I was like “Oh she’s coming!” It was like this surge of, “I can’t wait to meet her.” Even though I knew she was dead, I couldn’t wait to meet her, see her for the first time...But, having been through that experience, there was still so much joy when she finally arrived. Even though she was dead, she was perfect.

For many parents in this study, their assigned doctor was not in town and was not there for delivery. Describing this period, couples discussed their appreciation for clarity and directness from medical staff on what procedures were going to be taking place. One mother described what took place saying:

They asked us what we wanted to do... [We wanted] to be able to see and hold (baby girl) and stuff, and they said, “Well, just to prepare you, we don’t know how she will look and we don’t know how her body will be...we need you to be prepared for that... We can wrap (the baby), and you guys can hold her and we can continue and deliver baby B and make sure he’s ok.” And so, delivery went...was fantastic.

Many couples were given the option to either return home and prepare for delivery or to go ahead and start labor. While some appreciated having the time to return home for an evening to process what was happening, others wanted to start the process right away.

After the birth, parents described a spectrum in terms of physical appearance of the baby. When talking about the physical appearance of their baby, one mother reported:

The baby didn’t look very attractive because she had been dead for so long, her skin had started to slip off, and that kind of thing. And so, I think that was that other part of the hush. Because she kind of looked like an alien. Most newborns do anyway. But she looked different. She didn’t look like this cute baby, that’s when it became real.

The other end of this spectrum of what was reported in terms of physical appearance was one father reported:

They pulled her out, and I could see her immediately before they held her up. But, she was absolutely perfect, and I was shocked that she was that perfect. I mean, she looked absolutely fine. Totally healthy. She was gorgeous. Absolutely beautiful.

Time with their baby. Each of the couples reported having the opportunity to spend time and say goodbye to their baby. Parents reported a variety of emotions taking place during this time. Parents reported this being a time to choose a new, take pictures, bond with their baby, and introduce the baby to family members.

Some parents wished for more time with their baby. At the same time, some parents felt a sense of guilt for doing so because of how fragile the baby was. In some cases, parents noted that the skin of the baby had already begun to “slip” off. Some parents noted a worry that they might “damage” the baby. As mentioned earlier, others noted being somewhat taken back by the “alien” look their baby had.

When given an opportunity to share advice on how to approach this situation, some parents recommend to spend the time you’d like to with your baby. One father encouraged, “You don’t want to rush it. Especially where it’s so little time. You don’t want to miss anything.” Parents reported cherishing this time they had to examine their baby, take photos, give them baths, dress them, and create hand and foot molds. Many couples described how they wanted to have a few minutes alone with their child before they said goodbye. One mother described:

We just asked everybody to leave...after everybody left, it was probably 11:40 at night, almost midnight. Everybody went home, they were gone, it was just us. And, we said our goodbye, then the nurses came and took her.... I appreciated that they didn’t like treat her like she was gross.

Parents reported appreciating the connections hospitals had with third-party support groups. While in the hospital, and afterwards, these support groups were able to provide a number of services that the parents reported being especially helpful. Parents reported they

appreciated and were able to connect with individuals from these groups as they often had experienced a similar type of loss. These groups helped to provide meaningful mementos, including pictures and molds of the baby's hands and feet. Other mementos such as stuffed animals and jewelry were provided to the parents and the baby. In addition, these groups were able to provide knowledge and direction on what to expect from the stillbirth experience moving forward. Parents reported these groups were able to spend time with them and did not have to rush to other patients like medical professionals would often have to.

Accommodations and hospital care. Many parents discussed the accommodations they were given in the hospital. For many, the parents were given a room in a separate area so that they would hear the cries of other babies or the conversations of those after a live birth. Many parents discussed some type of symbol that was placed on their room door that let those entering the room know that they had lost their baby. One mother noted that staff had put "a sticker on the door, it was just a little leaf card, that they put on our door to let the staff know that she was stillborn, or a demise." Parents reported feeling that this helped medical professionals that would visit the room be more sympathetic to the situations.

One couple noted how they wanted to perform a religious ordinance of giving their child a "name and a blessing." They described how the hospital helped to make arrangements for that to be done:

They rearranged a conference room so you wouldn't know it was a conference room. So that we could have that gathering. So that it didn't have to be just in a hospital room. And it was really thoughtful of them to think of those little details to make sure that we didn't feel like just another patient. I feel that they took really good care of us.

Interactions with the medical staff. Many parents felt overwhelmingly positive about how they were treated by medical staff during this difficult time. Other parents noted negative

interactions they wish could have been avoided. Parents reported appreciating any time that medical staff could keep them informed of what was happening or what was going to be happening.

Parents reported that medical staff, both positively and negatively, impacted their overall hospital experience. One mother described an interaction that left her wanting to leave the hospital right away:

There was one [that was] really abrupt, and it was on the last day... (a nurse) had been rounding all night, and she was tired and wanted to go home. And she came in, and I just had been on the phone with my family, so I was crying. And, she needed to take my blood pressure. And it came up really really high, and it hadn't been high any other time, and she said, I'm just gonna go and wait for you to calm down and then I'll come back and wait to check it. I was kind of taken aback, because she seemed really abrupt. And I [said] sorry, I was just talking to my family, we lost his sister. And she [said] "I know, I saw the thing on the door, I just didn't have time to talk to you about it"... I was... ready to go home. I started getting out of bed and... was ready to leave.

When it was possible, parents reported appreciating being given options. When one couple found out they had lost their baby, their doctor instructed them that "you don't need to make a decision right now, just go home and think about all these options you have and then you can tell us what you'd like to do." Many parents appreciated the skill the medical professionals had, but reported a sense that maybe they were just another thing to do on their long lists. One father reported that:

At least in my experience, if you don't speak up, medical professionals, they're just doing... it's so routine for them to just go through and do their thing, and the next thing. And they're great, and they're very skilled, but it's almost like they think everyone else thinks this is routine, too.

Parents felt the rules or protocol after the baby is born are there to help keep the baby safe. Parents reported these rules to keep the baby safe should no longer apply as "they're not

going to die, they're already dead.” One mother expressed appreciation for flexibility in what was allowed:

One other thing the hospital allowed us to do, it was the night that we had to stay. They helped to make my hospital bed bigger to allow him (husband), and then we were able to have our son with us, instead of just in the bassinet across the room. And I think that helped us a lot. Just throwing rules out the window.

Parents felt grateful for the expression of kindness, sympathy, and empathy that they received from hospital staff. Many parents reported that staff would consistently offer help and ask if anything was needed. Some mothers expressed a worry that the fathers were often forgotten and not cared for as much as the mother was during this process. One mother expressed the following:

I do think there's some amazing support for moms. Like I had people reach out to me that were amazing, and I don't feel like there's that same support for Dad's so in a way, I do think a lot of times, he did get forgotten.

Among the many things parents appreciated from medical staff, parents reported appreciating when staff chose to treat their stillborn as they would a live baby. Examples provided were when staff would point out and make comments about the baby's features, take measurements, and hold the baby as they would a live baby. One mother noted her appreciation for such gestures:

I loved it when the nurses would come in, and say, “Oh, what's her name?”, “Oh, how big was she?” They would ask how much she weighed. They would ask who she looked like, whose nose does she have. They would ask those detailed questions. Or they would comment about...her long skinny fingers, or [make] comments about her just like she were a living baby. It was really nice, and I really appreciated it.

In addition, some parents reported appreciated when medical staff would take time to be with them and experience the difficult time with them. Some parents, mothers specifically, appreciated physical gestures (hand on hand, hand on shoulder, etc.) when

medical staff gave comfort. Others however reported an aversion to these types of gestures.

Grief and loss. Grief was a common response that was reported. Couples described this grief both in the short and in the long term. Associated with the grief of losing the pregnancy, parents described feelings of shock, disbelief, devastation, sadness, and anger. Parents reported having experienced an anticipation or excitement for their baby.

Differing grieving styles among partners. Couples consistently reported that their grief looked different from one another. Their responses highlighted more long-term experiences with grief. One couple described their differences in grief as:

Mother: I think we definitely grieve differently. I got really depressed, I kind of clammed up to myself a lot. I probably just laid in bed for like three months after. And then (my husband)'s like, "OK, you gotta get up. You gotta go do something." ... **Father:** Yeah, I have to keep my mind going, because if you focus on it it drives you down. So, the more focused you are, the further on you can go.

One mother described the differences in grieving styles saying:

And we grieve really differently. I remember I was really open, I cried about it, I wanted to go to (support groups), I talk to anybody who will share my grief, anybody at all, but not in a way that would force it on anybody. Nobody has to, I don't feel like somebody has to. If somebody's interested, I'd be happy to talk about it, so. And (spouse) hasn't as much. He is 100% OK to do it his way. We give each other a lot of slack. A lot of people have...different ways to grieve.

One parent discussed the importance of grief being a personal journey:

Follow your heart, nobody can tell another person how to grieve. It is so individual. It is so personal...no two people are going to move through it the same. Some people stay in it forever. I realized that the only way to go through it, was to feel it, and to own it.

When asked what advice would be given to a couple that experiences stillbirth, one mother reported:

You're going to grieve differently. The wife needs to see the husband cry. The husband doesn't need to be tough, and yeah, the husband doesn't need to be tough. He may think, I'm the man, I don't need to cry. He needs to grieve too. And he has to go through his own process. Because it is a process, and you have to go through all the stages. There's nothing wrong with that. Especially for the males. I mean if they're supposed to be the big tough, nothing affects them...

When discussing grief, one father noted how he felt that he and his wife remember details of events differently:

I'd say, it was more of a blur, for me. She has a lot more memory of the little details, those kind of things. You know when she mentions those things that comes back to me, but if you were to ask me what details I remember, I just remember generalities, things like that. So, some of it may be that it was probably just a shock for me. My mind kind of blocked out all the detail. But, for me, it was a bonding experience, I think, just to be there. Be with (wife). And that was one of the main things that I took out of it.

Some fathers reported that perhaps they were less emotional, at least outwardly, about the experience. Fathers reported feeling that their role in the experience was to be a support to their wife. One father expressed the need for fathers to find a way to express the variety of emotions associated with the experience:

I've always had a hard time showing emotion. But, experiencing a stillbirth of your own child, is hard, but it's still something, as a guy, not really wanting to open up emotionally and let people see that, because there's the whole, you know, "you need to be strong" for this person, for this situation, for all these reasons. Although, in the hospital room, there was kind of a bathroom connected to it, and I think as emotions go, there's ups and downs. Even in tough situations. So, we get there, we understand what's going on. We're kind of numb to the whole everything. But then, when it starts hitting ya, your emotions start coming to the surface. At those times, I was able to go to the bathroom to just be by myself. You know, I was able to go in there, shut the door, and just open up and cry. Just as anyone would do. I was able to stand there as long as I needed to, and then I was able to, just kind of, let it all go. And then I was able to come back out and be the strong person that I felt that I needed to be.

Another idea discussed was that similar emotions were felt by both partners, but at different points in time. One mother described this by saying:

He was the strong person when I was a mess, and then when I kind of started to come out of, like, the dark cloud of gloom. He kind of was, and so we flip-flopped for each other I guess.

Mothers noted a unique feature of their grief was physical reminders that the baby was gone. One mother described:

...my milk came in, and that was a horrible experience, because it felt like it was a reminder of, I don't have a baby to feed. And on top of it, it was painful, because I couldn't do anything...They made me bind my breasts. Couldn't take a warm shower for like a week, because they were trying to get my milk to go away.

Paradoxes associated with stillbirth. Couples reported a number of activities they did not expect to be engaging in. Activities that were in direct opposition to what they thought they would be doing. One couple recalled that, "Instead of looking for cribs, we were shopping for coffins. And instead of looking for best educational stuff, and baby monitors, and stuff, we were looking for headstones." Some parents reported being overwhelmed by the arrangements that needed to be made for a funeral when a live birth would have allowed time to go home and recover. One mother expressed that:

We had a funeral to plan. We had arrangements to make. We needed a florist. We needed to go to a mortician. I didn't get even just to sit at home for a few days, like if I had had my baby and to recover. I had to be back, and getting stuff done.

Relationship with spouse and family. Parents reported relationships being a crucial piece to their experience. Whether it be their spouse, family, or friends, parents reported a variety of different acts of kindness and support.

Friends and extended family. Many parents reported friends and family being a tremendous help through the experience. Many friends and family members made an effort to be there at the hospital to be with the family and meet the baby. Parents reported offers to help came

in the form of helping plan the services, letting other people know about the loss, purchasing a plot where the baby could be buried, or by simply being there with the couple.

When describing the help her mother provided through the process, one mother reported: “And I just told her, ‘Mom, you tell everybody else please.’ So she was my voice. I told her and asked her to contact everybody else. Then, I just went home.” She later added that her mother “planned everything.” Parents reported being grateful for the efforts family members put forth to helping make arrangements for the funeral, luncheons, and so forth.

While some couples did stress the need for some time to be alone, overall participants were happy and eager to have family members meet their baby. Some couples reported that family member’s efforts to help did not align with how they would like to grieve. One more reported:

My mom kind of was hard for me, because in her day, you didn’t, you certainly didn’t look at the baby. You didn’t cry about it. You just absolutely moved on and tried to talk yourself out of that it ever really happened. That’s kind of what she wanted me to do. But at Share Parent’s, everyone else’s mom tried the same thing. And it’s their day. That what they did in their day. You didn’t accept your grief, you didn’t let it come. You just closed off the doors. I had to realize that that doesn’t work for me. It’s OK, I’m all good. She doesn’t have to tell me what to do. I’m grown up.

Parents reported other difficulties related to their interactions with family members. Some parents noted a feeling that they had to be strong for other family members when they saw that they were in pain. Something else that made interactions with family members difficult is when family member seemed nervous or hesitant to talk about what had happened.

Impact stillbirth had on the relationship. Most couples discussed how the experience of stillbirth would either bring a couple closer together or it would bring them apart. When describing the idea of stillbirth either bringing you closer or tearing you apart, one mother noted:

I absolutely perceive it being one or the other. For us, I definitely think it brought us closer together... There's still no one [else] that felt the same pain... my mom had a hard time because it was her first grandchild, and his mom had a hard time. But no one else was going through the loss of their child. And so for me, when I wanted to cry about it, no when else got it. Like, it didn't matter how good of a friend they were, how much they loved me. No one understood that like (husband) did.

Among those that participated in this study, the vast majority felt that the experience had brought them closer together. One father described the situation as what “glued us together as a family.” For one couple, different responses came when asked about if the experience brought them closer or bring them apart. In this couple, the father reported, “I think if anything, it brought us closer together. Because I think after that, I was with (wife) non-stop.” The mother in this couple reported “I think at the beginning it kind of did, but now that time is going on, I just feel like it's kind of slow down. Growing apart a little bit.” When asked if she felt that the stillbirth was the cause of them growing apart, the mother responded, “I don't think so. It just is, you know like as time passes, things change. I guess that's a big part of what it is.”

When talking about grief, one mother's encouragement to couples was that they “Just cut each other some slack. Let each other grieve... Just because you don't see another person's grief, or it doesn't look like yours. It doesn't mean that they don't have grief. They're just experiencing it differently.”

Long-term impacts. Many couples reported on the long-term impacts of their loss. Couples discussed the importance of having the opportunity to help others in their journey with grief. Couples discussed the constant reminders that exist of their loss. These include due dates, anniversaries, birthdays, and seeing staff that were at the hospital that day. Couples reported the flood of emotions will often appear without warning. One couple described having a code word to use with their spouse when they when the difficulties of the loss had returned. Many parents

described the need to allow the grief to happen. One mother expressed a particular reminder of the day she lost her baby:

But I don't resist it, I like it to come back to me. And if I cry, I cry if I want to. If somebody sees me, who cares? I don't try to hide my grief. I embrace it. It's a memory and it's part of me.

While the emotions could be difficult, parents reported wanting to remember the baby and keep them as part of their family. Many reported they celebrate birthdays for the baby and speak openly about the child with other children. Parents described how they wanted to be sure their child wasn't forgotten.

Guilt. Parents reported that a sense of guilt would overcome them when they would begin to smile again or have joy. One father reported this guilt even extended into fulfilling basic needs by saying, "We shouldn't be laughing together, or like, having joy... that soon after. It felt like it would be disrespecting of our loss or something. So we often had to remind each other to eat."

Mental health and suicidality. Couples reported multiple struggles that impacted their mental health following the stillbirth. For some, it was a manageable amount of depression that was overcome by the passage of time. For others, the depression became debilitating and brought on thoughts of ending their life. One mother described how she got to the point of authoring a suicide note about a month after losing her daughter. This mother said:

There were times when I didn't get out of bed. I was struggling. And, there is even a point where I wrote a suicide note, I just wrote it out, and then I shredded it, and it seemed like that was the turning point. You know, I just rolled up thinking, I cannot handle this anymore. I just, I, I seriously contemplated it. But like I said, I wrote that suicide note and shredded it, and it just felt like a burden has been lifted. That was my turning point.

Multiple participants reported the need to seek out professional counseling after the loss. One mother discussed how she was strongly encouraged by family members to seek out help for her depression related to the loss.

Parents described feelings of emptiness as part of this process. One mother described the emptiness she felt upon returning home:

I felt very empty. Because, I had just given birth. I think that most women at this point, they get to learn how to be a mom. They're learning how to breast-feed, and they have their baby, but I was just there. Instead of being a person and a half, I was just a person, and I didn't have the half.

Many mothers reported the coming home experience became even more difficult when others, particularly their husband, would return to normal activities like work. One mother recounted when her husband returned to his normal activities that, "it was just me, alone. By myself. Without a baby, without a husband. Without anything. That was probably my lowest point. When it actually hits you. When you're just like, this is me now."

Support groups. Just as support groups were reported to be helpful during the clinical period, participants reported they continued to be helpful in the long-term. One mother discussed how meeting with a support group helped to normalize her grief. Parents often spoke about the mementos that these groups help to create or provide and how much they appreciated having them. One participant described how the mementos these groups had provided became more meaningful with time by saying, "looking back now, I didn't know I wanted them then. But now, that's literally, like, the only tangible thing we have."

Lasting grief. Many discussed the idea that the pain does not ever completely leave. One expressed simply that, "you have to stop loving for it to stop hurting." One participant encouraged those that grieve to remain strong in the grieving process:

Go forward, and just be strong. But, at the same time, I would say, and I have told people this, it's ok to cry. It's ok to just have days where you're just furious at the situation. It's ok to have days where you're sad about the situation, and it's ok to...be upset. Because people handle things differently.

The purpose of this chapter has been to review the major themes that emerged from this study: *the clinical encounter, grief and loss, relationship with spouse and family, and long-term impacts*. Quotes from participants have been included to help illustrate these different themes. Trustworthiness and how it was addressed in this study has also been discussed. The focus now turns to a discussion of the findings of this project, limitations, and possible future directions for research.

CHAPTER 5

DISCUSSION

For participants of this study, it was evident that there was an overall appreciation for having the opportunity to share their experience. There may be a fear, when carrying out this type of research, that individuals will not want to revisit and be open about painful experiences. However, as previous researchers have discussed, parents that experience stillbirth often appreciate having the opportunity to take part in projects to benefit those that will experience stillbirth in the future (Burden et al., 2016; Kelley & Trinidad, 2012). In this project, further evidence of parents' willingness to discuss this difficult experience came from the relatively short amount of time it took to recruit the needed participants. Among those not included in this study were multiple couples that, for a variety of reasons, were not able to participate in this study. It was not difficult to recruit couples that wanted to talk about their stillbirth experience. It appeared this motivation to participate came from sources such as wanting to have pregnancy loss more commonly talked about, improve care for future couples, or to simply have a chance to remember their baby. Not only are couples willing to share, it appears they benefit from being able to share.

When discussing their experience taking part in the interviews, participants would make comments that the interview had "been helpful" or had "been good" for them. When compensation for participation was offered, one couple responded, "You do not need to compensate us, we are happy to share." Further evidence of opportunities like this being positive for couples came from a post-interview survey couples completed. In these surveys, participants were given an opportunity to "rate your overall experience sharing your story for our project."

This question was on a 5-point scale including very negative, somewhat negative, neutral, somewhat positive, and very positive. In response to this question, 14 participants reported the experience being “very positive.” The remaining 2 participants reported the experience being “somewhat positive.”

Many findings from this project provide support for existing projects. This project provides support for previous research that has found stillbirth to often be an unexpected and life changing experience (Burden et al., 2016; Cacciatore, 2013). With stillbirth, comes biological, psychological, social, and spiritual consequences (Campbell-Jackson & Horsch, 2014). While difficult for the individual, the experience of stillbirth will be a shared one. Couples navigating this difficult period of life are at increased risk for marital difficulties as well (Cacciatore, 2013).

Discussion of Results

The results of this study help to highlight the phenomenon of stillbirth both within and outside of the context of the clinical encounter. The results of this study also help to highlight the differences in how partners might experience this time period, as well as long-term grief, differently. The BPSS model also assisted in the highlighting of the many biological, psychological, social, and spiritual impacts that came as a result of stillbirth. As will be discussed, much of what has been found in this project supports what has been found in previous research.

The clinical encounter. Among this sample, a variety of experiences were presented during their time in the hospital. A few themes however did emerge. Within these themes, participants seemed to appreciate the simple gestures that hospital staff were often willing to give. As found in previous research, parents expressed appreciation for when hospital staff could

keep them informed about what was happening and give the parents options where possible (Pullen, Golden, & Cacciatore, 2012). For parents, communication from hospital staff appeared to be crucial.

Interactions with hospital staff. Whether positive or negative, it appeared the medical professionals did not have to do much to leave a lasting impression. Couples discussed how a simple word or gesture brought comfort or validation when they needed it. Other simple comments left couples feeling discouraged or angry. Whether positive or negative, parents reported they have vivid memories of these seemingly insignificant interactions. Indeed, parents using titles such as “gems” and “angels” suggests medical professionals play a key role in shaping the experience as an overall positive or negative one. As mentioned in the results, simple comments that invalidate the loss lead parents to want to leave the hospital as quickly as possible.

Hospital care/accommodation. Within this sample, hospitals appeared to put a significant amount of effort into creating an environment where couples were allowed privacy. In most cases, couples were given a room distanced from other patients so they would not hear the cries of other babies and other celebrations of live birth. An unexpected theme among these parents was that their regular obstetrician was out of town or on vacation when the stillbirth occurred, meaning parents had to experience labor and delivery with a doctor they had not met before and had not built a relationship with.

Couples, especially mothers, appreciated when hospital staff would make exceptions to protocol. One mother, who endured a 24-hour labor, described the doctor that took over her care 10 hours into labor as “my angel.” This was all the result of a simple deviation from the protocol of not letting the patients eat while they are in active labor. Upon an examination, the doctor

instructed medical staff with “let’s get this girl some food.” While seemingly insignificant, these gestures appear to make a significant difference in how couples experience the clinical encounter. One mother felt it was important for stillbirth to be treated differently than a live birth and that she was helped in her situation by the staff “throwing rules out the window.” This mother described how rules meant to keep the baby safe no longer have merit because, “they’re not going to die, they’re already dead.” The mother noted that other common rules, such as not being able to walk around with your baby, should no longer apply as this is the parent’s one chance to walk around with their baby.

Grief and loss. It may be difficult for those outside of the stillbirth experience to understand how grief can be so profound for a couple when they never had the opportunity to see their baby alive. While true the baby never came home, it is apparent from these interviews that couples began building connections with their children when they found out they were pregnant. In some cases, parents wanted to make a routine of listening to their growing baby’s heartbeat. Other family members and friends simply never had this opportunity to connect with the baby. The couples in this study made it abundantly clear that they consider their stillborn to be a member of the family and they have every intention of making sure they are remembered.

The process of grief for stillbirth appears to start as feelings of shock and devastation. As found in previous research (Lindgren et al., 2014), these couples have a difficult time processing the magnitude of the situation. As time passes however, it appears these feelings are replaced by feelings of emptiness and depression. The lowest point for some participants came when they returned home without the baby and supporting family members now returned to their normal routines. This was a key difference between mothers and fathers, where fathers often had a

routine to return to while the mother had to return home to recover. This recovery was often described as an experience of being pain without the reward.

Some participants made reference to the stages of grief as discussed by Kübler-Ross (2009). Many discussed the feelings of denial, anger, depression, and eventual acceptance of what had happened. Participants described how the different emotions would come and go. One of the hopes for this project is that the data would yield insight on how these couples potentially grieve, or handle, the hospital experience differently following a stillbirth. The couples made it clear that they grieved differently from each other. What also became apparent from this project was that each individual person had their unique way to grieve. It appears problems would arise when others would make assumptions about how the other should grieve. Couples continually encouraged those going through this situation to recognize that you and your partner are going to grieve differently. While participants did reference models of grief, including the Kübler-Ross model (2009), it appears that more important than a certain pattern to follow with regards to grief, was *giving yourself permission to grieve*. Just as important, is “cutting your partner some slack” and allowing them to grieve in their own way. It seems the balance that couples need to strike is being able to pursue their individual grieving style without sacrificing the connection made possible by this shared experience.

For some mothers, there was a sense of guilt, a feeling that they had somehow failed in their responsibility as a mother to carry a baby to full-term. Other thoughts would come up for these mothers that perhaps if they had done something differently that they're baby would be alive. This was especially prevalent for those who felt their baby kicking just hours before. In this study, fathers did not bring up the idea of feeling guilt for the stillbirth. This supports previous research that fathers do not experience guilt like mothers do (Badenhorst, et al., 2006).

Fathers also discussed a reluctance about being as open with their emotions and grief as their wife was. Fathers expressed a need to be “strong” for their wife and not show emotion. Mothers were also put in a situation where they returned home to recover from the physical toll of childbirth, but did not have the reward of a beautiful baby at their side. Mothers discussed the difficult reminders of the loss of their baby. These included breasts that were full of milk, scars from a caesarean section, and the supplies and furniture sitting around the house that had been purchased for the baby.

Relationship with spouse and family. Family and friends proved to be a support to these couples in their time of need. Many instances were reported where a family member stepped in to help make the needed arrangements for the burial or a funeral. These were important gestures as they allowed the couple to focus on spending time with the baby they would not get to take home. Some family members were able to take on the role of “contact person” and took charge of contacting other family and friends to let them know of what had happened. For others, church members and friends took on this role of letting community members know what had happened. Again, this appeared to be important as it allowed the couple to focus on medical decisions to be made and allowed them the opportunity to focus on being with their child.

Parents seemed willing, or wanted, to have family members and friends meet and hold their stillborn. The parents of the stillborn seemed to appreciate when these family members treated their baby like a live baby. This seemed to be helpful in legitimizing the parent’s loss as a real one and it came across as a kind gesture of compassion towards the family.

With regards to the marital relationship, parents seemed to agree the experience of stillbirth presented their relationship with either great risk or great possibility (Cacciatore et al.,

2008b). In this study, couples overwhelmingly felt that the experience had brought them closer together. Others considered the event as a special bond between them and their partner. This is supportive of previous research that has found couples to see events like stillbirth as providing a meaningful connection between them (Burden et al., 2016; Cacciatore et al., 2008b). For one participant, there was a feeling that the stillbirth had initially brought her and her husband closer together, but that they began to grow apart after a while. In the interview, when asked if she would attribute the growing apart to the stillbirth, the mother responded, “I don’t think so. It just is, you know like as time passes, things change. I guess that’s a big part of what it is.” The husband in this case felt that the experience of stillbirth had brought them closer together.

Long-term Impacts. Many parents voiced the idea that the pain associated with their grief has not stopped. One mother summed up pain simply, “You have to stop loving for it to stop hurting.” Parents are often reminded by the loss of their child through anniversaries, birthdays, and other reminders. These reminders bring on a flow of emotions. While difficult, some parents expressed that these emotions were not unwelcome. In fact, some reported embracing these difficult moments and using it as an opportunity to reflect on the baby they lost. Important for researchers to understand is that many of these parents like to be reminded of their experiences with their baby. Supporting previous research, some parents described how ceremonies and rituals were helpful to the entire family (Kelley & Trinidad, 2012).

Mental health. As reported in previous studies (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014), mental health was a major concern for many participants. Many that struggled with depression were fortunately able to receive the needed help. For some, depression got to the point where the mother considered suicide. The period of going home and having to settle back into a new normal or a new routine appeared to be the most prone for these types of

symptoms. The graduate student conducting the interview is a training therapist that was diligent in checking in on current symptoms, ensuring there was not an immediate threat, and offering referrals for therapy. One participant reported suicidal ideation on the assessment that was completed before the interviews. During the interview, this same participant reported currently having a therapist that was “really good.”

Ambiguity. Couples in this study seemed to struggle with the ambiguity of the situation. Some of the couples were left unsure of how they should grieve. It was difficult for many of these couples to come to a resolution about the loss as many questions were and remain unanswerable. Just as has been found in previous research (Cacciatore et al., 2008a), some parents in this study mentioned not having an answer to why their baby died. What appeared to be helpful was when couples had the opportunity to participate in rituals or ceremonies. This supports previous research that suggested these types of activities can be helpful to the entire family (Kelley & Trinidad, 2012).

Bio-psycho-social-spiritual Model

As much happened for these couples in a short amount of time, it is helpful to have an intuitive model like the BPSS model to help describe the different needs and experiences that these couples reported during and following the clinical encounter.

Biological considerations. In these interviews it seemed that the parents were saying something to the effect of, “give us options where you can, and where you can’t, at least explain what is going to happen.” From these interviews, it appeared that parents trusted and appreciated the expertise of the medical professionals but appeared to appreciate having a measure of autonomy during this time period.

It is important to remember that the mothers in this study endured and had to recover from the same labor and delivery process as any other mother. This *pain without reward* became especially difficult when physical symptoms following birth, like breasts full of milk, were painful but also a reminder that they had lost their baby.

Psychological considerations. Both in the time immediately following notification of stillbirth and in the long-term, multiple mental health considerations were evident. As it appears mental health concerns and even suicidality manifest after the clinical encounter, follow up and encouragement to seek out psychological help was key. While working with therapists to navigate loss was mentioned, collaborative care with mental health professionals did not appear to be utilized.

Social considerations. It appears among the strongest resources for healthy grieving was having a group of people that partners could connect with that had also gone through a stillbirth. This comradery allowed mothers and fathers a safe place where they could have their grief normalized and be able to voice any frustrations they have. Also helpful were supportive friends and family that could help with physical and logistical needs. These family members and friends also appears to be a strong emotional support. It would have been interesting if this study had participants that were not able to identify a significant support network surrounding them.

Spiritual considerations. As it is not uncommon for parents to express a frustration or anger at God for the stillbirth, there clearly appears to be a spiritual component to stillbirth. As found in previous studies (Bakker & Paris, 2013), some participants took time to evaluate their spiritual beliefs and practices. For some, the experience of stillbirth became a spiritual one.

Summary. For medical professionals, their primary responsibility is to the biological/physical health of their patients. However, as Engel (1977) would encourage, it is

important to keep in mind the other major areas of health that stillbirth impacts. If medical professionals feel they are not able to adequately treat these other areas of health, considerations and efforts should be made to collaborate with other professionals/third-party groups so that these other areas of health can be addressed.

Limitations

While having a number of strengths in what this study can add to what is known about the clinical encounter, this study possesses notable limitations. As such, the ability to generalize the results is limited. A larger sample size would have allowed for the results to be more generalizable. While eight couples, sixteen participants, is an appropriate size for this phenomenological study, this limited sample does also act as a limitation. Future projects should and will examine larger and more diverse groups.

Another notable limitation is the lack of diversity in our sample. Nearly all, 93.75%, of the sample self-reported as white/Caucasian. A more racially diverse sample would have allowed for a better understanding of these experiences from the perspectives of different cultures. While we had a homogenous sample to allow for a focus on the phenomenon, this also ends up being a limitation. This study looked specifically at the experience of intact couples that were married at the time of stillbirth. This excluded the experiences of populations including single parents, couples that have since divorced, couples that were not the biological parents, and certainly other populations not listed here. Another limitation is the diversity of geography; 87.5% of participants were located in the state of Utah. While attempts were made to advertise out of the state, by far most responses came from the social networks of those located in Utah.

Another limitation is trying to better understand an individual's experience with both partners present. Spoken words by mothers appeared to outweigh the amount spoken by fathers. While all questions were posed to both partners, it is possible that the husband felt that he should defer to the wife's experience, that he did not know what to share or what to say, or simply had less to say about the experience. While the reason for why is not known, there is clearly more we could have gained from the fathers in this study. A limitation of this study is we potentially know less about the husband's individual experience regarding stillbirth than we do about the wife's. Future research will look to gain and examine a greater depth of the experience for the father.

Implications for Individuals, Couples, and Families

The couples in this study, while having common themes, each had a unique experience. Couples found it helpful to talk openly about how they would need to grieve. Also important was giving themselves permission to grieve. Where needed, improvements could be made on how hospitals follow-up with patients about their mental health. This care and follow-up should include the father of the baby as well. As noted by one father, follow-up is as crucial as the normal follow-up for the care of these patients is meeting with a pediatrician.

Stillbirth has again shown to have the ability to bring couples closer together or further apart (Cacciatore et al., 2008b). The period of the clinical encounter appears a prime opportunity to put couples on a healthy trajectory for grief. Couples in this study reported that the most helpful thing for healthy grieving was giving your partner permission to grieve how they needed to and recognize their way of grieving may not be the same as yours. Couples can be helped to recognize that different grieving styles are not an indicator of weakness in the relationship, but instead is the norm. From the interviews, couples appeared to be able to best achieve this with

open communication and taking the time to listen to what their partner was experiencing.

Appendix B illustrates how a couple may be able to find a balance between their individual experience and the shared experience with their partner.

Future Directions

With the amount of salient themes that have emerged from this study, a number of future directions should be considered. Researchers should be encouraged by the willingness and desire of parents to participate in these types of studies. As a major motivator of this project was examining stillbirth as a systemic issue, future studies should seek to better understand the experience for siblings of a stillborn. It would be particularly salient to discover how children approach grieving these types of situation. In addition, research could be benefitted by the further examination of this experience on grandparents and extended family.

With the unbalance between responses of mothers and fathers (approximately seven words from mothers for each three words from fathers), it would be beneficial to have additional studies that explore the experience of fathers and stillbirth. Researchers could consider holding interviews with the father separately so a greater depth into his experience could be gained. In addition, similar studies ought to be conducted with diverse populations and those that have a smaller or no support network.

Additional studies could look into the impact of an evidence-based training for medical professionals. From this study, it was clear that medical staff had a significant impact on how the clinical encounter was experienced. These studies should seek to understand what, if any, impact additional training for medical professionals can have on how couples experience the clinical encounter and their long-term grief response.

Parents often expressed appreciation for pursuing this topic. Each of the participants took part in a post-interview survey and had the opportunity to respond their overall experience of sharing their story for this project. The options were (1) very negative (2) somewhat negative (3) neither positive or negative (4) somewhat positive and (5) very positive. Of the 16 responses to this question, 14 reported having “very positive” feelings towards sharing their experience. This aligns with previous research that has found that parents often find it beneficial to take part in research projects, provide support and mentorship to others, and work with hospitals to improve service (Burden et al., 2016; Kelley & Trinidad, 2012). Two participants marked “somewhat positive” feelings toward the experience of sharing. This further suggests that parents are ready and willing to discuss this difficult part of their lives.

Conclusion

While difficult, many couples found a way to come away from the stillbirth experience stronger as a couple. Important to remember is that grief has been found once again to be a process, rather than a one-time event. It is important to keep in mind the finding of Burden and colleagues (2016) that relational difficulties following a stillbirth are seen as the result of incongruent grieving styles. This study has replicated a finding that couples find a great deal of strength coming from having, and giving, permission to grieve in the way that felt best for the individual (Cacciatore et al., 2008b).

Four major themes emerged as a result of this study: *the clinical encounter, grief and loss, relationship with spouse and family, and long-term impacts*. Naturally many of the issues that were raised by either partner could fit into multiple categories. From this study comes a reminder of the need to approach care for those experiencing stillbirth with a more holistically.

Significant symptoms within each section of the BPSS model were found within this sample. This study suggests that no one group of people or profession provided this population with everything they needed to successfully grieve. What was required was a collaborative approach where the hospital was able to call in additional resources or third-party groups to help couples begin to navigate this difficult process. Where it does not already exist, collaboration with mental health professionals would serve as a great asset to medical professionals. Support groups should be reassured by this study that the work that they do makes a significant difference in the lives of individuals and couples navigating the stillbirth experience.

Future research should continue to investigate the relational components of difficult experiences like stillbirth. That special bond that comes from sharing an experience like this allows for healthier coping. Together, support groups, mental health professionals, and physicians can continue to seek to improve care for this population.

REFERENCES

- Badenhorst, W., Riches, S., Turton, P., & Hughes, P. (2006). The psychological effects of stillbirth and neonatal death on fathers: Systematic review. *Journal of Psychosomatic Obstetrics & Gynecology*, 27(4), 245-256.
- Bakker, J. K., & Paris, J. (2013). Bereavement and religion online: Stillbirth, neonatal loss, and parental religiosity. *Journal for the Scientific Study of Religion*, 52, 657-674.
- Bonnette, S., & Broom, A. (2011). On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology*, doi: 1440783311413485.
- Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family*, 66(3), 551-566.
- Boss, P., Dahl, C., & Kaplan, L. (1996). The meaning of family: The phenomenological perspective in family research. *Research Methods in Family Therapy*, 83-106.
- Burden, C., Bradley, S., Storey, C., Ellis, A., Heazell, A. P., Downe, S., Cacciatore, J., & Siassakos, D. (2016). From grief, guilt pain and stigma to hope and pride - a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy & Childbirth*, 161-12. doi:10.1186/s12884-016-0800-8
- Cacciatore, J. (2013). Psychological effects of stillbirth. *Seminars in Fetal and Neonatal Medicine*, 18(2), 76-82.
- Cacciatore, J., DeFrain, J., & Jones, K. L. (2008a). When a baby dies: Ambiguity and stillbirth. *Marriage & Family Review*, 44(4), 439-454.
- Cacciatore, J., DeFrain, J., Jones, K. L., & Jones, H. (2008b). Stillbirth and the couple: A gender-based exploration. *Journal of Family Social Work*, 11(4), 351-372.

- Campbell-Jackson, L., & Horsch, A. (2014). The psychological impact of stillbirth on women: A systematic review. *Illness, Crisis & Loss, 22*(3), 237-256.
- Centers for Disease Control and Prevention. (2015a). 2013 fetal death data set. Retrieved from http://www.cdc.gov/nchs/data_access/Vitalstatsonline.htm
- Centers for Disease Control and Prevention. (2015b). 2013 natality detail data set. Retrieved from http://www.cdc.gov/nchs/data_access/Vitalstatsonline.htm
- Cohen, D., & Crabtree, B. (2006, July). Member Checks. Retrieved August 28, 2017 from <http://www.qualres.org/HomeMemb-3696.html>
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Los Angeles, CA: Sage.
- Dahl, C. M., & Boss, P. (2005). The use of phenomenology for family therapy research. In D. H. Sprenkle & F. P. Piercy (Eds.), *Research methods in family therapy* (pp. 63-84). New York, NY: The Guilford Press.
- DeFrain, J. D. (1986). *Stillborn: The invisible death*. Lexington, MA: Lexington Books.
- Erlandsson, K., Säflund, K., Wredling, R., & Rådestad, I. (2011). Support after stillbirth and its effect on parental grief over time. *Journal of Social Work in End-of-Life & Palliative Care, 7*(2-3), 139-152.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*, 129-136.
- Farrow, V. A., Goldenberg, R. L., Fretts, R., & Schulkin, J. (2013). Psychological impact of stillbirths on obstetricians. *The Journal of Maternal-Fetal & Neonatal Medicine, 26*(8), 748-752.

- Funk, J. L., & Rogge, R. (2007). Testing the Ruler with Item Response Theory: Increasing Precision of Measurement for Relationship Satisfaction with the Couples Satisfaction Index. *Journal of Family Psychology, 21*(4), 572-583.
- Kelley, M. C., & Trinidad, S. B. (2012). Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth—a qualitative analysis. *BMC Pregnancy and Childbirth, 12*(1), 1.
- Kübler-Ross, E. (2009). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families*. New York, NY: Taylor & Francis.
- Kübler-Ross, E. (2011). *On children and death*. New York, NY: Simon and Schuster.
- Lindgren, H., Malm, M. C., & Rådestad, I. (2014). You Don't Leave Your Baby—Mother's Experiences after a Stillbirth. *OMEGA-Journal of Death and Dying, 68*(4), 337-346.
- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care* (2nd ed.). Washington, DC: American Psychological Association.
- McWey, L. M., James, E. J., & Smock, S. A. (2005). A Graduate Student Guide to Conducting Research in Marriage and Family Therapy. In D. H. Sprenkle & F. P. Piercy (2nd ed.), *Research methods in family therapy* (pp. 63-84). New York, NY: The Guilford Press.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Prest, L. A., & Robinson, W. D. (2006). Systemic assessment and treatment of depression and anxiety in families: The BPSS model in practice. *Journal of Systemic Therapies, 25*(3), 4-24.
- Pullen, S., Golden, M. A., & Cacciatore, J. (2012). "I'll Never Forget Those Cold Words as Long as I Live": Parent perceptions of death notification for stillbirth. *Journal of Social Work in end-of-life & Palliative Care, 8*(4), 339-355.

Silver, R. M. (2007). Fetal death. *Obstetrics & Gynecology*, *109*(1), 153-167.

Smith, S. R., & Hamon, R. R. (2012). *Exploring family theories* (3rd ed.). New York, NY:

Oxford University Press.

Stinson, K. M., Lasker, J. N., Lohmann, J., & Toedter, L. J. (1992). Parents' grief following pregnancy loss: A comparison of mothers and fathers. *Family Relations*, *41*(2), 218-223.

APPENDICES

APPENDICES

Appendix A: Demographics of Sample

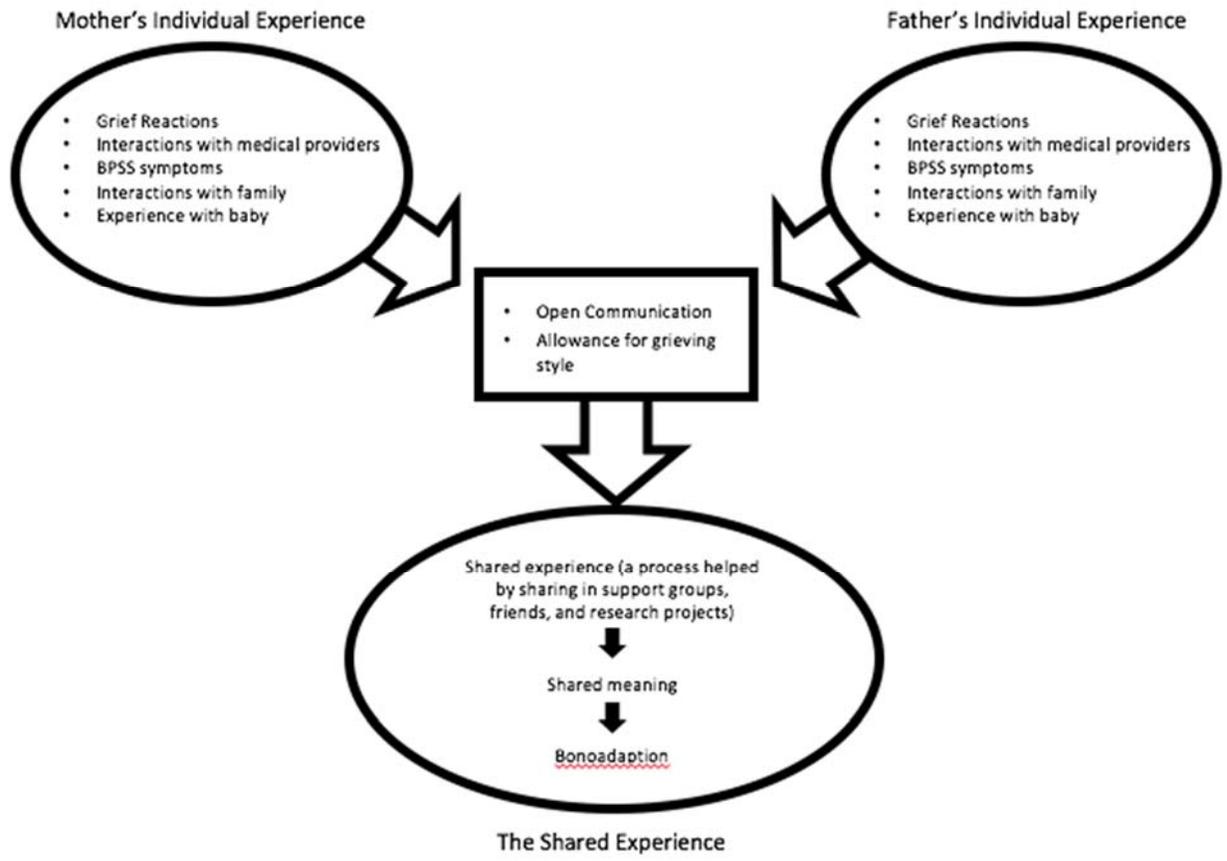
<i>Demographics of sample</i>				
Variables	<i>n</i>	%	Mean	<i>SD</i>
Age	16		30.75	6.21
Female	8	50	29.87	6.05
Male	8	50	31.62	6.65
Gender	16			
Female	8	50		
Male	8	50		
Race	16			
Caucasian/White	15	93.75		
Bolivian	1	6.25		
Years in current marriage				
5-9	8	50		
10-14	6	37.5		
15-19	2	12.5		
Pregnancies before stillbirth	8			
0	4	50		
1	1	12.5		
2	1	12.5		
4	2	25		
Location	16			
Utah	14	87.5		
Pennsylvania	2	12.5		
Education level	16			
High school diploma/GED	2	12.5		
Some college	7	43.75		
Bachelor's degree	5	31.25		

or equivalent Master's degree or equivalent	2	12.5
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Income level (Combined)

\$20,000-24,999	1
\$25,000-29,999	
\$30,000-34,999	2
\$35,000 and over	13

Appendix B. Model for Balancing Individual Grief With Establishing a Shared Experience



Appendix C: Questions for Participating Couples

1. To start, I'd love to hear about your overall experience related to stillbirth.
 - a. What memories do you have of that day?
2. What were your interactions like with medical staff?
3. How did you both grieve during your time in the hospital?
 - a. What similarities and differences were there?
4. What impact would you say the hospital experience had on your relationship?
5. If you had the opportunity to meet with a couple that had just experienced a stillbirth, what would you tell them or what would you want them to know?
6. If you had the opportunity to meet with medical professionals, what advice would you give them with regards of how to care for couples that have experienced a stillbirth?
7. Is there anything else you'd like to share with regards to your experience with stillbirth?

Appendix D: Addition from Member Check

One participant, a mother, decided to make one addition to her interview. She wrote:

The only thing I'd add to your list is the postpartum healing paradox for mom. Childbirth is rough on a woman's body and with my three other pregnancies, I couldn't wait to finally be healed, drop some of the weight, become a little regulated with the whole breastfeeding bit, and basically, start looking and feeling like a normal person. With my stillborn, it was completely different. The physical signs that I had once been expecting a baby were some of the precious few reminders that could tell the outside world that my baby had, in fact, existed. I remember a follow up OB/GYN visit where the Doctor told me that I was healing well and looked like my uterus had returned to its normal size- and that was only 6 weeks post delivery. I was very emotional because I felt like my body, in that sense, had already completely forgotten that it had carried her for nine months and was already able to make the "replacement" baby. To this day I have a tiny, almost invisible scar from my labor IV that I cherish because it's the only physical sign of that experience. When I needed IVs for my next two, I asked the nurses to use the other arm so they wouldn't damage the scar with a new one. Lactation was bittersweet, too. I remember being painfully engorged for three whole months- constantly uncomfortable, wondering if my breasts would ever be the same because I was so swollen, clear to my collarbone and underarms. Eventually though, it got better and I remember when I could no longer squeeze out a single drop of breastmilk- more than 6 months after delivery. It was as though the last manifestation of her vanished, and I was very

bothered by that. I remember thinking that nature takes its course regardless of how someone “feels” about it, and that there are all these instincts a mother has that are still in place even when the baby is not there. Things like waking up every few hours at night with the first thought “gotta check on the baby!” and then realizing that there is no baby. So life goes on, the body heals, even the buried baby starts to decay, and with a stillborn- whom the world never knew, the signs of their life disappear with every step of a mother’s physical healing.