

UNDERSTANDING THE NATURE AND IMPACT OF EARLY PREGNANCY LOSS
THROUGH WOMEN'S STORIES

by

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ABSTRACT
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Guided by Harter's narrative framework for health communication this thematic narrative analysis sought to understand women's experiences of early pregnancy loss with focus on sense making and communication by gathering stories from women who lost a wanted or accepted pregnancy at or prior to at twenty weeks in utero. Ten women ranging in age from twenty-six to seventy years old participated. Time since loss experience ranged from two months to forty years prior to the interview. Ellingson's crystallization technique was employed with focus given to creating two related texts. Analysis of both individual core narratives at the time of loss and sub-stories located across the entire interview data strengthened early pregnancy loss understanding. Three core narrative summaries provide commonalities of experience within the following convergent core narratives: (a) conceptualization (what was lost?) (b) secret motherhood (disenfranchised grief), and (c) anchoring emotions (talking helps). Two sub-stories occur throughout the data, lost at sea and processing EPL. Lost at sea consists of three themes: (a) blindsided by the unexpected, (b) lack of acknowledgment within interpersonal interactions, and (c) EPL as marginalized by society. Processing EPL consists of: (d) cause of EPL, (e) emotional anchors, and (f) "time heals...it doesn't erase." The six themes indicate participants' shared reactions from the first moments of experiencing loss to current

understandings of the EPL experience. The three core narratives symbiotically interact with the six themes to provide a coherent picture of the participants' early pregnancy loss experiences. Stories gathered provide a depth of understanding early pregnancy loss experiences and communication surrounding the topic both closer to the time of incident and how women understand the experience at the time of interview. Results contribute support for and extension of existing knowledge of disenfranchised grief and the power of the story in the context of early pregnancy loss. Results suggest that in situations of disenfranchised grief of early pregnancy loss, the first step in moving toward working with and/or living in one's new normal is the ability to speak of the early pregnancy loss. The results provide a deep understanding of the emotional turmoil women experience at time of early pregnancy loss and how the emotions may resurface many years after the event. The new normal exists on a continuum. Women often continue to understand, live into, and with the unexpected early pregnancy loss years beyond the occurrence. As demonstrated through participant's stories, even though the pain remains the ability to create an alternative option to the original family plan exists. As the data demonstrates, women experience communicative interactions that fail to acknowledge EPL and that acknowledge EPL. Often communication regarding early pregnancy loss is described as societally and interpersonally disenfranchised, silenced, dismissed, and not talked about. Apparent in the stories, the inability to acknowledge and talk about EPL within interpersonal and societal contexts detracts from a woman's ability to work through the emotions that accompany such a blindsiding event. However, when interactions involve the acknowledgment of EPL, communication is described as anchoring, supportive, and assisting with coping with the pain of loss. Particularly salient to participants' adjustment

to the situation, or new normal, were the memorable moments where practitioners said or did things that positively impacted the participants' EPL experience. Participants' stories indicate women benefit from telling stories of early pregnancy loss. The stories remain present long beyond the loss occurrence, highlighting the potential need for more discussions to occur both with women recently experiencing early pregnancy loss and women carrying the secret motherhood story years beyond the occurrence. Understanding "*time heals...it doesn't erase*" may warrant further investigation of stories from women experiencing early pregnancy loss and the need to provide discussion with an avid, empathic listener. Women may benefit from anchoring conversations whether the loss occurred recently or long ago.

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Chapter One

Introduction

A death is difficult and often tragic for close friends and family, whether the individual lived a full life or died at a young age. When discussing such loss, sadness often accompanied by remembering fond moments shared with the individual, can assist with the grief process. Loss discussions may be trickier when an early pregnancy loss occurs (defined as a loss of a pregnancy up to the 20th week, The American Congress of Obstetricians and Gynecologists, 2002). Attempting to discuss the loss of what was never born proves difficult (Layne, 1997). Yet with 10 to 25% of pregnancies ending in early pregnancy losses as reported and confirmed by a doctor (American Pregnancy Association, 2007) and the potential for additional unreported experiences, understanding what contributes to the difficulties around discussing early pregnancy loss (EPL) from the viewpoint of the patient appears relevant.

This study extends current knowledge of the influence and impact of interpersonal and societal communication surrounding (or missing from) early pregnancy loss interactions on women's understanding and experience of EPL. Findings obtained and analyzed from personal stories of EPL uphold and further existing literature on early pregnancy loss experiences and support prior calls for utilizing narratives to better understand individual's healthcare experiences. Results of this study may influence and benefit practitioners and academics working to improve communication surrounding early pregnancy loss occurrences.

To better understand existing knowledge of difficulties present in women's EPL experiences the chapter begins with a brief overview of supportive communication.

Knowledge of supportive communication assists in understanding the material that follows which highlights the social complications existing in early pregnancy loss experiences, including communication within the healthcare context. Discussion of the value narrative inquiry provides focuses on the functions stories serve. Next, the narrative framework for health communication guiding this research, Harter's (2013) "imagining new normals" is presented. The chapter closes with the research questions.

Supportive Communication

Extensive research exists regarding the construct of social support. Many different definitions and applications for social support exist across varying academic fields (Dunkel-Schetter, Blasband, Feinstein, & Herbert, 1992; Goldsmith, 2004). Broadly defined, social support refers to behaviors that communicate to a person that he or she is "valued or cared for by others" (Barnes & Duck, 1994, p. 176). Such behaviors may present as indirect or direct. Behaviors include both nonverbal and verbal acts intended to provide assistance to those perceived as requiring aid (Burlison & MacGeorge, 2002). Many studies focus on identifying supportive communication typologies present in encounters to understand and categorize support (Cutrona & Suhr, 1994; Dakof & Taylor, 1990; Goldsmith, 2004; House, 1981; Jacobson, 1986; Schaefer, Coyne, & Lazarus, 1981). Other studies focus on types of support understood as helpful or hurtful/harmful if said or done in a particular context (Brock & Lawrence, 2009; Burlison, 1994; Burlison & MacGeorge, 2002; Dunkel-Schetter, et al., 1992; Goldsmith, 2004; Hawkins, 2012; Schaefer, Coyne, & Lazarus, 1981; Vangelisti & Crumley, 1998; Vangelisti, 2009). This discussion of supportive communication includes the benefits of enacted support; "the things people say and do for each other" (Goldsmith, 2004, p. 4), constructs often applied

to supportive communication, and messages of support within the context of early pregnancy loss.

Schaefer et al. (1981) state the importance of understanding the different types of support and how they may impact health and psyche. These researchers identified three types of social support: tangible, emotional, and informational. Tangible support involves actual items provided or services given that provide direct help. Emotional support involves “feeling that one is loved or cared about (p.386)”;

one belongs. Informational support involves information or advice being given to another to assist with problem solving. Dunkel-Schetter, et al. (1992) broaden the definition of informational support to include advice and information of any kind, including information about the environment and one’s self. The types of support may occur alone or in tandem. Schaefer et al. (1981) found that the combination of more tangible and emotional support result in less depression and/or negative thoughts. Goldsmith (2004) adapted Schaefer et al.’s (1981) typology to her study of enacted supportive communication similarly describing tangible and informational support. She adds to emotional support by including the communication act of expressing instead of just being on the receiving end of feeling. Emotional support involves “expressions of caring, concern, empathy, and reassurance of worth” (Goldsmith, 2004 p.13).

Cutrona and Suhr (1994) add to Schaefer et al.’s typology the constructs of esteem support, and social network support. Esteem support can serve multiple functions, facilitating or nurturing by noticing an individual’s skills, abilities and values (Cutrona & Suhr, 1994). Esteem support compliments an individual, or emphasizes abilities sending messages of reassurance to the person in need (Cutrona & Suhr, 1994). Validating and

agreeing with the person needing support, by taking their side to show support or relieve thoughts of blame are critical to esteem support. Social network support allows an individual to know another is present to listen, be there, and show companionship. Often the supporter demonstrates an understanding of the person's experience, sharing a similar situation (Cutrona & Suhr, 1994). The benefits of all five types may occur alone or in tandem to express social support.

According to Goldsmith (2004), social support's purpose lies in improving the ability to cope with stress. However, sometimes the enacted type of support offered does not match the type of support needed (Albrecht & Goldsmith, 2003). People providing messages intended to socially support, sometimes achieve their intended purpose, but others unknowingly may actually harm in the attempt to offer support. Conversations about everyday stressors or health emergencies can either reduce or increase the impact that stressor has dependent on whether the supportive communication is reported as helpful or unhelpful. Dunkel-Schetter et al.'s (1992) research of supportive communication focuses on instances of actual received support existing as helpful or unhelpful to the person experiencing pain to best understand "why some support attempts succeed and others fail (p.83)." They found the type of support, who that support comes from, and the context influences whether the receiver reports the communication as helpful or unhelpful. For example, Dunkel-Schetter et al. (1992) report that emotional support tends to consistently help the most across health related issues whereas informational support less consistently occurs as helpful. In fact, informational support in the form of advice tends to be unhelpful. Any attributes of wrongdoing, stupidity, or lack

of success found in the advice received are especially unhelpful (Dunkel-Schetter et al., 1992).

Messages relaying care and concern greatly benefit people (Burleson & MacGeorge, 2002). Schaefer et al. (1981) found that combining tangible and emotional support result in less depression and/or negative thoughts. Burleson (1994) explains person-centered messages, messages that respectfully recognize and confirm the emotional state of an individual undergoing stress, as particularly helpful. Person-centered messages assist the individual in opening up more, thus providing the opportunity to further discuss the stress causing issue. Discussion allows for making sense of the stressful situation, providing understanding and meaning. Often conversations void of person-centered messages lack understanding and meaning. Burleson and MacGeorge (2002) do note instances exist when informational support may prove helpful, specifically if combined with person-centered supportive emotional messages.

In situations of loss Burleson and MacGeorge (2002) and Goldsmith (2004) suggest that emotional person-centered messages may be more beneficial than informational messages. Studies indicate participants with pregnancy loss experiences report the benefits of disclosing the situation receiving positive, helpful support (Abboud & Liamputtong, 2005; Black, 1991; Corbet-Owen, 2003; Dunkel-Shetter et al. (1992); Hawkins, 2012; Lasker & Toedter 2003; Maker & Ogden, 2003; Rowlands & Lee, 2010). For example, Corbet-Owen (2003) found the emotional support a woman's partner provides helps the mourning process and brings the couple closer. Participants in Abboud and Liamputtong's study (2005) share that tangible support in the form of meals cooked

for the couple helps to ease the pain of loss. Dunkel-Schetter et al. (1992) indicate healthcare providers as the one place where advice and informational support are both sought and accepted by people undergoing early pregnancy loss. However, often these studies include reports of supportive communication as absent and the presence of hurtful messages existing in interactions. A recent study conducted by Hawkins (2012) found messages containing tangible, emotional, esteem, and/or social network support as helpful to women; with esteem support most prevalent and informational support nonexistent. Esteem support in the forms of validation of feelings, acknowledging the early pregnancy loss, and relieving the woman from blame were present. Within the same study, reports of hurtful messages indicate the absence of supportive communication.

The information found in these studies of EPL suggest that the type or content of the helpful message one recognizes as supportive communication varies, confirming Dunkel-Schetter et al.'s (1992) aforementioned findings regarding type of support, who that support comes from, and the context influencing whether the receiver reports the communication as supportive. Discussions of the need for person-centered messages may benefit from less attention to support type and specific message. Instead, attention to assisting the individual in discussing the stress causing issue to provide understanding and meaning to the situation may prove more beneficial. Prior to discussion of the value of narrative inquiry and the function of personal stories, discussion of the social complications specific to the context of early pregnancy loss occurs.

Social Complications of Early Pregnancy Loss

In the U.S., miscarriage and pregnancy loss exist as taboo topics the culture often dismisses (Layne, 1997). However, women experiencing early pregnancy loss do not live

in a world without others (Corbet- Owen, 2003). Even if a woman chooses to quietly undergo the early pregnancy loss experience as discretely as possible, inevitably she encounters others that exist within her world. Often she has contacted if not seen a healthcare provider, for example. Therefore, discussion of the social complications involved in understanding early pregnancy loss includes understanding the nature of communicative encounters experienced by women primarily within the context of healthcare. To better understand the social complications surrounding women's early pregnancy loss experiences and communication relating to EPL (a) disenfranchised loss, (b) the emotional impact of grief, (c) coping with and understanding meaning, and (d) communication within healthcare contexts follow.

Disenfranchised Loss

One social complication of an early pregnancy loss situation that may further silence an individual is the disenfranchisement of the loss (Conway & Russell, 2000; Lang et al., 2011; Moulder, 1994; Mulvihill & Walsh, 2013; Musters, Taminiou-Bloem, van den Boogaard, van der Veen, & Goddijn, 2011). According to Doka (1989, p. 4), disenfranchised loss describes a loss that is “not openly acknowledged, publicly mourned or socially supported.” *Lack of recognition and invalidation* of early pregnancy loss often leaves women to work through early pregnancy loss silently: alone. “Miscarriage is seen as a private, minor event in a woman's life, which entails a short visit to a hospital, full recovery and the expectation of a successful pregnancy afterwards” (Conway & Russell, 2000, p. 531). A study by Rowlands and Lee (2010) confirms that family friends, medical practitioners, and society in general lack recognition for the loss of an unborn child. Lack of recognition of EPL from society, close friends and relatives causes many to keep the

EPL experience quiet. As stated by Adolfsson, Bertero, Larsson, and Wijma, (2004) individuals experiencing pregnancy loss need to feel safe sharing highly intimate personal information regarding the loss. Often the need for safety regarding the issue results in silence. These researchers discovered that some couples keep quiet because they lack interest in sharing hopes of giving birth to a healthy baby publicly. Other individuals keep quiet due to concern that social support remains unavailable for pregnancy loss situations. Often miscarriage is viewed as a representation of the loss of a potential person: the loss of memories yet to be created versus memories that exist (Layne, 1997). Many attribute the grief of early pregnancy loss to mourning the potential hopes for the future, believing no actual experiences exist to remember and mourn the loss (Brier, 2008).

In addition, the disenfranchisement of pregnancy losses complicates matters by offering *little to no way of publically mourning the loss*. Practical, tangible, symbolic representations of the loss of an unborn child remain uncommon in society. A participant in Rowlands and Lee's study (2010) shares the disenfranchisement demonstrated by the lack of any societal rituals such as receiving flowers, holding a funeral or sanctioned leave time from work for mourning contributes to the difficulty of loss. Baddeley and Singer (2009) state "individuals who have experienced what are known as disenfranchised losses" that is, losses whose significance is "not socially recognized or validated" such as miscarriage may encounter "*trouble getting appropriate social support for the telling of their story*"(p. 214). According to Rogers (1951) when others refuse to accept the emotional piece of loss the individual undergoing loss feels personally dismissed.

Emotional Impact of Grief

Women grieving over early pregnancy loss may present with an array of emotions. Just as grief may present differently in times of other significant loss, a range of grief experiences may occur after experiencing miscarriage (Brier, 2008; Lasker & Lin, 1996). Many women anticipating a child find the experience of early pregnancy loss devastating. Descriptions of grief in early pregnancy loss resemble descriptions of other significant losses and include “yearning, sadness, crying, fatigue, appetite and sleep changes preoccupation with the loss, and guilt (Brier, 2008, p. 454).” Ross and Geist, (1997, p. 181) share from their own understanding and experience that “the grief of losing a baby at 7 weeks in a pregnancy can be just as intense for some women as the grief of losing a 2 month old child.” Moulder (1994) discovered that women with subsequent early losses at similar gestational ages, experienced grief differently with each loss, which indicates that each loss experience may elicit different emotions.

In some cases grief due to early pregnancy loss may never go away. In a two-year longitudinal study of people experiencing pregnancy loss Lasker and Lin (1996) found that grief patterns did not lower over time as expected. In a study focusing on both the long term and short term effects of ectopic pregnancy loss, a type of early pregnancy loss where the embryo implants outside of the uterus and if undiagnosed may become life-threatening, Lasker and Toedter (2003) interviewed women two months after the experience and then again sixteen years later to identify how the loss affected women over time. Thirteen women participated. After fifteen years, over 50% of the women still experienced grief, thus supporting the idea that the grief of ectopic pregnancy loss may

never go away. Although most grief models point to an eventual end point in grief, this suggests otherwise (Lasker & Toedter, 2003). Lasker and Toedter (2003) also note that in prior studies they found grief levels for women experiencing ectopic pregnancy occurring as high as grief levels for women experiencing miscarriage later in pregnancy or stillbirth, suggesting comparable emotional impact.

Often the lack of information available to understand why loss occurs or to predict if early pregnancy loss may occur again in the future also influences emotions surrounding the grief experience. Bergner, Beyer, Klapp, and Rauchfuss, (2008) found that a miscarriage leaves a woman feeling uncertain “about their own reproductive ability” (p. 110). The researchers found that women experiencing recurrent miscarriage do not experience an increase in depression. Rather, recurrent miscarriage may increase anxiety. Bergner et al. take care to note that the increase in anxiety occurs as normal, not a pathological issue. According to Maker and Ogden (2003), instead of looking at miscarriage as leading to clinical level psychological issues, miscarriage needs to be “understood as a process which involves shifting emotions and active coping” (p. 414).

Coping with and Understanding Meaning

A third social complication when discussing EPL is that coping with early pregnancy loss may present in a variety of ways. Some women choose not to talk about early pregnancy loss, while others may choose to talk about the loss in effort to seek support. Yet other women may tell stories that minimize the significance of the early pregnancy loss. Some women focus solely on returning to the life existing prior to the experience (Corbet-Owen & Kruger, 2001). The variety of social meanings women attribute to early pregnancy loss complicates the experience altogether, (Corbet-Owen &

Kruger, 2001; Corbet–Owen, 2003) greatly impacting coping (Black, 1991). Often the meaning of the loss includes other roles and structures as part of the definition of loss (i.e. the identity of being pregnant, a mother, losing a relative, and/or belonging to a larger family system). These identity roles pose different meaning for women. The variety of understandings given to the roles may further complicate the grief experience (Brier, 2008). Due to the nature of how differently women define and understand early pregnancy loss, Brier (2008) stresses the importance of health practitioners encouraging conversation surrounding the loss, to assist the patient with defining and understanding the early pregnancy loss. According to Tedeschi and Calhoun (2007) should no meaning or understanding of loss occur, troubles with coping might surface. Thus, further supporting the importance of EPL conversations within the healthcare setting.

Communication within Healthcare Contexts

With up to 10 to 25% of all pregnancies ending in early pregnancy loss as reported and confirmed by doctors (American Pregnancy Association, 2007), a number of women interact with healthcare providers during early pregnancy loss episodes. Although early pregnancy loss remains a relatively taboo topic of discussion in U.S. culture, one might expect healthcare providers working in settings that assist women in pregnancy and childbirth to possess familiarity and skill in handling situations of loss, including how to discuss a variety of situations. Thus, attention to interactions across healthcare settings surrounding early pregnancy loss represents an important topic.

Prior literature points to the following issues existing within the healthcare setting regarding early pregnancy loss: (a) insensitive healthcare providers (Crawford, Gask, Grinyer, & Wong, 2003; Rowlands & Lee, 2010), and (b) the need for patient-centered

understanding of early pregnancy loss because of women experiencing EPL as disenfranchised within healthcare interactions (Conway & Russell, 2000; Moulder, 1994; Mulvihill & Walsh, 2013; Musters, Taminiou-Bloem, van den Boogaard, van der Veen, & Goddijn, 2011). In a study conducted by Rowlands and Lee (2010) women reported unhappiness with communication from the medical community. Women report receiving inappropriate, insensitive comments from medical providers who fail to consider the patient's emotions. Additionally lacking from the communication occurring during this type of incident, was asking if the woman may need counseling and how/if the early pregnancy loss was affecting the marriage (Conway & Russell, 2000). Only 1/3 of women received questions regarding how they were dealing with the miscarriage. Yet, 70% of the women reported potential benefit if someone asked about the loss experience (Conway & Russell, 2000). Instead the doctors spoke about medical issues, failing to make an emotional connection. For example, healthcare professionals following the biomedical model for dealing with early pregnancy loss focus on making sure the contents of a lost pregnancy completely expel from the woman, simply telling her to wait one to three months before attempting another pregnancy (Moulder, 1994). Often no "I'm sorry" or emotional communication exists. One woman's practitioner said, "It was a good thing she did not get so attached to the pregnancy." Although her doctor disregarded the pregnancy as nothing the woman questioned, "If it's a non-event then why am I so upset?" (Rowlands & Lee, 2010, p. 280). This information suggests a disconnect between those experiencing EPL and those serving the needs of women undergoing EPL.

Narrative Inquiry and the Function of Personal Stories

Narrative theorists believe people communicate important life events through story (Riessman, 1993) and stories “inform life” (Frank, 2010, p. 2). The story as a means to understand our existence distinguishes the human species (Neimeyer, 2004; Ochs, 2011). Personal narrative scholars hold interest in the specific stories of one’s life as told by the individual experiencing that life (Chase, 2005). Scholars focus on how stories act; going beyond the gathering of stories to understand what those stories do for and with the teller (Frank, 2010). The process of storytelling uncovers both information regarding past occurrences and insights into how individuals create and understand the meaning of those actions (Riessman, 2003; Ochs, 2011). Bruner (1990) claims stories function to solve problems, reduce tension, and/or resolve dilemmas. Stories allow people to deal with and explain mismatches between the exceptional and the ordinary. Storytelling allows the re-casting of chaotic experiences into causal stories to make sense of them and render them safe. Telling stories assists individuals in making sense of events when “a breach between ideal and real, self and society” (Riessman, 1993, p. 3) occurs. According to Pennebaker, (1997) the ability to speak of a silenced issue allows for understanding the occurrence, working the occurrence into the life story, and eventually placing the issue in the past. In addition, personal storytelling offers a meaning –making space that benefits not only the teller but also the reader/listener, providing a window through which one may view another’s experiences (Riessman, 2001).

Interpretive Nature

Narrative inquiry involves interpretation and representations of stories at multiple levels. The individual telling the story is in fact representing an interpretation, as is the

researcher who interprets the story provided from the first-hand account (Riessman, 2001). In turn, whether present in a peer-reviewed journal, mainstream literature, or performance that story is interpreted by the reader/listener/viewer. At the individual level, the teller applies meaning-making processes to experience, inherently interpreting self, relationships, and one's life (Koenig Kellas, 2010).

McCreight (2004) points to the importance in understanding how reconstruction assists with the recounting of the past. Reconstructions do not claim to imply interpretations held at the moment the event happened, but instead show the sense-making process when reflecting back upon the experience. Thus, providing insights regarding interpretation of the experience in the present. "Knowledge is never 'point-of-view-less'" (Bruner, 1991, p. 3). Narratives communicate "the narrator's point of view, including why the narrative is worth telling in the first place" (Bal, 1985, p. 656). "There is the complication and the evaluation of that complication that the narrator provides. How does the individual telling the story evaluate what happened? Therein lies the meaning that can influence future actions as well as future evaluations" (personal communication P.E. Stevens, September 18, 2012).

"Thinking through narratives" helps both the researcher and the researched "understand a world filled with multiple sense-making frameworks and voices" (Baglia, Eisenberg, & Pynes, 2006, p. 198). Frank (2010) discusses that narrative researchers do more than interpret stories. Coining the term "meta-interpretive" he states that narrative analysts study "how people interpret as they do, and how interpretations mediate the effects that stories have" (p. 18). Many narrative scholars pay close attention to both *how*

items are storied as much as *what* is storied when interpreting the meanings storytellers attribute to experience (Chase, 2005).

The Case as Story

Narrative inquiry employs a case-based analysis with the story as the unit of analysis, rather than categorical fragments (Frank, 2010; Riessman, 2008).

Narrativization's importance as an analytic tool lies in focusing on content to identify the primary theme, meaning, or point in the story. According to Stake (2005) narrative scholars work with cases to locate the story that "best represents" (p. 456) each case and "describe the case in sufficient descriptive narrative" allowing readers to vicariously experience the events of the story (Stake, 2005, p. 450). Themes are identified from the entire account or case. Variations exist regarding the boundaries of an individual narrative unit ranging from entire biographies to small segments that focus on a particular event (Riessman, 2008). Stories may range from (a) a short story focusing on one topic and an interaction with a particular other, (b) "an extended story about a significant aspect of one's life", or (c) a story of an entire life (Chase, 2005, p. 652). Narrative scholars do not reduce data to extrapolating words and sentences as themes.

Understanding the story in its entirety to apply the proper context to specific parts is necessary for thematic narrative analysis. Themes need to provide deeper insight into the specific case (Stake, 2005).

Narrative researchers, intending to understand a case in depth ask, "Which issues seek out compelling uniqueness" (Stake, 2005, p. 448)? Stories (and themes) may reach beyond the storyteller, with themes connecting information from the micro level to the macro level providing insight to larger social structures (Neimeyer, 2004; Riessman,

2008). Neimeyer (2004, p. 53) describes stories as existing in “three dimensions: personal, interpersonal” and cultural. According to Chase, (1995) life stories tie the social action/event to the social world the teller shares with others. The story provides insight into struggles, resources and constraints the storyteller experiences within the shared culture. Frank (2010, p. 133) suggests that, “stories and social movements have a natural affinity because stories *move* people, in the sense of both generating emotions and in creating agitation that shifts people’s position.”

Imagining New Normals – Harter’s Narrative Framework for Health Communication

Often narrative inquiry assists in fully understanding a particular illness or healthcare experience from the participant’s perspective (Patton, 2002). Narrative health communication scholars subscribe to the understanding adding that people’s personal narratives offer alternative insights into what occurs in the world (Harter, 2009) including allowing for understanding the patient’s perspective beyond the confines of biomedicine (Harter & Bochner, 2009). Telling one’s narrative allows for what Harter, Paterson, and Gerbensky-Kerber refer to as “making sense of embodied disruptions” thus creating “new normals” (2010, p. 467). Storytelling exists as a powerful way to both express and experience “suffering and loss” (Harter, 2013, p. 5). When individuals tell stories of disruptions in their life plans, they include how the events are “perceived and responded to” (Harter, 2013, p. 9). Harter explains that representing the story in this fashion opens up the opportunity for the teller to (re)frame the “cause and effect.” Thus, allowing one to “live in the pain (p. 9).” Storytellers “focus attention on experience and interpret it, creating a representation from raw experience” (Harter, 2013, p. 14) highlighting

vulnerabilities and struggles in ways medicine cannot. In healthcare, often the news of the break or disruption to plans comes from healthcare providers. After learning of a break in one's path, an individual needs to navigate how to exist in the new situation.

Stories not only hold the power to transform self, but also society within the context of health related issues (Harter, 2013). Harter explains that telling others one's story can both assist the self in dealing with life issues while at the same time bringing awareness to larger salient social issues, allowing for change to occur on both the individual and societal levels. Often listeners hear their own story in the story told (Buechner, 1991). "We read, listen and engage the accounts from storytellers from where we are, amidst our own bodies' vulnerabilities and uncertainties. Stories of others can help us envision what is possible" (Harter, Broderick, Venable, & Quinlan, 2013, p. 158). In addition to envisioning the possible, "hearing how another person has reacted to and dealt with a similar loss" (Baddeley & Singer 2009, p. 206) may assist in comforting those feeling alone or invalidated. Sharf (2009, p.136) offers the utility of empathic listening to help the storyteller "re-story their life" assisting the person in finding a "more constructive way of understanding and living" the story. As Bowman (1999) suggests loss stories containing messages of hope may benefit the teller and/or the listener by bringing forth hope and healing.

In Harter's (2013, p. 60) call to move "beyond our own bodies and experiences to appreciate others' realities" she explicitly addresses the necessity for healthcare providers to use narrative to "marshal their clinical imaginations" to understand the "changes patients face and losses they endure," adding that "procedures may be routine, but people

are not” (p. 60). Harter’s implicit message appears an invitation for healthcare providers to bring empathy and understanding to health issues experienced as unfamiliar.

Research Questions

The purpose of this research was to further understand women’s experience of early pregnancy loss from first person accounts. Influenced by Harter’s narrative framework for health communication, the overarching question guiding the work is: What do stories regarding the early pregnancy loss experience tell about the process and understanding involving the “new normal” (Harter, Paterson, and Gerbensky-Kerber, 2010; Harter, 2013)? The following two research questions more specifically explore this question.

RQ1: How do women’s stories explicitly and implicitly express how they make sense of experiences surrounding early pregnancy loss?

RQ2: How do women describe communication regarding early pregnancy loss?

Chapter Two

Methods

Data Collection

Recruiting. Participants were recruited using criterion sampling (Patton, 2002). Inclusion criteria to participate in the study were (a) English speaking, (b) eighteen years of age or older and (c) experience of one or more early pregnancy losses. Early pregnancy loss, defined as any loss experienced up to the twentieth week, may include but was not limited to ectopic, miscarriage, and/or chemical pregnancy.

The study sought to understand stories of women losing a wanted or accepted early pregnancy. Therefore, criteria for exclusion from the study were: (a) women who were relieved to have lost the pregnancy, (b) women currently taking medications to induce an impending loss or currently in the process of experiencing a loss naturally, and (c) women not fully recovered from any surgeries related to early pregnancy loss. The Institutional Review Board requested an amount of time between experiencing early pregnancy loss and participating in the study. Two weeks was chosen. In prior studies the researcher conducted, women experiencing a loss as recently as a month prior self-selected to participate. Therefore, women experiencing an early pregnancy loss within two weeks prior to interview were excluded from the study. The purpose of the research was to understand women's stories of EPL, therefore, any woman experiencing a later term (over twenty weeks) loss, loss at birth or shortly after in addition to early pregnancy loss was excluded from the project. In a prior study design where the exclusion did not occur, an individual who experienced both EPL and later term pregnancy loss over forty years ago kept having memories of later losses override her story of EPL. This particular

study focused strictly on pregnancy losses occurring at twenty weeks or less, making the exclusion appropriate. The choice not to limit the time since EPL experience was intentional. Only women who fit the above criteria and elected to participate in the study were interviewed.

Recruiting employed the following methods. Participants involved in prior early pregnancy loss studies that indicated interest in future contact for later studies and who fit within the criteria, were identified and contacted via phone and or email to inquire about participation in the study. The email and/or phone call message asked of interest in participating in a follow up interview. Participants were informed that the interview would involve some follow up questions to previously collected data and additional questions would focus on how the participant currently experiences the past early pregnancy loss(es). Past participants indicating interest were sent an email to schedule the follow up interview (see Appendix A for example). New participants were recruited by announcing the study in a group setting the researcher frequented (see appendix B for recruitment flyer and message announced). In the message, people were also encouraged to take a flyer in case they knew of someone who might hold interest in participating in an interview. The message was intentional so that if someone took the information people would not assume that the person experienced EPL. Also, word of mouth recruiting by members of the group was encouraged. Flyers left out on the counter by the door for people to take upon leaving assisted with privacy. Recruitment began in June and continued through August of 2014.

Participants. Ten women from twenty-six to seventy years old participated. Seven of the ten were prior participants recruited from Wisconsin. Three were newly

recruited from California. All women reported being heterosexual. Eight women were Caucasian, two were biracial: one African American/Caucasian and one First Nation/Caucasian. Nine listed Christianity under religious affiliation (with one specifying spiritual, no organized religion), and one listed “none.” Six remained married to the partner that was married to them when the loss(es) occurred, with length of relationship ranging from seven to forty-five years. Three were divorced (one remarried) and one widowed (and remarried). Household income ranged from \$50,000 to over \$100,000 with six women reporting income of \$50,000 to \$75,000, two between \$75,000 to \$100,000, and two reporting income of over \$100,000. Women worked in the fields of Special Education, Disability Services, University Career Services, Human Resources, Community Engagement, Public Health, Nursing, and Law. Two women were listed as housewives, with one retired from teaching. All of the women held college degrees with six earning advanced degrees (MA, PhD, JD).

Early pregnancy loss experiences included miscarriages, a blighted ovum, ectopic pregnancies and losses of twins. Time since loss ranged from two months to forty years prior to the interview. Women’s ages at time of loss ranged from twenty-four to thirty-eight years old. Two of the ten women experienced EPL after thirty-five. Of the ten women, four experienced more than one early pregnancy loss. Five women experienced EPL during the first pregnancy. Two women never experienced a successful pregnancy.

Interviews.

Protocol design. The goal of the interview protocol design was to gather as holistic a picture as possible of each woman’s EPL experience, interactions surrounding EPL and what she thinks about EPL today. Therefore in-depth interviewing (Lewis,

2011) provided the opportunity to explore the delicate and complex issue of early pregnancy loss within each individual's personal situation. Baker (2006) states that an interview where the participant talks the majority of the time indicates a successful qualitative interview; the researcher guides and probes deeper into the participant's response. Interview questions invited the participants to tell stories with use of probes and questions to gain additional insight and clarify previously stated items (see Appendix C for in-depth interview protocol).

Women experiencing early pregnancy loss do not live in a world without others (Corbet-Owen, 2003). The experience of loss takes place within in the context of the overall life, which involves many others. Therefore, when gathering stories of early pregnancy loss through open-ended questions previously, conversations with both healthcare providers and others presented in the organic extended stories told. To tease out more detail and depth to the stories, the interview protocol includes more focused questions referring to healthcare provider experiences and communication with other individuals, allowing the opportunity for more detail regarding experiences and conversations surrounding the early pregnancy loss experience from a holistic view. In addition, some women organically told stories of how conversations and situations both at the time of EPL and currently affected them. Additional questions added to the protocol specifically focused on how the experience currently affects participants.

Procedures. Interview data collection differed dependent upon whether or not an individual previously participated in one of the two prior studies that directly informed the project. The first study was a single case study interview using an open-ended interview guide. The guide solicited stories focused on the woman's thoughts on

motherhood prior to pregnancy, her story of early pregnancy loss, and then her thoughts on motherhood after loss. The second study was a multi-case study that used an open-ended semi-structured interview protocol. That protocol included gathering stories regarding the woman's (a) thoughts on motherhood and pregnancy prior to pregnancy, her loss story (or stories) and then her thoughts on motherhood and pregnancy after loss, (b) interactions with healthcare providers regarding the early pregnancy loss, and (c) conversations with others regarding the early pregnancy loss. The researcher already established rapport with individuals who participated in each of the prior studies. Initial interviews were conducted in person. Therefore, follow up interviews were conducted via Skype or phone, at the participant's preference. Different data was collected from the single case study participant and the multi-case study participants, with some overlap. Therefore descriptions of how follow up interviews were prepared for and conducted for each of these separate groups to match the data requested of new participants precedes discussion of how new participant interviews were conducted.

For all follow up interviews most of the questions focused on the feelings and impact of the events previously storied. Prior to interviewing the participant again, transcripts were read for information related to the current interview protocol (Appendix C) designed for the study. Any content present in the initial transcript that clearly related to a question in the protocol was noted. Only stories and questions not previously solicited were included in the follow up interview. For any previously gained information that required follow up or clarifying questions, background regarding what was mentioned in the previous interview was provided to the participant, prior to asking the

question. Participants received encouragement to include any new information or items that needed adjusting.

Single-case study participant. Interview data obtained in the spring of 2012 was previously fully transcribed by the researcher (see Appendix D for Single-Case Interview Guide). A clean copy of the transcript was included in the data analyzed for the project. At the start of the interview, verbal consent was gained and audio-recorded in a separate file from the interview audio-file. The demographic and history of pregnancy and early pregnancy loss form (see Appendix E) was verbally completed with the participant before the interview began. The follow up interview lasted one hour. Any insights or processing of the interview were included in researcher memos shortly after the interview.

Multi-case study participants. Interview data obtained during the summer of 2013 had been partially transcribed to complete a preliminary exam. This project's interview protocol (Appendix C) directly built off of the multi-case study's interview protocol (see Appendix F), and the researcher went back and fully transcribed all of the audio-files for participants who continued to participate in the line of work. A clean copy of each transcript was included in the data analyzed for the project. At the start of the interview, verbal consent was gained and audio-recorded in a separate file from the interview audio-file. Information on the previously completed demographic and history of pregnancy and early pregnancy loss form (Appendix E) was verbally confirmed and updated as needed with the participant before the interview began. The additional item asking about highest level of education obtained was included at this time. Each follow up interview lasted from forty-three minutes to two hours. Any insights or processing of the interview was included in researcher memos shortly after the interview.

New participants. All new participants were given the option of being interviewed in person in their homes or in a private neutral setting at a library. All chose a home setting. Written consent was gained at the beginning, followed by the participant filling out the demographic and history of pregnancy and early pregnancy loss form (Appendix E). All participants consented to have interviews audio-taped. The interview protocol included gathering stories regarding the woman's (a) thoughts on motherhood and pregnancy prior to pregnancy, her loss story (or stories) and then her thoughts on motherhood and pregnancy after loss, (b) interactions with healthcare providers regarding the early pregnancy loss, (c) conversations with others regarding the early pregnancy loss and (d) information on how women currently experience the past loss(es) (Appendix D). Interview sessions lasted from sixty to one hundred and twenty minutes. Upon closing the interview process, the participant received a resource list that included local resources for women experiencing early pregnancy loss (see Appendix G). Immediately after the interview, completion of Stevens and Galvao's (2007) field note guide document occurred. The field note guide captured information regarding the (a) participant, (b) environmental situation, (c) temporal context, (d) participant's nonverbal behaviors, (e) rapport, (f) participant's motives for participation, (g) power dynamic occurring within the interview, (h) the researcher's emotional reactions, (i) reflection on the interview process, and (j) any other notes (see Appendix H for the full guide). In addition, personal notes were audio recorded for initial insights regarding main themes or salient stories mentioned during the interview.

During all interviews a pen and paper were available to make note of (a) any questions that may need further probing or clarification once the woman finished her

story, (b) observations of the setting, participant, and body language of the participant, as well as (c) any reflexive items that may occur during the process. The researcher followed the patterns of the interviewee and adjusted to their style. Some participants possessed a natural ability to tell stories, telling long stories with need for less prompting or supportive listening techniques. For those tending to require encouragement in elaborating, often “MmmHmms” incited further detail or continuance of the interviewee expanding upon the story.

Interviews with previous participants and new participants were conducted during June, July, and August of 2014. No compensation was provided for participation in the study.

Data Management

The researcher transcribed twenty hours of audio recordings with the assistance of speech recognition software (Dragon Dictate for Mac). For the software to capture the speech, each audio recording was repeated aloud, bringing the researcher into a space of sitting with the data. Words were intentionally kept in the manner that they were spoken. No liberty to “fix” “misspoken words” or eliminate repetitive language occurred. At this point transcription notation using symbols described below occurred, guided by a modified version of Jefferson’s transcript notation (Jefferson, 1984). Transcription yielded three hundred and fifty-three single-spaced pages of data.

When communication overlapped, interrupted or cut off the speaker, the point where one person’s language intersected the others was marked with a single left hand bracket, linking communication in progress with the overlapping communication at the point where the overlap started:

I: Um, for your care in the hospital, or in the doctor's office, or at home. Any

G: [it was
nothing.

Short untimed pauses mid sentence or thought were indicated by a dash:

So that was in Mar- March 30, of 1979.

A colon indicates an extension of the sound or syllable it follows:

It so:unds silly

More colons indicate a prolonged stretch to the sound or syllable:

Um, I::: hadn't known, no one else I don't recall at that time knowing any friends
that had miscarried.

Underlining indicated an emphasis:

I remember being very hurt.

Capital letters paired with an underline indicated an utterance, or phrase, that was spoken
much louder than the surrounding talk:

You know once again, it just sort of trivialized what I had gone through and what
happened to MY body.

Single parentheses enclosed a description of an occurrence happening during the talk:

I'm a workaholic, so. (Laughs)

Um, I haven't really, you know, talked with someone too much about it (voice
crackles from crying) so.

Single parentheses also included other items occurring during the conversation:

Oh, thank you (as I give her a Kleenex)

Um, (now hear cicadas) but I was off work.

The following symbolic notation was added: Initial reactions to the data, including but not limited to interpretive insights and/or reflective comments, reoccurring concepts and items that occurred as initially salient were indicated by placing brackets at each end of the thought and typed directly into the transcript document at the time of first transcription, employing initial analysis to the data:

So it would've been nice to have some acknowledgment of that. [strong need for acknowledgment]

A final check of each transcription for accuracy allowed additional use of brackets to identify themes and salient items occurring among the data.

All transcripts included page numbers for ease of reference. All participants consenting to have their real first names used understood that any other identifying information (names of doctors, hospitals, states) was de-identified at the time of transcription. Pseudonyms were given to those not choosing to use first names. All participants agreed to the researcher's use of the data indefinitely. Data is stored on a password-protected computer.

Data Analysis

Influenced by Harter's (2013) narrative framework for health communication, data was analyzed qualitatively using thematic narrative analysis (Riessman, 2008). Consistent with the inductive approach to this study, analysis involved identifying themes based on recurring patterns and concepts (Patton, 2002). Salient items not shared by others but related to the research questions were identified recognizing areas of divergence. Ellingson's (2009) crystallization technique of using different methods of

analysis and interpretation to create either one “coherent text or a series of related texts” (p. 4) was employed with focus given to creating two related texts. Guided by the research questions, two separate approaches to case-based analysis were employed to procure breadth and depth of what occurred within and across the data. First, core narratives were created focusing on an embedded unit of the participant’s story, specifically the actual early pregnancy loss experience. The second approach viewed the data as a holistic unit. Sub-stories were identified from all data collected during the interview. As stated under data management, initial analysis began during transcription. Therefore, the following provides the systematic strategies utilized during the inductive iterative process involved in each case-based analytic approach to the data from that point forward.

Core narratives. Interview data were systematically reduced to narrative summaries (See Appendix J). The summaries were analyzed to determine each woman’s core narrative and core narratives were compared across cases to determine both convergent and divergent narratives (Riessman, 1993).

Process at a glance. Phases in the process are listed here as a general guide to show how analysis proceeded. Some phases involved multiple analytic choices and those are more fully explained below.

Phase #1 - General viewing of the transcripts and initial data reduction

Phase #2 – Further analysis and reduction of data

Phase #3 - Narrative summaries created

Phase #4 – Identification of each individual’s overarching theme

Phase #5 – Across case comparison of themes, with identification of convergent

and divergent themes

Each phase fully described.

Phase #1. During the first readings of each hard copy transcript, reactions were written as notes on the page and included (a) emotional reactions to remain self-reflexive, (b) ideas or concepts appearing of importance to the storyteller, and (c) evaluative moments in the storied data regarding communicative events/interactions. Blue ink indicated notes made in phase 1. During initial analysis of each separate case, the researcher kept an open mind and was cognizant of both similar and dissimilar items occurring within and across cases, taking care not to categorize any particular interview into needing to fit a certain narrative “type.” Recalling what Riessman (2008) shares regarding Rita Charon's view of the need for "narrative competence." "Fluency in hearing different forms" is what leads to that competence (p. 80). Items storied that did not fit the research questions or the lines of interview protocol, were marked with an “x” to assist with the first attempt at data reduction. An example of such a story was when Mary spoke at length about a leg injury she had as a child.

Phase #2.

Step 1 - The transcripts were analyzed a second time, with focus on understanding answers to the research questions present in all previously marked items in blue. Items in blue that were repeated, of interest, and/or existed as back-story leading to the early pregnancy loss story were highlighted in pink. Items indicating a similar connection with or comment to another participant’s story were highlighted in yellow. With focus on items indicated in blue, any additional notes and insights were written on the page in pencil.

Step 2- A word document titled “Summary” was created for each participant and all transcript data highlighted in pink were moved to the document. Items previously written on the transcripts in blue and pencil that provided insights to what was occurring in the data were typed onto the summary page and included in brackets next to the corresponding words of the participant. Any additional analytic insights were also included in brackets at the time. Each narrative summary was to tell the overarching story of the individual. Therefore the previously mentioned items that were highlighted in yellow indicating similarities with other cases were not transferred to the “Summary” word document. The resulting summary documents contained between seven to twenty-three pages of single-spaced text for each participant, resulting in a total of one hundred and fifty-nine pages of data.

Phase #3. To create a mini-story or an “adequate paraphrase” that represented and summarized the thread or heart of each individual participant’s story (Pat Stevens personal communication, October 3rd, 2012) in relation to the research questions, the data from the “Summary” documents was further reduced. The analytic choice was made to focus narrative summaries on the main story of EPL; what occurred surrounding the time of loss. Focus was on the organic recollection of loss story at the time of loss that was solicited when women were asked to “tell me about your experience of loss.” This provided a thick description of feelings, communication encounters, and the range of early pregnancy loss experiences the women had. Focus on the story of the early pregnancy loss experience at the time of loss as the unit of analysis and placing the story within the context of how women viewed motherhood and pregnancy prior to and after the loss occurred. Each narrative summary was created by viewing data one participant at

a time, and limited to a maximum of three single-spaced pages of text to keep each to a mini-paraphrase.

A template was created to ensure systematic analysis and representation occurred in narrative summaries (see Appendix I). Each narrative summary began with an overall history of children and EPL experiences listed first, followed by the story that led up to the participant's early pregnancy loss, which included how women felt about pregnancy and motherhood prior to getting pregnant. Then each EPL story had a section, followed by a brief wrap up which included how women currently felt about motherhood and pregnancy. The process resulted in thirty pages of single spaced text (see Appendix J for narrative summaries).

Phase #4. With narrative summaries created, another attempt at data reduction involved understanding the answers to each research question provided by each individual's narrative summary. Writing about each individual's sense-making and communication surrounding EPL resulted in finding the overarching theme within each case. Analysis of each woman's narrative summary often resulted in understanding the story at the time of EPL and at the present time of the interview. Therefore, results for each research question are indicated under a "then" and "now" area when this occurred. However, the "now" was not directly solicited and did not present in each woman's core narrative summary. Analysis of the answers to the research questions via data present in the narrative summaries led to identification of the overarching theme that encompassed each woman's core narrative.

Phase #5. Comparison of the overarching themes across all core narratives, allowed the indication of both convergent and divergent themes related to EPL experiences to emerge.

Locating sub-stories. Locating sub-stories allows for delving deeper into each storied account. Guided by Braun and Clark's (2006) inductive approach to thematic analysis, locating sub-stories within the larger narrative generated insights related to the research questions. The process at a glance is indicated below, followed by a thicker description of what each phase of the process entailed.

Process at a glance.

Phase #1 - Become familiar with the data

Phase #2 - Generate initial codes

Phase #3 - Identify overarching themes and sub-themes, including excerpts to support themes

Phase #4 - Review themes for strength of meaning

Phase #5 - Define and name themes

Phase #6 - Produce the report that tells the story

Each phase fully described.

Phase #1. Already very familiar with the data due to transcribing all interviews and completing core narratives, the researcher approached the entire set of data anew by printing off and reading through clean copies of all transcripts.

Phase #2. The clean transcripts were read to find stories that provided insights into salient items in the data that focused on sense-making and descriptions of communication occurrences surrounding EPL. Initial codes were made on the hard copies of transcripts.

As Braun and Clarke (2006) suggest, stories that appeared as outliers from the larger story located within the data were also identified.

Phase #3. Codes identified were sorted to inform initial themes. During this phase word documents were created indicating themes and included excerpts from the data that supported the themes.

Phase #4. Hard copies of the word documents were printed off to assist with reviewing previously identified themes. Coherent themes with data in support of the themes were located within the data. Themes and sub-themes were reviewed for strength of meaning with close attention to excerpts from the data that supported the themes. Recoding and reordering data occurred as needed. Themes were reviewed to ensure representation of the data set occurred. In phase #4 the themes, how themes worked together, and what themes said about the data came together.

Phase #5. Themes were defined and named to demonstrate (a) the essence of what was occurring within each theme and (b) how each theme captured the data. Defining and naming themes was accomplished by reviewing previously gathered excerpts that supported each theme. Themes were organized into coherent accounts that included the narrative. Each theme (a) was analyzed for the story the theme told and (b) included the story of how the theme fits into the larger story the data provided in relation to the research questions. Names given to themes envelop the substance of the theme.

Phase #6. The report tells the story the data tell within and across themes. Vivid extracts chosen to illustrate the theme are accompanied by the analytic story of the data in relation to the research questions posed.

Ensuring Scientific Rigor and Adequacy

To ensure scientific rigor use of (a) a researcher's journal and (b) the following criteria for achieving scientific adequacy outlined by Hall and Stevens (1991) were employed: reflexivity, rapport, coherence, consensus, relevance, honesty and mutuality, and naming. Descriptions of both the journal and the criteria employed in the current study follow.

Researcher's journal. From the onset of the research project and throughout, the researcher kept a journal. The journal provided a space for (a) an audit trail, (b) recording initial analytic insights in the form of memos, and (c) reflexivity. The audit trail allowed recording all items that needed focus and completion. Also, how and when items were completed was indicated. Memos recorded in the journal assisted in capturing continual insights occurring throughout the review of literature, data gathering, transcription, and analytic processes. According to Riessman (2008), "investigators carry their identities with them like tortoise shells into the research setting, reflexively interrogating their influences on the production and interpretation of narrative data" (p. 139). Inclusion of reflexive thoughts in the journal provided a space to comment and work through any difference in understanding, or reactions to data gathered, transcribed or analyzed. Keeping record of one's own difference in understanding or biases allows for an internal check when writing up the final report (Patton, 2002).

Hall and Stevens' (1991) Guidelines for Scientific Adequacy. The following criteria for achieving scientific adequacy outlined by Hall and Stevens (1991) were important to the study design, gathering and analysis of the data: reflexivity, rapport, coherence, consensus, relevance, honesty and mutuality, and naming. *Reflexivity* has

“become an expected and integral part of most qualitative inquiry” (Carolan, 2003, p. 10). In addition to the previously mentioned inclusion of reflexive items in the journal, completion of Stevens’ and Galvao’s (2007) field note guide shortly after the initial interviews served as a tool to reflect upon similarities and differences the researcher held in relation to the participant interviewed, and comment on any power dynamics occurring within the interview (see Appendix H for the full guide). Careful attention was also given to how the role of researcher combined with experiential knowledge of early pregnancy loss influenced data collection, interpretation and representation.

Led by interest in engaging participants to better understand their story, *rapport* building throughout the recruiting process, setting up of interviews, and during and after interviews occurred. According to Hall and Stevens (1991), participants’ openness for involvement in the research over a period of time and/or interest in recruiting other participants indicates rapport. All previously interviewed participants who fit the study criteria agreed to participate in follow up interviews. All new participants offered to assist in recruitment of participants, which resulted in recruiting an additional participant. Continued involvement and assistance with recruiting demonstrate rapport was gained with participants.

Locating conclusions within the data obtained allows for *coherence*. Attention was given to whether or not the story remained consistent within a separate case and across cases or if the story deviated from other cases. Interpretations representing core meanings of the data collected and aligning with the original purpose indicated by the research questions support coherence.

According to Hall and Stevens (1991) *consensus* involves both recognizing recurring themes and divergent experience. “The more the researcher confirms women’s expressive meanings by recurring themes, the greater the accuracy of the data. By searching for negative cases, divergent experiences, and alternative explanations, researchers can strengthen conclusions regarding experiential consensus” (p. 24). Rather than invalidating previous findings, a divergent case opens up deeper understanding of how the context of the particular case influences meaning making and experience. Therefore, to identify analytic convergence and divergence in relation to early pregnancy loss experiences, application of cross-case analysis with identification of both similar and dissimilar themes occurred for both core narratives and sub-stories. Riessman (2008) refers to the process of analytically making sense of the two as strengthening trustworthiness.

Relevance refers to whether or not women’s concerns are addressed by the research questions and if the outcome of the questions might ultimately be useful in improving women’s lives. Relevance also takes into account how others may use the research findings. Relevance particular to this study is addressed in the discussion.

Honesty and mutuality involves open disclosure of the purpose of the research with no hidden agendas. In alignment with honesty, *mutuality* means working to make the power imbalance often present in research studies equalized. A participant is treated more like a peer than a subject of investigation.

Egalitarian cooperation is more likely than researcher domination to allow participants to talk about what is important to them, express emotions in a spontaneous fashion, and act in ways that have meaning for them rather than in ways perceived to be desired by researchers. (Hall & Stevens, 1991, p. 25)

Close attention to power dynamics occurring while interviewing assists in gathering information that may allow more adequate conclusions to be drawn from the data.

Mutuality involves allowing the participant to know that their particular story is important and valid and includes demonstrating sincere gratitude for the sharing of the story.

Naming refers to discussing women's experiences using the terms women use and "generating concepts through words directly expressive of women's experiences" (Hall & Stevens, 1991, p. 26). Use of naming occurs in the Results chapter.

Strategies Employed to Address Potential Ethical Issues

Informed consent. Special care was taken when consenting individuals participating in the study. For new participants, consent was gathered via written consent form prior to the interview. Items on the consent form were read aloud to the participant who received a hard copy. For previously interviewed participants, consent was gathered verbally and recorded in a separate audio-file from the follow up interview. These participants were offered an electronic copy of the verbal consent form. For all participants, any potential implications of participation in the study or choices opted into or out of by the participant were fully explained at the time. Participants were given the option to opt out of indefinite use of data. Participants were also verbally informed of the ability to end the interview at any time. Any questions the participants had about any of the forms were addressed prior to the interview starting.

Confidentiality. All data gathered in interviews was safeguarded immediately by de-identifying information at the time of transcription that might pose a risk to confidentiality (i.e. health care settings, states, names of people included in stories).

Although women had the option to have first names used in connection to study data, only the researcher knows who chose an assigned pseudonym and who chose actual first name. Participants consented to indefinite use of data, yet were fully informed of the right at any time to contact the researcher and request data use cease.

Potential harms. Participants were informed at the beginning of the interview to tell the researcher if at any point during survey completion or the interview process the questions resulted in hardship or grief. If while talking about EPL the participant wanted to stop the interview, they held the right to do so at any time. Throughout the interview process, close attention to a participant's reactions allowed the researcher to check in with the participant to ensure she was okay. When strong emotional reactions were expressed (tears, crying, or anger), the participant was asked if she preferred to continue, needed a break, or wanted to stop the interview altogether. No participant chose to stop the interview altogether. Two participants did ask for a break but were clear on the intent interest to complete the entire interview. Upon point of check in it was common for women to say that the interview and talking about the loss(es) was helpful. One woman referenced the importance of telling her story and her appreciation of being heard. Another shared her hope that participation in the study might incite or impact change, even if for one person. All the women chose to participate fully. At the completion of the interview, participants received a list of potential resources, which included local and online resources for counseling and support groups (see Appendix E).

Review and approval of the research, was granted by the University of Milwaukee Wisconsin's Institutional Review Board.

Chapter Three

Results

Chapter three highlights the results of both the embedded and holistic approaches to thematic narrative analysis of the data as described in the preceding chapter. First, the results of analyzing the narrative summaries for core narratives, both individually and across cases, guided by the research questions and Harter's (2013) narrative framework of imagining new normals are provided. The second, holistic approach to the data provides results in the form of sub-stories present across the entire data set.

Individual Case Core Narratives

The core narratives address how women (a) make sense of early pregnancy loss experiences, and (b) describe communication surrounding EPL with focus on each woman's organic telling of the EPL experience primarily focused closer to the time of loss, indicated by "then." Present understandings and experiences women naturally included through reflection are included and indicated by "now." The overarching themes describing individual case's core narrative are: (a) unrelenting hope (unexplained recurrent early pregnancy loss), (b) secret motherhood (disenfranchised grief), (c) survivor, (d) handle with kid gloves ("time heals...it doesn't erase"), (e) circumventing disenfranchisement (seeking acknowledgment and healing), (f) (releasing self from blame: the scarlet letter of early pregnancy loss, (g) anchoring emotions (talking helps), (h) a body's betrayal (guilt lingers), (i) conceptualization (what was lost?), and (j) God is in control (an overarching philosophy). The stories are discussed in order of participant's time since loss, beginning with Chelsea continuing the quest for motherhood.

Unrelenting hope (Unexplained recurrent early pregnancy loss). Chelsea experienced many losses within the last few months.

RQ1: Sense-making.

Then. For Chelsea sense-making adjusted as each new loss occurred. With no medical diagnosis, Chelsea continued on the quest for motherhood and quest for answers to explain the losses. However, self-blame lurked. The lack of answers meant the fault existed within Chelsea.

Now. Recently receiving a diagnosis of unexplained recurrent early pregnancy loss, Chelsea views EPL as outside of her control. Deep pain exists for each of the five early pregnancy losses, indicating the significance of each loss. Until an answer exists or options run out, Chelsea continues the quest to give birth to a healthy baby. Hope remains.

RQ2: Communication

Then. Socially, Chelsea understood early pregnancy loss as a silenced topic of discussion, which made her feel alone. After Chelsea's first EPL a healthcare worker shared her own story of EPL while wheeling Chelsea to the recovery room. The woman's story shared similarities to Chelsea's experience, providing Chelsea comfort. Chelsea's husband, mom, and sister-in-law provided support surrounding her early pregnancy losses. Her sister-in-law shared stories of experiencing EPL.

Always present for all medical decision-making, Chelsea's husband provided hugs, listening, and reassurance, stating the couple "would be fine if the family consisted of just the two of them." After the couple told everyone of the first pregnancy, the couple experienced difficulty telling everyone the pregnancy ended. After several early pregnancy losses, Chelsea sought counseling. The counselor provided Chelsea the tool of

writing a letter to the lost children. Completing the letter helped Chelsea organize emotions, providing her the opportunity to move on and continue to attempt to experience a successful pregnancy. Chelsea described communication with healthcare providers, “I’ve had pretty nice providers all around.”

Now. Chelsea’s husband, mom, and sister-in-law continue to help and exist as the only people Chelsea speaks of EPL and pregnancy situations. The couple chooses to keep pregnancy talk fairly private now. When people hear of Chelsea’s situation and make comments about strength, Chelsea denies the claim of strength, describing herself as stubborn. As long as Chelsea holds onto hope and medical treatment options remain available, trying for a successful pregnancy continues. Giving up will occur when she exhausts all chances for hope. Therefore, currently Chelsea exhibits unrelenting hope within the context of the unique medical status of unexplained recurrent early pregnancy loss.

Secret motherhood (Disenfranchised grief). Angela experienced the loss of twins a little over a year ago.

RQ1: Sense-making.

Then. When the loss occurred, Angela responded with denial, thinking she incorrectly viewed the ultrasound image of the twins. When told the HcG numbers went down, an indication of non-viable pregnancy, Angela kept the ultrasound appointment and hoped for positive results. Once the EPL occurred, Angela clung to any symbol validating the EPL experience. She lacked interest in the memory of the two children fading. The lost twins belonged to the family.

Now. Angela, a secret mother to the twins that died, wishes to share secret parenting with her husband. However, Angela thinks the twins do not exist as real to him. In hindsight, Angela wonders whether her husband's presence during the dilation and curettage (D&C) would have made the experience of EPL real. Overall, Angela experiences EPL as a disenfranchised grief: feeling alone, a secret mother to the lost twins. The picture of the family remains forever altered, only for Angela, not anyone else.

RQ2: Communication.

Then. Angela missed a message regarding blood work results and felt frustrated. Prior to calling the midwife no one helped Angela with the EPL experience. In an appointment with the midwife, Angela was granted "permission" to cry. Angela cried. The day of the D&C, Angela planned to avoid emotional expression. An unexpected line of questioning regarding how to, or what to do to honor the lost twins caught Angela off guard, interrupting the plan to avoid processing emotions. Angela lacked interest in dealing with anything emotional at the time. Angela just wanted the D&C completed. Attention to emotions and options for what to do with the remains really threw her.

Although Angela kept the losses pretty quiet, people told responded politely yet briefly. The response impressed upon Angela that telling stories about dead children was inappropriate. People talk about living children. No one talked about children that died. Talking about EPL meant acknowledging loss. No one wanted to listen or talk, including Angela's husband. Angela's counselor, however, listened and believed her, which provided some release.

Now. Although Angela longs to speak about the lost twins the EPL remains quiet. While others dismiss the EPL, Angela refuses to. The secret mother longs for the father

to participate in the secret. If only Angela's husband wanted to participate in parenting the lost twins she would not feel alone. Thus, Angela's story presents as one of secret motherhood (disenfranchised grief).

Survivor. Kim experienced two losses less than two years ago.

RQ1: Sense-Making.

Then. Kim recognized people lacked acknowledgment of early pregnancy loss as the loss of a child. Kim understood the first EPL as "no big deal." Trained as a nurse, Kim made sense of the EPL situation by medical statistics. EPL was common. A religious person, Kim understood God held control over the event. With the second EPL situation, Kim ignored the symptoms, attributing the pain to gas from food, or appendicitis. Unaware of her pregnant status, the news of the need for an emergency ectopic surgery was difficult to process. Kim learned of the pregnancy while experiencing EPL. No time to recognize the loss existed.

Thoughts of potential responsibility for the early pregnancy losses entered the mind after her father said, "Slow down." Kim led a busy life. The father's comment hurt. Kim felt blamed for the early pregnancy losses.

Now. Believing the soul of a baby exists at the time of conception and thankful for successful pregnancy after EPL Kim says, "Time heals." She remembers the early pregnancy losses, but knows that had either survived the current infant would not exist. "Thinking of the EPL experiences feels less traumatic now. Time heals." Kim recognizes that without the successful pregnancy after her losses the experience of grief would occur more intensely now. The understanding of EPL has changed, however. "EPL is a big deal."

Kim describes herself as a survivor due to successfully giving birth to a baby after most of her reproductive parts were surgically removed. The family “will be okay” because she “can still have children.” Kim literally survived a very dangerous EPL situation and overcame EPL by giving birth to a healthy son.

RQ2: Communication.

Then. Talking and crying helped Kim through the first loss. The doctor and her husband listened and provided space to cry. Yet, Kim felt alone during both EPL experiences. Kim recognized and gave thanks for her mother’s presence during the second early pregnancy loss. With the second loss, the ectopic rupture that led to emergency surgery, no one including Kim’s husband spoke of the loss of a child afterward. Focusing solely on Kim’s *body* recovering, everyone asked Kim about recovery from surgery. No one asked about Kim’s *emotional* recovery from EPL. Only the doctor addressed the emotional piece. Kim’s experience of grief over the loss of a baby was disenfranchised.

Now. (Not addressed in items focused on for narrative summary.)

Handle with kid gloves (“Time heals...it doesn’t erase”). Jenny’s loss occurred five years ago.

RQ1: Sense-Making.

Then. The doctor’s surprise over Jenny’s crying at the time of confirmation of loss made Jenny think the doctor lacked understanding the loss held significance. On the day of the D&C at the hospital, the way the healthcare providers handled Jenny with “kid gloves” meant the team understood the sensitivity of the EPL. After the D&C Jenny felt empty, with no one to talk to because “no one talks about EPL.” Therefore, Jenny turned

to an online environment where women experiencing similar issues posted information. Jenny no longer felt alone due to the ability to read the stories of others going through early pregnancy loss simultaneously. Jenny explained that women experiencing EPL understood EPL at a level other people just could not. The online message board group existed as “the club that no one wants to be a member of.” However, once in the club, the kindness of the members helped. The online space provided comfort. Jenny blamed her body for the inability to successfully give birth to a baby, feeling both guilty and responsible for the husband’s lack of opportunity to parent. Jenny’s husband listened unconditionally to concerns, as she repeated items over and over. Jenny understood the listening meant he validated her and experienced the EPL as a loss.

Now. Due to Jenny’s first pregnancy ending in miscarriage, she felt deprived of experiencing pregnancy from the space of naivety and innocence women who never miscarry experience. Reflecting upon subsequent pregnancy experiences, Jenny shares the miscarriage caused extreme anxiety while pregnant and adds, “time heals...it doesn’t erase.” Although healing occurs, memories of the loss experience remain. The way the EPL affected two subsequent pregnancies causes Jenny to stop attempting further pregnancy.

RQ2: Communication.

Then. Jenny needed handling with kid gloves. She needed comfort, validation, care, gentleness, to understand she was not alone, and unconditional listening. Although the obstetrician (OB) was generally cold, Jenny received nonverbal communication from medical staff indicating sensitive care on the day of the D&C, reassurance that she was not alone via the online community, and unconditional listening from her husband.

Now. (Not addressed in items focused on for narrative summary.)

Circumventing disenfranchisement (Seeking acknowledgment and healing).

Kiersten's loss occurred eight years ago.

RQ1: Sense-Making.

Then. During the time taken to identify what was occurring, Kiersten was in denial. She wanted the pregnancy. Being questioned by the doctor about common reasons for ectopic pregnancy made Kiersten feel blame. With doctors unable to provide Kiersten information, she went online to find women with similar experiences to assist with sense making. Told that the medicine prescribed to assist her with the medical completion of her ectopic pregnancy, essentially went in and "killed any living cells," Kiersten thought this meant she was killing the baby. Kiersten felt at fault. Although not identifying with the risk factors for ectopic pregnancy outlined by the doctor, Kiersten felt at fault for the situation and at fault for the inability to stop the impending loss. Her body's lack of ideal functioning existed as the only way to make sense of the situation. God did not plan for the baby to die.

Now. Kiersten's body works. She successfully bore two children after the EPL incident. Kiersten intentionally remembers the EPL and attributes remembering to helping with healing. Remembering is better than "sweeping it under the rug." A spiritual person, Kiersten believes she will be reunited with the baby.

RQ2: Communication.

Then. Kiersten experienced very different types of interactions with healthcare providers. Up until three weeks into the experience when Kiersten met an oncology nurse, unpleasant communication with healthcare providers occurred. The night in the ER terms

provided regarding the impending ectopic pregnancy lacked explanation and opportunity for clarification: no time for questions existed. The ER doctor insinuated Kiersten was at fault for the EPL situation. Kiersten's OB was "by the book," "official," and "brilliant" but demonstrated "poor communication skills." The OB and office staff failed to provide sympathy or support, offer a follow up appointment, address emotions, speak of grief, or offer support groups. No messages indicating assistance existed.

Kiersten found ways to fulfill emotional and informational needs through an online community of women experiencing pregnancy loss. The online community provided a sense of connection where information and support obtained from women with experiential knowledge provided a refreshingly safe space. Online, people did not say the "dumb things" others said in face-to-face interactions. The online community members listened, shared, asked questions, and offered, "Hugs."

At week three, with the ectopic situation confirmed, Kiersten was sent to oncology. The nurse explained the situation thoroughly to Kiersten, said, "I'm sorry," and provided a hug. Kiersten stated several times during the interview that the first medical provider to say, "I'm sorry," the nurse, was met three weeks into the experience of EPL. Kiersten greatly appreciated the nurse but held disappointment with interactions with all other healthcare providers. No healthcare provider expressed empathy except for the oncology nurse.

In addition to the lack of acknowledgment of the need for addressing feelings experienced with the OB and the OB's office personnel, Kiersten felt her mother and in-laws dismissed the EPL. Kiersten's mother experienced her own loss thirty years prior, showed Kiersten some care but led with the attitude that one just gets over the experience.

The in-law's attempts to support backfired. Messages of "God had a plan" and "there were reasons for the loss" were not well received. Filled with rage, Kiersten responded to her in-laws with, "I'm pretty sure that God wouldn't want my baby to be dead."

Now. Items in the home nonverbally acknowledge and assist the couple in remembering the EPL. Acknowledgment helps with healing. Every Christmas an ornament placed on the Christmas tree bears the lost baby's name. A statue of a mother and child received from Kiersten's mother a while after the loss occurred sits out in the home; a reminder of the EPL and symbol that Kiersten's mother acknowledges the EPL.

(Releasing self from) Blame: The scarlet letter of early pregnancy loss.

Keya's last loss occurred thirteen years ago.

RQ1: Sense-Making.

Then. Keya lacked knowledge of miscarriage when experiencing the first EPL. When speaking to the nurse over the phone, no specific language referred to the symptoms as a possible miscarriage. Therefore, Keya searched online for information to confirm what was happening.

Keya felt blamed for the EPL by her husband who said, "Perhaps your endometriosis is back?" She felt at fault. The fault existed within the body. Keya understood socially people saw EPL as "no big deal," attributing fault to the woman. Marked with a Scarlet letter, everyone knew about the early pregnancy loss.

Keya attributed the second EPL to getting in the middle of a student fight. After the second loss, the couple had "full work ups" and learned the husband produced low quality sperm. Keya kept his secret per request, enduring conversations from his side of the family that marked Keya with blame. Eventually, Keya released self from the blame.

When attempts at pregnancy failed in the second marriage, Keya placed fault on the body. Separating mind from body Keya told herself, “Some bodies don’t hold babies.” The situation was not her fault.

Now. Keya released herself mentally from blame, and understands the early pregnancy losses as a fault of the body and beyond her control. She still experiences pain regarding the two early pregnancy losses and lack of successful pregnancy after the losses.

RQ2: Communication.

Then. The initial call to the doctor’s office resulted in an unexpected conversation. She expected the office would say, “Come in and get a pill or a shot to help the pregnancy.” Unclear the message about canceling the appointment meant she no longer carried a viable pregnancy, Keya searched online for information. After, when Keya went in for a follow up appointment the doctor used cold language. He referred to the loss as an “evacuated pregnancy.”

Keya’s husband failed to be supportive. She learned that some of the lack of support stemmed from his family’s understanding of miscarriage. Due to his mother’s own pregnancy loss experiences, his family did not conceptualize a pregnancy as a baby. During the second EPL experience, hearing “I’m sorry” coupled with true concern from an ER doctor released Keya from feelings of fault. The ER doctor mentioned that getting in the middle of the student fight potentially affected the situation.

Overall, Keya experienced conversations with people thinking loss was no big deal. She wanted to talk about the early pregnancy losses, but no one wanted to listen. Keeping the first husband’s secret caused Keya to recognize how often people assumed

and blamed pregnancy loss and failed attempts at pregnancy on women. Fully aware of how gossip spreads and blame exists as an invisible mark, Keya referred to the experience as a Scarlet letter. Keya went to a counselor who provided assistance and tools for working through the early pregnancy losses. However, Keya states that in the end, the change in the belief that the early pregnancy losses were not her fault came from within.

Now. After seven years of keeping quiet, Keya now talks about the EPL experiences openly. However, even when sharing the stories to help others, Keya still recognizes how talking about the early pregnancy losses bothers her. [Keya attributes willingness to talk about the losses directly to participation in this study, claiming the only thing she did differently within the past year was talk about the losses within the context of the study.]

Anchoring emotions (Talking helps). Shannon's early pregnancy loss occurred seventeen years ago.

RQ1: Sense-Making.

Then. When Shannon spoke of the situation, she used the metaphor of floating at sea. She felt "adrift in a sea of medical crap." The ER doctor inundated her with medical information and expressed no connection, no empathy. The ER doctor called Shannon's doctor. Shannon's doctor spoke with Shannon on the phone and explained everything that was occurring, including what to expect regarding the dilation and evacuation (D&E). Speaking with her doctor provided Shannon an anchor. Shannon would survive the situation.

Shannon's room at the hospital was cold and sterile. Shannon perceived the space indicated that the Women's Center at that hospital held little concern about EPL. Shannon's awareness of sterilized, comfortable birthing suites existing at the same Woman's Center supported the perception. The lack of attention to the need for comfort in the room invalidated EPL experiences.

Thankfully no one (family, friends or colleagues) other than the ER doctor discounted the EPL. Shannon recognized the support received helped her cope with the early pregnancy loss. Had no one acknowledged the EPL, Shannon would have felt alone.

Now. Shannon states the importance of remembering the pain of EPL. Remembering the pain keeps the memories and the love surrounding the EPL experience present. Shannon misses her lost pregnancy that brought such excitement for around thirteen weeks, just as much as she misses her fourteen year-old who died in a tragic accident within the last year. Shannon holds fond memories of both girls.

RQ2: Communication.

Then. Talking to her doctor on the phone while in the ER provided Shannon the anchor needed to survive feeling left adrift by the female ER doctor's lack of connection or empathy. The room provided for the patient communicated EPL as not valued. EPL was no big deal. EPL did not matter. Although fully supported at the time of and shortly after the EPL by her social network, at around three months after the EPL people encouraged Shannon to "move on." Shannon's husband communicated the need "to move on and get over the EPL." Shannon did not appreciate that sentiment. After three months passed, only her aunt and mother would talk about the EPL with her. Although at first

Shannon experienced an outpouring of support, there appeared a limit, or maximum amount of time since EPL granted to talk about the experience.

Now. Shannon mentions still needing to talk about EPL. “People do not understand, it always hurts to talk about it, but it hurts more to not talk about it.”

Pretending EPL does not happen is worse than acknowledging EPL does occur. She adds that she does not bring the EPL up all the time, but when a reason presents for her to discuss the EPL, she will.

A body’s betrayal (Guilt lingers). Mary experienced an early pregnancy loss twenty-three years ago.

RQ1: Sense-Making.

Then. Mary’s doctor demonstrated no concern for EPL He dismissed the EPL, thus invalidating the EPL experience altogether.

Mary felt torn between blaming self for the EPL and upset by the betrayal of the body. Mary expressed extreme anger during an argument with her husband and the bleeding started shortly after. Thus Mary felt at fault for the EPL. Yet, Mary strongly felt betrayed by her body as well. Her body successfully provided two children during the first marriage. Mary, older when the EPL occurred within the second marriage, felt guilty and responsible for the second husband’s inability to become a father.

Now. Mary handles the EPL more pragmatically, “It is what it is, and what will be will be.” Mary shares that she tries not to carry guilt about what happened (which implies a bit of guilt still lingers).

RQ2: Communication.

Then. When Mary told the doctor of interest in attempting pregnancy within the second marriage the doctor said, “Don’t call until [you are] four weeks late.” When Mary experienced the EPL and received no “I’m sorry” from the doctor or anyone at the doctor’s office, she understood that the doctor did not care about EPL. Mary described the communication as “business as usual.” Mary made a point later in the interview to switch topics and revisit a prior piece of the EPL story to clearly explain the meaning behind the “business as usual” statement. “They were not going to make money off of me, so ‘next’.” No compassion, concern, empathy, or offer to seek counseling existed.

Mary’s second husband and friends provided support. Her husband sweetly said “not to worry,” the couple “could try again.” No one Mary knew was “snarky.”

Now. “It is what it is and what will be will be.”

Conceptualization (What was lost?) Ginny’s last early pregnancy loss occurred just under thirty-eight years ago.

RQ1: Sense-Making.

Then. With Ginny’s first EPL the fetus looked like a baby. Ginny understood the loss as a soul she would be reunited with. Ginny’s second EPL lacked the devastating impact of the first EPL due to the medical explanation provided by the doctor. He told Ginny “blighted ovums commonly occur” and meant, “The embryo failed to form.”

Therefore, to Ginny, that second EPL lacked a soul.

Now. Ginny knows one son will be seen again in heaven.

RQ2: Communication.

Then. When Ginny experienced the first EPL, she could not bear to look to determine whether the remains of the fetus indicated she lost a boy or a girl. When Ginny's husband took the remains from the toilet and placed them into a container to take to the ER, he confirmed the fetus was a boy.

Overall, Ginny felt the healthcare providers handled the EPL situations well. Yet, one incident with a nurse clearly recalled thirty-eight years later held salient. After a thorough check in the ER, healthcare providers moved Ginny to a hospital room for 24-hour watch to make sure hemorrhaging did not occur. Upon entering the room, the nurse saw Ginny's blood shot eyes, and asked Ginny, "Why are you crying?" Ginny could not understand, both at the time of the occurrence and at the time of interview, how the nurse lacked compassion for EPL.

Praying with her pastor while in the hospital helped. As did praying with him, friends and family members throughout the grieving process.

When Ginny walked out of a church service due to crying, a fellow church member really helped her. The woman, who met Ginny in the parking lot, prayed with Ginny and shared a story of infant loss. The woman comforting Ginny that day grew into a new friend and continued to provide support.

Now. (Not addressed in items focused on for narrative summary.)

God is in control (An overarching philosophy). Sherie experienced early pregnancy loss forty years ago.

RQ1: Sense-Making.

Then. Sherie firmly believed in God's control over life. Sherie's complete faith in God and Jesus Christ provided the ability to handle any difficulty. Sherie gave up all pain surrounding the EPL to God and Jesus Christ. Instead of focusing on the pain of EPL, Sherie chose to focus energies on her young child and dying mother.

Now. Sherie believes that she lost a child, even though her doctor discounted the pregnancy and said, "It was just a bunch of tissue...you may not have even really been pregnant." Sherie "will see the little one in Heaven." She adds, "I will know for sure when I get there" [whether or not she truly lost a baby].

RQ2: Communication.

Then. The doctor's communication style was cold, and lacked an "I'm sorry." However, the care and concern from the members of Sherie's tight knit family made the lack of care from the doctor less important. Sherie's family mattered. The family subscribed to the same philosophy regarding God's control of life circumstances. Communication of God's Will from loved ones (husband and family) made up for any poor communication coming from the doctor.

Sherie and her husband openly shared the EPL with members in the prayer group. Sherie recognized that other people would spread the word of EPL and that the lack of wearing maternity clothes provided a nonverbal cue indicating the pregnancy ended.

Now. Sherie does not think [or talk] about the EPL much now.

Across Case Convergent Core Narratives

The three main convergent themes existing across the cases were (a) conceptualization (what was lost?), (b) secret motherhood (disenfranchised grief), and (c) anchoring emotions (talking helps).

Conceptualization (What was lost?) Ginny recognized the first early pregnancy loss as the loss of a baby, sharing her distress over that loss. Yet the second EPL she did not recognize as the loss of a baby, and accepted the biomedical explanation the doctor provided to mean no potential baby existed in the instance of the blighted ovum. Ginny experienced less distress over the second EPL. Other women in the study told stories of (a) ultrasound screens showing missing yolk sacs, (b) losing very early, or (c) hearing “you may not have really been pregnant” from the doctor but conceptualized the EPL as the loss of a baby, despite what healthcare providers said. More often than not the latter occurred. Women, who conceptualized the experience as the loss of a child, or the EPL as the loss of a potential child, often felt the role of mother dismissed by people and society. The women felt unable to publicly or interpersonally acknowledge the loss, which leads to the second convergent theme present in the data, secret motherhood (disenfranchised grief).

Secret motherhood (Disenfranchised grief). Angela’s situation of secret motherhood: disenfranchised grief converges with other women’s stories of EPL. Angela’s story of secret motherhood involved only her recognition of the family as forever changed. The family holds a void that only the twins would fill. Angela asks for acknowledgment, but no one views the family in a similar fashion. Angela identifies as the mother of five children, not only the three currently living children. No one else

recognizes the two lost children. Other women experienced situations that dismissed, made silent or secret the EPL experience, thus placing the women in a situation of disenfranchised grief. Often secret motherhood stories involved the experience of disenfranchisement within the healthcare context where providers failed to understand EPL from the woman's perspective. In addition, some women's stories demonstrated experiencing disenfranchisement from family members and other people women encountered. For example, Kim's experience of EPL due to a ruptured ectopic pregnancy lacked acknowledgment by the ER doctor and others (friends, family, and colleagues) as the loss of a pregnancy. Instead, the ectopic pregnancy existed as a scary and dangerous emergency situation. No one ever asked Kim about the emotional pain or recovery, only the physical pain and recovery. Although Kim understood people tend not to ask about emotional pain, she wished someone recognized the EPL. Shannon's story provided another example. Shannon encountered disenfranchisement in the ER. However, other people originally highly supported Shannon's experience of EPL. Yet, a time came when the people who originally supported her in her EPL experience, no longer found the EPL of such importance to warrant continued discussion. Despite the lack of support for continued discussion, Shannon still identified as a mother to the EPL and shared the importance of remembering EPL. Although often experiencing EPL as disenfranchised, women in the study spoke of supportive interactions during the EPL experience. Discussion of the last convergent theme anchoring emotions (talking helps) follows.

Anchoring emotions (Talking helps). Shannon's theme of anchoring emotions (talking helps) presents across many other cases in this study, although at differing levels. Shannon's first instance of support came from the medical doctor who spoke with her on

the phone after confirmation of the impending EPL occurred in the ER. Shannon mentioned the doctor provided support by acknowledging the EPL, stating he was sorry and offering to join Shannon if needed. Speaking with the doctor provided the grounding Shannon needed when feeling adrift in the sea of medical information provided by the ER doctor who lacked compassion when breaking the news. Women found strength and support when people understood the EPL experience. When listened to by a husband, a counselor/therapist, a nurse or doctor, a close family member, and/or another woman who experienced a loss, women felt validated. The anchors provided grounding, emotional release and processing, and “permission” to grieve.

Across Case Divergent Core Narratives

The divergent cases salient in the data were Chelsea’s situation of unrelenting hope (unexplained recurrent early pregnancy loss), and Sherie’s belief that God is in control (an overarching philosophy). Both EPL experiences exist as strongly influenced by the contexts within which they occur. The following provide insight into understanding EPL within the unique contexts of a woman still attempting to experience a successful pregnancy after multiple losses and a woman whose religiosity offers a different understanding and acceptance of EPL than what other women experienced in this study.

Unrelenting hope (Unexplained recurrent early pregnancy loss). Chelsea’s entire case was encompassed by repeated failed attempts at successful pregnancy, and adjustments made to assist in future attempts toward a successful outcome. Unlike other participants, Chelsea’s early pregnancy loss story continues in a different fashion. Currently pregnant, Chelsea holds continued hope, in the face of an even less common

situation of unexplained recurrent early pregnancy loss. Chelsea believes she will carry a healthy baby to term. With little to no control over the matter and no diagnosis to provide answers, Chelsea resolves to continue trying until all options are exhausted. Chelsea's present day attempt to keep trying for a healthy baby exists within the current EPL story. She refutes other's comments of holding great strength due to the circumstances of early pregnancy losses and current pregnancy. Chelsea continues to endure and simply describes self as stubborn.

God is in control (An overarching philosophy). Sherie's story provided a second divergent case. God was in control of every aspect of Sherie's life and contributed to how she handled any obstacle encountered, including early pregnancy loss. With the exception of the doctor's office, all others in Sherie's world (family and friends) subscribed to the same philosophy. Sherie was the only participant in this study that showed little negative emotion while sharing the EPL experience, except for when she mentioned the doctor's cold delivery of the bad news (indicated by a gasp). Sherie's divergent understanding of EPL may point to ways in which some women possess the ability to raise troubles to God, especially when indoctrinated into the belief since birth. When surrounded by a social network that believes the same, the overarching philosophy is reinforced. Although Sherie recognized that she would join her child in Heaven someday, she truly gave up the pains to God both at the time of her early pregnancy loss and now, forty years later. Her experience appears divergent because her story and disposition during the interview demonstrated no turmoil or pain over the EPL. All other participant's stories demonstrated some turmoil or pain at the time of EPL, and/or while

telling the story during the interview. While some other participants referenced religious and or spiritual beliefs, no other woman faced EPL with such religious fortitude.

Evident in the results of the individual core narratives is the variety of ways through which women make sense of EPL and encounters surrounding EPL. However, whether a woman blames herself or recognizes the EPL as God's will, understands the biomedical explanation of nonviable pregnancy or believes a baby was lost, many recognize the grief that accompanies EPL as disenfranchised. The descriptions of communication or lack thereof, surrounding EPL provide evidence of EPL experienced as a disenfranchised grief. Stories of communication involve discussion of the need for acknowledgment and/or the strong impact the occurrence of acknowledgment of EPL holds due to the rarity of occurrence. Acknowledgment of EPL is demonstrated through/or called for in the form of (a) providing comfort, (b) providing the ability for women to talk about EPL and/or express emotions, (c) truly listening, and/or (d) expressing an empathic "I'm sorry." Due to the variety of sense making evident in women's stories, the need for the acknowledgment to occur without judgment or unsolicited advice is implicitly understood.

The second approach to analysis provides complementary results to the core narratives in the form of sub-stories located within the interview data. Discussion of the sub-stories and themes present within the sub-stories follow.

Sub-stories

Two salient sub-stories, identified within and across the data provide insight into (a) how women explicitly and implicitly make sense of early pregnancy loss experiences and (b) describe communication regarding early pregnancy loss. The first sub-story,

feeling lost at sea, encompasses (a) blindsided by the unexpected, (b) lack of acknowledgment within interpersonal interactions, and (c) EPL as marginalized by society. The second sub-story, processing early pregnancy loss, comprises (a) cause of EPL (b) emotional anchors and (c) “time heals... it doesn’t erase.”

Feeling lost at sea. The image of a person lost at sea provides the idea of feeling thrust into a situation for which she feels unprepared, caught off guard, alone, and isolated from others in the world. Women’s stories of EPL involved such feelings. The sub-story feeling lost at sea comprises three themes evident in stories of EPL; (a) blindsided by the unexpected, (b) lack of acknowledgment in interpersonal interactions, and (c) EPL as marginalized by society.

Blindsided by the unexpected. Participants’ stories often revealed the lack of early pregnancy loss existing as a potential outcome of pregnancy. Jenny shared, “When I saw that positive pregnancy test, I wasn’t expecting to miscarry.” Stories reflect a sense of surprise, shock and/or disbelief, and feeling lost. Kim compared the excitement of pregnancy and disappointment due to EPL to the excitement one might feel when holding a winning lottery ticket, only to discover one number was mistaken.

It's like if you ...you get your hopes up for something. I think would be similar to like – if you thought you won the lottery. (Laughs)... if you read your lottery tickets and you're like “Oh my god I won a million dollars!” Then you realize you got a number wrong. Or that was last week's drawing...you would get so excited and then it's gone.

Often individuals dream about and envision the life changes that might occur as a result of winning the lottery. Kim’s analogy provides insight into how women with hopes of becoming pregnant often dream about and envision the new life experiences that

accompany the addition of a baby as a result of pregnancy. With a confirmed pregnancy, “You get so excited” and when the unexpected occurs suddenly, “it’s gone.”

Chelsea, recently diagnosed with unexplained recurrent early pregnancy loss, described the first EPL of twins as the most difficult. Chelsea’s healthy condition provided “no reason to expect that anything would go wrong.”

We went in for the 12- week ultrasound and there was no heartbeat from either baby. And it was- (breathes in) a big shock. Um, I hadn’t been experiencing any symptoms of miscarriage and- you know I was a healthy person so it wasn’t something I was expecting... (breathes) so it was quite a shock when we learned um, that I had a miscarriage.

Chelsea restated the shock of the first loss again later in the story. “Especially, that- the first miscarriage, I was a lot in shock. - It was no::t something that I expected to happen” (breathes out).

Sherie experienced surprise when hearing of the impending EPL at the twenty-week appointment. “The doctor came in to listen and he said, ‘I don’t hear a heartbeat...I think that you’ve lost your pregnancy’ ...It was- it was a surprise. Wasn’t expecting that.” At all of Sherie’s previous routine appointments, the pregnancy was progressing in an expected fashion. In Sherie’s mind there existed no reason to think that the outcome of the appointment that day would occur differently.

Evident within the theme blindsided by the unexpected are stories of women holding no reason to believe, nor expectation of something going wrong with the pregnancy. The idea that healthy women may do “everything right” prepping for and during pregnancy and still experience EPL exists as particularly difficult to comprehend. Whether the pregnancy ended earlier or later in the first twenty weeks, women often undergo shock, surprise, and/or deep disappointment.

Lack of acknowledgment within interpersonal interactions. Often women felt alone in the experience of EPL, recognizing EPL as a silenced topic of conversation within interpersonal contexts. Even when situations presented for discussion of EPL, women encountered instances of topic avoidance, with focus shifting elsewhere.

Jenny shares how understanding EPL as an unspoken topic affected her experience.

Um, So then had the D&C. Um, recovery was fine. Um, felt empty. (Pause.) Um, nobody that I had ever known had had this. Nobody had really ever talk- you know if they did they never really talked about it. So I felt like I was truly, truly alone.

Lacking experience speaking of EPL with anyone previously in her social circles, Jenny felt as though there existed no one to talk to about EPL. Jenny recognizes that potentially someone Jenny knew experienced EPL, but remained silent about the situation.

Understanding EPL as a silenced topic impressed upon Jenny the need to remain silent, which added to feelings of isolation.

In addition to understanding EPL as a silenced topic, women experienced interactions with individuals aware of the EPL that focused the conversation away from EPL. After an EPL at age thirty-eight, Mary's doctor dismissed any expressed concern for future pregnancies, focusing on the children Mary already had, and failing to address the EPL altogether. Mary describes the encounter with the doctor as exhibiting a "business as usual" attitude:

"Well you'll get pregnant again." And "don't worry about it." ...I was kind of worried frankly... You know I didn't know... "Well you've already had your two children." Or whatever... "You already had your two children... So what if you don't get pregnant again." ...I just didn't feel that there was any major concern about whether I'd, you know that I- this had happened.

In the example, Mary speaks of responses provided by the doctor while attempting to discuss the EPL and inquire about the potential implications of EPL on future pregnancy outcomes. Neither acknowledgment that “this had happened” nor Mary’s concern for future pregnancies were recognized or responded to in a fashion demonstrating concern for Mary’s situation.

Kim underwent emergency surgery to remove an ectopic pregnancy and previously experienced an EPL. When Kim’s family and friends spoke about the recent ectopic pregnancy situation, communication focused on the *physical* recovery from surgery, instead of the *emotional* recovery from EPL.

People don’t really want to talk (talk is said quietly) about it, you know? ...they know it and you know that they know that’s what happened but they don’t say anything because it’s like a [*sic*] awkward subject to talk about. (laughs) ...they would ask how I was recovering from the surgery, but not how I’m recovering from the pregnancy loss.

As Kim continues, she recognizes the emotional impact of EPL as a topic that many lack experience addressing within interpersonal contexts. Kim includes items lacking in response to the EPL that provide insight into language that would acknowledge the EPL experience.

It’s a little more comfortable to... (quiets) say you know, “How’s your incisional [*sic*] pain doing?” rather than “How’s your emotional pain doing?” I don’t think anyone really said... “I’m sorry for your loss”...the focus was on...me and like, “Oh how are you feeling?”... “Are you healing?” ... “How’s your health?” Like I’d had any kind of surgery... ‘Oh she had a knee surgery. Let’s wish her well in recovery’ ...wishing me well to get better, but not addressing...the emotional healing that I needed... just focused on the physical healing...not even my husband...said anything to the effect of you know “sor – sorry we lost another child”...it was like more focused on my physical health at that point...I think I would’ve wanted or needed someone to just acknowledge the fact that even though [it] was...very early and I hadn’t know:n for any time with the – especially the second one that I had lost...that I was even pregnant... the facts of the situation was- that I was, and I lost the baby...it would’ve

been nice to have some acknowledgment of that.

Often when death occurs, individuals experience difficulty knowing what to say to the individual. Kim longed for an “I’m sorry for your loss,” or “Sorry we lost another child” to indicate acknowledgment of the EPL. Kim’s story indicates how an “I’m sorry” would speak volumes, recognizing EPL as a legitimate loss.

Shannon understood EPL as a difficult topic of conversation in interpersonal contexts, expressing that people may shy away from the topic due to lack of interest in bringing up painful emotions or memories. However, Shannon adds that not talking about EPL hurts more than talking about EPL.

The worst thing that you can do is not acknowledge a name or acknowledge the pregnancy or to just pretend that (crying) it didn't happen. Because it did. And parts of it were (quietly) beautiful... It hurts. And a lot of people don't understand...it always hurts to talk about it but it hurts more to not talk about it (crying).

An example of how much hurt may arise due to not talking about EPL exists within Angela’s story. She feels that an unresolved piece exists between her and her husband due to the inability to speak about the EPL. EPL exists as an “unresolved piece.”

It makes me feel alone...one time I mentioned it – I said something to the effect of, “I just want you to acknowledge this” or, or “Let me have this experience.” And (her voice is crackling here as if she may be teary on the other end of the phone) he just kind of said, “Okay,” but then back to the same thing. So, I don't even want to ever mention it or bring it up with him, but I'd like to talk about it.

I: How do you handle that?

Well, (pause) I guess I don't really. It's just kind of this unresolved piece.

Throughout women’s stories regarding the lack of acknowledgment of EPL in interpersonal interactions, a call for recognition of EPL exists. To facilitate emotional healing, discussion of EPL needs addressing versus ignoring. The last theme in the story

of feeling lost at sea provides additional insight into how women make sense of the difficulty discussing early pregnancy loss within interpersonal interactions. Women recognize the insignificant treatment of EPL by society.

EPL as marginalized by society. Women's stories included indication of understanding the lack of recognition of EPL by individuals as influenced by larger societal norms, describing early pregnancy loss as dismissed and frequently silenced by society. Jenny refers to the topic of EPL as taboo. "Um, (laughs) but, you know because it's one of those taboo topics that people don't- talk about." Angela sarcastically states that "people freely share about what happens with -their kids are – whatever. But not, not their kids who aren't here sort of (laughs) 'oh let me tell you about...'" (trails off in laughter). In the stories of understanding EPL as marginalized by society, women share the need to move EPL out of the margins and into mainstream conversation.

Through Angela's experience of EPL she learned how frequently EPL occurs. The following indicates Angela's concern for other women experiencing feeling disenfranchised in the emotional piece of loss.

Finding out how many moms actually go through this. - And how it's not out there - people feel like I feel who don't get to talk about it, and don't get (pause) significant attention (sniffing) Or um support? We're -definitely not public on acknowledgment of what they're feeling... -makes me feel for this very large population of women um, who are kind of silent, or silenced but who we know are there... they have all the emotional- stuff and are probably not allowed to talk about it...(trails off here)

In the following example, Kim discusses society's lack of emotional reaction to EPL and personal attempts to disregard the feelings associated with EPL to fit society's understanding.

If you met someone who lost a baby at thirty-six weeks you would definitely feel terrible...for them, but we don't have that same societal reaction to

someone who lost a baby in the first trimester...that's really unfortunate because you still have the same emotions, and the same feelings of loss and grief, no matter when it happens...I tried to tell myself I was okay and not to have those feelings, but those feelings were still there.

Later in the interview, Kim expands on the need to recognize EPL as valid, describing EPL as deserving of recognition given to any type of later loss of someone a person cares about.

When you have a loss of a loved one it doesn't matter how old they are... it still is painful...it doesn't matter if it was...a-day-old baby or... a day from delivery, you're still gonna have those feelings just like you would if you lost your, your mother...age fifty versus age ninety...that's still your mother. You're still gonna be sad and upset and grieving and go through that process. I think the same is true for losing a baby. That's your baby and you lost it. So we have to as a society be able to acknowledge that and support that.

Shannon experienced EPL and then gave birth to a child a year later at the same hospital, but in extremely different settings. The dichotomy between the room for birthing and the room she visited during the EPL situation spoke volumes about the low value or concern given to women's experiences of EPL by the hospital system.

It was not the pretty birthing suite...it was very white...very cold. (pause) Isolated is another word I would use...inaccessible from anywhere in the Women's Department...one chair...a rolling stool... the exam table slash bed...When my mother and grandmother came it was... difficult for them... to get to. And...uncomfortable for them to stay. The purpose of the room was not for comfort.

I: What would have helped make it comfortable for you?

If everything hadn't been white, gray, and steel... a comfortable chair... more than one chair...When you think about what your doctor's office looks like...generic art print on the wall and it's painted sort of a mauve, the sort of painting, or maybe a beige *[sic]* sort of yellow with blue and gray accents...that ...is 100% more welcoming than the room that I was in... When I delivered my older daughter...hard to believe it was the same hospital...a couch, and carpet, an en suite, and a refrigerator...a bed converted to a delivery bed...soft lighting and soft colors...and you think, 'I know they have not changed the little white room downstairs in the year

and a month that it took me to get back'... It didn't have to be hard and cold...a culture shock...to compare and contrast the two rooms...in the same Women's Center.

Shannon understood the difference in design, arrangement and decoration of the birthing suite versus the space where women experienced loss, as communicating low value of and concern for EPL. The small isolated room lacked ease of access and ease for family members to physically stay with the Shannon in time of need. Shannon's story emphasizes a need for comfort during EPL and how the space for patients undergoing EPL failed to allow for comfort.

Angela's experience losing twins at a hospital demonstrates an organization's efforts towards recognizing the need for some acknowledgment of EPL, yet reinforces the grief of EPL as disenfranchised: not publicly mourned. In the following example, Angela shares the understanding that the potential exists for uncomfortable interpersonal interactions as a result of choosing to publicly acknowledge the EPL, should she choose to utilize the "little white square."

In the folder packet of stuff...there was this one little white square um, material that had an iron on the back from some religious type organization that said..."You can use this...if you were to have a funeral, or you can keep it as a keepsake of your baby." And I wanted to call them back and get another one, (voice cracks at one here -crying) so I would have two. ("two" is expressed as a deep mourning sound) ...And kinda make a little, um, picture frame with that... I haven't taken any action on it though...I kind of don't do it because I know if I put it up then someone will ask me why I put it up or what that is. And I'd like to tell them but then I – I don't want them to think it's weird...So I want it to be public, but I don't want it to be public and judged. I think they would think to themselves "why in the heck would she do something like that when she knows I would ask this question and feel like this?"

Angela expressed needing and wanting to remember and publicly mourn the lost twins. However, due to the lack of societal norms in place for determining exactly how to

honor the twins without making people in her life think she intended to “do something negative to them, or have a negative effect on them,” Angela did nothing. Angela’s comments demonstrate that the lack of a publicly recognized way to honor EPL through universally understood symbols provides a boundary to determining a way to personally recognize the EPL without potentially complicating interpersonal relationships.

When women experience EPL as marginalized by society the metaphorical image of the woman feeling lost at sea would involve a woman drifting further and further away from the opportunity of locating safety, assistance, or rescue. Apparent in the stories, the inability to acknowledge and talk about EPL within interpersonal and societal contexts detracts from a woman’s ability to work through the emotions that accompany such a blindsiding event.

Processing early pregnancy loss. The second sub-story processing early pregnancy loss provides insight into EPL interactions and sense-making ranging from the time of loss through the time of interview. The sub-story includes how women process the loss years after loss occurred; in essence, how woman experience the EPL today. Examples of how communication influences one’s understanding of EPL and impacts a woman’s experience of EPL present within the following themes: (a) cause of early pregnancy loss, (b) emotional anchors, and (c) “time heals...it doesn’t erase.”

Cause of early pregnancy loss. In an attempt to make sense of the unexpected situation of early pregnancy loss, women report attributing responsibility for the situation to self, chance, and/or God. Some women’s stories vacillated between attributing more than one reason for EPL.

Self. Often women's stories involve blaming self for the EPL, with the cause existing as either behavioral (items within control) or physical (the body). Some women feel a strong sense of guilt for EPL, whereas others seem to rationalize the body as a separate entity for which one holds no control, and therefore no responsibility for the EPL. Stories reveal moments where another's communication influences the woman to believe EPL exists as her fault.

Mary's story of EPL led with feeling betrayed by the body. However, Mary admits to feeling at fault for the loss due to a fight with her spouse the night before bleeding began. The fight caused great emotional stress.

I felt very let down by my body...one of the reasons why [I] didn't call the doctor for the two days, cuz I felt so bad...I just felt betrayed by my body... And I felt very, it was very vulnerable...and part of it is that I felt partly to blame. Cuz I was so angry at my husband. That I felt like I'd possibly caused it because I was really upset.

In the next two exemplars Jenny and Keya acknowledge EPL as no fault of their own, but instead attribute EPL to the body, almost as if the body exists as a separate entity. Jenny:

Even in the few short weeks that I knew I was pregnant, I followed, every, single, rule, to the T and never strayed from...making the right choice when it came to...those written rules and unwritten rules of pregnancy. So, I knew I didn't, I knew I didn't do anything wrong...the worst I felt about was just my body letting me down. I didn't do anything to cause it...my body, just, didn't know how to be pregnant.

Keya's explanation of the fault lying with the body actually let her "off the hook," and provided a new sense of understanding. Keya no longer connected her self-worth to whether or not her body could hold a baby.

I finally let myself off the hook and said, "It's your body. It's not you. You didn't do anything wrong. Some bodies hold babies. Some bodies don't. Your body is not holding a baby." That doesn't determine,

you know, my, my value. Or what I have to offer to my children or this world.

Interestingly placing fault with the body provided some women a sense of release from self - blame since no person held any control over actions of the body.

Both Kiersten's and Kim's stories demonstrate the influence communication with others had on thoughts of responsibility of EPL existing within their control. Kiersten began blaming self for the EPL after speaking with the ER doctor. The ER doctor's discussion of STDs and/or multiple sex partners leading to ectopic pregnancy combined with questions regarding Kiersten's sexual history led Kiersten to believe she may hold responsibility for the EPL. Although Kiersten knew no risk factor the doctor mentioned applied, she felt she caused the EPL.

I felt very much as though there was something that I had done to cause this... there was something about, about my health or I just, I:: felt a tremendous sense of, guilt. That there was something I did, or there was nothing that I could do um to stop it...the big biggest thing was guilt.

In Kiersten's case of ectopic pregnancy, the ectopic pregnancy presented long before any steps for intervention could take place. Therefore, Kiersten carried the ectopic pregnancy a few weeks prior to medical intervention. Not only did she feel guilty for the predicament existing, she felt guilty for the lack of ability to adjust the eventual outcome. The initial response and diagnosis of the situation by the ER doctor led Kiersten to believe she held fault for the situation.

For Kim, the most difficult comment made in direct response to the EPL diagnosis came from her father. "Oh you gotta slow down. You gotta take of yourself." Although familiar comments from her father, on the day she disclosed the EPL, the words took on new meaning.

It really made me feel like he was blaming the loss on my, workaholic-ness (laughs)...I felt like, "Really dad, like that's the nicest thing you have to say, 'Is this is a sign that you need to slow down?'"...in that moment that was not what I wanted or needed to hear. Because it made me feel like what I did, did that to my body. And I know that wasn't the case cuz I, despite being a workaholic, take good care of myself... I don't smoke, I don't drink, I don't do anything crazy. I eat healthy. I exercise almost regularly...I just remember being like dumbfounded because I couldn't even make eye contact with my father whom I love and have a great relationship with...I probably broke into tears after he walked out of the room...it was just very, very hurtful and made me feel a lot of like guilt and blame...your brain goes all different places... 'oh, what if he's right? What if it's not getting enough sleep or getting too much caffeine?'

Evident in the stories of self as the cause for EPL due to one's own behaviors, whether blame came from internal factors or conversations with others, an extreme sense of distress over EPL exists. When women rationalized the EPL as part of the self not under their control, the body, less distress occurred often opening the opportunity for release of blame.

Chance. Women considered EPL as "just something that happened." EPL exists as a random occurrence for which women held no control. Some women's stories indicate the difficulty in which the experience and no true reason for the EPL had on life. Some women attributed chance as the cause for EPL and storied self and/or God as cause for EPL. The variety of meanings women attribute to EPL may indicate the complexities involved in attempting to understand what often remains unexplainable. The variety and/or change of causes understood as reasons for EPL may adjust over time with new life experiences.

Keya, no stranger to obstacles and challenges in life including having "no idea that people had miscarriages," attributed the EPL experience as being "dealt another bad hand." In other words, her chance occurred as based in the luck of the cards dealt.

Chelsea understands that “bad things happen” and “life isn’t fair.” She sees the EPL situation caused by chance. Chelsea’s only option when no reason presents is to deal with EPL. Chelsea shares her struggle accepting the random situation.

This just isn't fair...I've done everything right and (breathes out) it feels like I'm...still being punished. (Breathes in and out) But, (breathes out) I mean I've like tried to accept that (breathes out) obviously life isn't fair and, different terrible things happen to undeserving people every day and (breathes in and out) it's just something that I have to deal...with the best that I can.

Even when a woman does all necessary to ensure a healthy body and healthy environment to hold a pregnancy, chance may take over and result in EPL. For both Keya and Chelsea, EPL appeared as some type of random punishment neither deserved.

Although she notes an increase in focus on religion later in her life, Mary understands the experience as related to chance. “Stuff happens and we don’t know why, and... my new motto in life, ‘it is what it is and what will be will be’ ...it’s just, something that happened.” In some instances the idea of chance as cause for EPL may indicate a woman’s choice to give up the struggle of attempting to understand why EPL occurred.

God. Throughout women’s stories of loss, divine intervention occurred as another cause of EPL. A few women previously spoke of self and/or chance as causes of EPL, added spirituality or religion briefly in comments pertaining to the EPL situation. For example, Kim said, “I’m a very religious person so was, you know, it wasn’t meant to be. Something must have been wrong with that baby or not the right time in our life that, that baby was not supposed to be here” (sniffles). Reflecting back on her life thus far, Keya said she could “chalk it up to God’s timing,” adding “it worked out this way (referring to her adopted children and children through marriage) and that’s fine.”

Sherie and Ginny mainly made sense out of EPL occurrence by believing EPL exists *primarily* as God's will. Sherie provides how her mother's council helped make sense of EPL:

[Sherie speaking as her mother] "God is in control. And we will just trust Him to make His plan known in your life." And He did...in retrospect I can say He did. (Laugh) It made sense to me...that's how I was raised... just have the right outlook on this. And trust.

As Sherie's story continues, a common philosophical view held by the entire family provides insight into how understanding the cause of EPL as God's will comforted Sherie in the EPL experience. "We all have the same philosophy...so it was not difficult for them to say (quiets almost whisper) 'jus- we're gonna trust God in this.' And, 'We're sorry.'"

Ginny subscribed to a similar philosophy: "I guess I had the belief that God know-, He knows what's best. And maybe there was something wrong with that baby?" Ginny shares the EPL exists as "probably the biggest trauma I've had in my life." Although she experienced the EPL as difficult, in the end all cause pointed to Divine intervention. Yet, for Ginny knowing God "knows what's best" failed to affect her in the same calming manner the understanding provided Sherie.

Even though I knew that there must've been something wrong with the baby and God knows what's best, I always feel He knows what's best in our lives and there must've been something physically wrong with the baby. But it was a terrible loss for me emotionally. I went through a lot.

Interestingly only Ginny and Sherie, the two women primarily placing the cause for EPL as God's Will, never considered EPL as something for which either held responsibility, blame, or thought of as random punishment. Although Ginny experienced quite a lot of emotional response directly after the EPL and reported feeling upset

whenever the topic of EPL came up over the years in conversation, understanding EPL as part of Divine intervention seemed to allow a different level of understanding and acceptance of the situation than for women understanding the cause of EPL to exist as self and/or chance.

Emotional anchors. The image of the anchor illustrates the concept of feeling grounded or stabilized versus adrift or lost at sea. Lost at sea, the first sub-story presented in the results consists of stories of women feeling blindsided by the unexpected, experiencing lack of acknowledgment of EPL within interpersonal interactions and understanding EPL as marginalized by society. In addition, as noted under the previous theme cause for EPL, some women struggle while attempting to make sense out of what often remains unknown. Women's stories of emotional anchors include interactions with others that allow women to feel heard, acknowledged and comforted; often bringing emotional release and/or acceptance of the woman's feelings of EPL to the foreground.

Emotional anchors provide women the ability to feel and work through the emotional piece of loss that so often appears ignored by the masses. Although emotional anchors occur in a variety of interactions with healthcare providers, family, friends and colleagues, some of the most salient stories of anchors exist within interactions with healthcare providers. Therefore, the majority of examples demonstrate anchoring interactions with healthcare providers. In addition, an unintended and unforeseen result evident in women's stories involved participation in the research serving as an emotional anchor. Whether women feel surrounded by emotional anchors, or only spoke of one or two interactions or individuals that provide anchoring, the value and importance the anchors provide appears apparent in the following stories.

Shannon described how she felt when learning of the EPL from an ER doctor with whom she shared no connection, as feeling “adrift. Like I was lost in the sea of medical crap-that was going on, and I couldn't (pause) I didn't have anything else to anchor to...” However, when handed the phone, Shannon spoke with her doctor, and his words made a world of difference.

Then I talked to Dr. White and it was like the anchor point. He kept saying “I can come in. If you need me to I can come in.” And I knew that he was leaving on vacation the next day...it wasn't necessary for him to come in and hold my hand. But just the phone call gave me the anchor point so that I could not feel quite so adrift with the ER doctor.

Overwhelmed, Shannon could not attend to or focus on the medical jargon heard. When the ER doctor handed Shannon the phone to speak with the regular OB, Shannon suddenly felt anchored by his words.

It was like a medical anchor... I was in a strange place, with strange people, and strange things were happening that I hadn't anticipated. Didn't really understand why it was happening. And so talking to the doctor was like, it gave me an anchor. ‘Okay this is normal. I have this point that is normal. It's with a man that I trust’... I was gonna survive.

Speaking with a familiar doctor, in the midst of the jolt out of an expected pregnancy experience, provided Shannon the sense that she would manage to keep going despite the current situation.

Three weeks into the ectopic pregnancy loss experience, Kiersten interacted with an oncology nurse. The interaction helped Kiersten move forward with the grieving process.

The only person that told me they were sorry was the oncology nurse. That was the first time they told me I was – they were sorry... first time that anyone really asked me if I had questions or really acknowledged, “You must be overwhelmed, upset, scared.” It was there, she was the absolute first person who had taken the time to... look past the medical aspect of it and to think about the communication and to think about what

the other person was going through. She was the first person.

Kiersten provides further explanation of how the nurse's actions affected the EPL situation.

That kind of validation made me feel not foolish about grieving... I didn't have people in my network that I could talk to...this was the first person who made me feel you know, "this is ok to be sad. This is ok to grieve"... that was helpful for letting me move forward with, with the grieving...feel like it was ok to go home, go under the blanket and cry... I didn't feel foolish... I felt like I was um, truly cared for... It didn't make me feel happy...it helped me to move forward and to, to grieve. (Sounds matter of fact and reflective regarding the experience, no tears or crying heard).

Although Kiersten's words lack explicit use of the idea of permission to grieve, the above example indicates that acknowledging EPL allowed Kiersten to move forward in the grieving process. Angela lacked knowledge of individuals to speak to regarding the EPL situation. She explicitly mentions the anchoring interaction with a midwife as granting her "permission" to grieve.

I was...pretty stoic... "Yes. No. What does this mean?"...She was like, "How do you feel about this?" And I was like, "Not very good." (Laughs) She was just like, "Well you can be upset about it if you want." And I'm like, "Okay." And then I started crying! (Laughs) Like I was waiting for- per::mission ... (Laughs) So I think that they might have sensed that, you know, it wasn't okay. And they told me that it was okay not to be okay (laughs while crying).

Angela's midwife served as an emotional anchor, allowing Angela the space to "be upset," which resulted in opening the floodgates of emotion.

Some women, either already in counseling or who sought counseling due to the EPL event, found the sessions anchoring. Counseling sessions provided a space where women felt heard, believed, and safe to release and work through emotions. Angela speaks of her counseling sessions as a space for emotional release:

Just having someone there listening to me, and kind of believing me, um, was important even though it was more just catharsis or

release. Because I don't think I was saying much intelligible (laughs)... that- was- good to have someone to, to listen...I was just completely incoherent when I was talking about this. Just crying, crying, crying, crying, crying, crying. But whenever I needed a place to do that it was nice to.

Recognizing the need to work through emotions, Chelsea sought help after the fourth loss. Chelsea found a therapist specializing in pregnancy issues.

(Breathes in and out) It, did, help to have someone just (pause) to talk to ... (breathes in and out/pause) try and work out some of my emotions with. One thing that she suggested um...was. That. I write a letter, um, and direct it to, the um, the children that I've, that I've lost...(breathes in and out) just to tell them how I felt about the whole experience...it was a hard letter to write...(pause) but I felt like it – helped me get – my emotions out ... help me put some, feelings into words... understand myself a little bit better... helped me make sense of how I was feeling about it.

Writing the letter, a tool for working through EPL suggested by the therapist, provided a space to help Chelsea make sense of the emotions associated with the experience.

Keya sought counseling and mentioned that at first she went once a week for six weeks and felt better, so “naturally” left. Keya returned to therapy when worry and concern with the EPL “all of a sudden” came back and hit her:

like a stack of bricks...I went back again...I went for (pause) probably two months...then I was done - permanently...I felt better. I felt like I had enough tools to get through the sadness.

I: Can you help me understand some of those tools that they shared with you?

Journaling... understanding that...feeling like...it was my fault would not help me cope or get through anything... understanding that sometimes there's no reason for ...sad things...it's what it is... a sad loss...Sometimes with Christianity I think that people try to make sense of stuff, and you're taught to make sense of it, so you have to make a connection from when this happened to why it happened... there may be no connection whatsoever... It was just a really bad thing that happened to me twice. So I think I got that out of counseling. (pause) ...other tools were deflecting those thoughts... allowing myself to have them. It didn't mean I...wasn't a Christian or a good person because I had thoughts of feeling sad or depressed. God doesn't expect us to walk around in a bubble and just be happy about every bad thing that happens. I could grieve and still move on.

And grieving didn't mean a tub of ice cream and sitting in bed. Grieving just means, “man that’s sad”... Giving myself permission to talk about it later. Or talk to someone about it... those are some of the tools.

Keya’s opening up about the tools that therapy helped her utilize to cope with the grieving provides in depth understanding of potential ways that may assist women in working through EPL. Instead of burying the pain in a “tub of ice cream,” Keya could recognize the situation as sad, allow self to grieve, and speak to people about the EPL. Keya did not need to feel like a bad Christian due to allowing herself to experience sadness. Therapy provided insights regarding how attributing cause for EPL such as self (through blame) or struggling to make sense out of what or why EPL occurred (which Keya attributes to religious influence) may exist as barriers to working through the grief. Attempting to make sense of what or why EPL occurred may take focus away from working through and experiencing grief associated with the loss. What Keya learned in therapy allowed release from concern about why EPL occurred and promoted talking through the grief. Allowing herself permission to speak about the EPL and understanding that no answer may exist, no sense provided for the EPL, helped Keya work through the grief.

As stated previously by Angela, Keya too felt granted “permission to talk” about EPL. The mention of receiving permission to speak about EPL reinforces women’s previously storied understanding of EPL as a taboo topic, often unacknowledged in interpersonal interactions and marginalized by society. If EPL existed as an openly discussed experience, no woman would feel the need for “permission” to speak of such loss.

Additional examples of anchoring experiences included coming to new understanding about the cause of the loss due to the special care other healthcare practitioners provided. Jenny experienced an “extra sensitive” healthcare team the day of the D&C. Everyone including the anesthesiologist, pre-op nurse, ultrasound technician and general hospital staff, appeared to understand the sensitive nature of the visit. Jenny said that although little was verbally stated, the manner in which the healthcare team handled her with “kid gloves” demonstrated understanding.

I appreciated ...their gentleness and their approach to me...it made that pre-op time, calm. Um, you know the anesthesiologist ...was really, just really nice...they obviously knew why I was there and it made...a hard time calm... I felt respected. I didn't feel like (breathes out) um, not that I ever really felt like I did anything wrong... in terms of the pregnancy...but they really made me feel like I didn't do anything wrong.

Previously, Jenny shared that although aware that *she* did not cause the EPL, she felt the *body* let her down and caused the EPL. In the statement above Jenny implicitly indicates potential struggle or grappling with the idea of cause or reason for the EPL as self. The way the healthcare providers treated her the day of the D&C reassured Jenny that she “didn’t do anything wrong.”

Keya shared an anchoring conversation occurring with an ER doctor. His special care greatly impacted Keya’s understanding of the EPL experience.

He sat down and he said, “You know (pause) you do have a positive result.” And then I kind of had a ‘YAY!’ on my face. And he said, “Um, but that is, uh normal sometimes after you- um, have a loss.” And he used the word loss. And I thought, ‘oh no, not again’... He didn't say anything else, then he said, “Can you tell me a little bit about your day today?” And I said to him, “Yeah, you know the only big thing that sticks out is that these kids were fighting and I got in the middle of it”....“We're really not sure, [referring to if what happened directly caused the loss] but the pain you were experiencing was uh, the loss of the baby...I'm sorry...You're not, you're not pregnant. Um, but it probably will show up positive for a while. Do you have any family you can go and stay with since your

husband's out of town?"

The ER doctor sat down, explained the situation thoroughly to Keya, expressed sorrow for the loss, and took time to ask open-ended questions. Later in the interview, Keya referred back to the conversation with the ER doctor. "The good experience with the ER doctor kinda helped me to feel like it wasn't my fault. You know that there wasn't something wrong with me." As previously noted, some women blame self for the cause of loss. Self-blame may originate from conversations with others (external forces) or one's own thoughts (internal forces). Keya's story demonstrates how an external force, a conversation with a caring healthcare provider may assist in releasing a woman from self-blame.

Some women referred to participation in this research project as serving as an emotional anchor. During initial interviews and follow up interviews some participants spoke at length about how the interview itself worked to free emotions, provide comfort, and serve as a catalyst for opening up and speaking about EPL to others.

Keya stated that participation in this study existed as the only item in the past year occurring as different in her life. After participating in the study, she felt freed to talk about the EPL experiences that were previously kept to herself and her husband for the past seven years.

My first time talking to you about it. Um, that was really like my first... time really, really, saying everything it is... So having that first interview thing with you like has kind of been a catalyst for me to say it... man I bet I've told this story like six or seven times since you and I have talked. Versus... seven years without saying a word. The only person who knew this stuff was my husband... starting this interview thingy a year ago kinda set that in motion... My husband can't even believe that... I told you that stuff. He's was like, "Wow! You're changing." And I'm like, "Yeah I am changing"... It really did. It really did. It, not putting on, I'm not adding extra... the only thing that I'd done different in the year was tell you my

story. So it has to mean something.

Keya's comments demonstrate a recognition that the ability to tell the story to someone who fully listened and acknowledged the experience, served as a catalyst to begin openly speaking of EPL. Keya now speaks of EPL with others when she sees the story may empower or assist another in a situation of EPL.

Shannon's following statement shows recognition of the impact of emotional anchors in her life, providing an overall sense of the important role moments or individuals serving as emotional anchors hold.

The fact that they acknowledged that it was a loss. Was huge... to have someone acknowledge it... it made coping easier. It would've been much harder if I had been (pause) if no one had acknowledged it and it was just me alone in this bubble of grief that no one else could see. Or seem to see. Stories of emotional anchors demonstrate acknowledgment of EPL by expressing care and concern, making women feel accepted, and providing women the ability to speak of grief. Acknowledgment works to anchor women experiencing EPL, a time where often women feel lost at sea. Women describe being listened to, told "I'm sorry" in an empathetic and/or sympathetic fashion, and/or hearing confirmation that EPL exists as a particularly difficult situation as providing room to grieve. Women report openly grieving and speaking of EPL experiences as a step toward moving forward. The interaction or person serving as an emotional anchor provides women some sense of stability, or sense of working through the uncertain situation of EPL, that occurs as a break from the expected.

Interestingly, although there may exist people or moments that assist in coping with EPL, often the pain of EPL remains. Thus, leading to the last theme in the sub-story processing EPL, "time heals...it doesn't erase."

“Time heals... it doesn’t erase.” Participant’s stories revealed how EPL experience(s) remained with them, whether the occurrence happened within the past year or long ago. Participants very close to the occurrence of the event spoke of gradual adaptation to life, but often felt grief. Others spoke of experiencing some healing from the loss as time passed, but that the pain of loss never fully went away. Participants that experienced great pain when EPL occurred often found the pain of loss resurfaced when hearing another’s pregnancy loss story. For all participants some memory of loss remained, indicating the strong impact EPL leaves. The theme “time heals...it doesn’t erase” consists of three increments of time since loss that correspond to the range of time since loss evident in the data: (a) within the last three years, (b) between five and seventeen years ago, and (c) twenty-three years ago and beyond.

EPL experiences occurring within the last three years. Angela’s pain has not lifted since the EPL. “Life just goes on even though there was so much pain... time just makes it feel farther away, but not less painful...the pain feels farther away but it’s still, still the same pain.” In addition, Angela talks about how she imagines the pain existing in the future. Angela recognizes the desire to talk about the EPL experience in the future and understands others may wonder why the need to talk exists.

I feel like that I should be over it now because it’s done. But it’s not done ...it’s not gonna go away (pause)...five, ten years from now, it’ll- this will still be significant and important to me...I feel like if I say something people will be like “why are you still talking about this?”...a month later or years later.

Angela’s comment demonstrates an understanding of a societal unspoken rule or limitation on time allowed for grieving and talking about EPL. Angela foresees the

memories of the lost twins remaining far into the future. No matter how much time passes, she expects to intensely feel the grief of the EPL.

Chelsea and Kim both experienced a pregnancy after recent losses and explain how the pregnancy or new baby, although welcomed, failed to remove or lessen the importance of the lost pregnancies. Chelsea, pregnant at the time of interview, mentioned that thinking toward the future and positive thoughts for the current pregnancy did not make the pain of the lost pregnancies disappear. “I wanted (breathes out) I wanted that pregnancy. I wanted those babies. I, and I felt really upset that, they were gone.” For Chelsea, new pregnancies do not replace or erase the memory of the pain of the prior losses.

Kim’s successful pregnancy resulted in a baby born almost a year to the day of the first EPL. She welcomed the positive memory to add to the time of year. However, the welcomed memory did not replace the feelings associated with her early pregnancy loss.

When we had the baby...I think I said something like “you know it's amazing what can happen in a year...It was a year ago around this time ...that I was in the hospital for a very different reason...in bed recovering for a very different reason. And it's a much happier time now than it was then, of course.” So we just kind of had this acknowledgment that it wasn't like a celebration or like a grieving moment...you thought about it and remembered it and are feeling good about having a positive memory associated with that same timeframe too.

Kim shared that her losses occurred while attending professional conferences, conferences that she would attend as long as she remained a member of the healthcare profession. Therefore, the memory of the two early pregnancy losses became permanently associated with the conferences.

My first pregnancy loss was when I went to a big national conference...

whenever that conference is mentioned or ...coming up, I just can't help but...mentally acknowledge that and emotionally acknowledge that because I will forever associate my travel to that conference with my first pregnancy loss...The second pregnancy loss was when I was traveling to a conference...whenever I think or hear of that conference coming up...that's just like what I will affiliate with. So as long as... for the rest of my life, as long as I'm working in public health...I will...by myself kind of have at least emotionally a recognition of that and kind of that reminder.

EPL experiences between five and seventeen years ago. Jenny's statement "Time heals...it doesn't erase" exists as her reflection on how the pain of EPL never truly goes away completely. Kiersten never stops thinking about the EPL. Similar to what Kim shared, Kiersten describes the little reminders that occur throughout the year:

I think about it. Every year in November, I think about it. Every year in the summer, I think about it...my oldest daughter is going to be um, six. An:d my first child would be turning 7 this month. An:d when I'm at school I see the kids...I think 'WOW...that's where my first child would be.'...8 years ago I would have probably broken down and cried...It still impacts me, um. I don't break down and cry. But it's, it's never something that I stopped thinking about. It doesn't...leave my mind...not that I'm happy about it, but...I'm always aware of it.

Kiersten mentions moments where the guilt of EPL resurfaces long after releasing self from blame. She mentions the sadness resurfaces when others share experiences of EPL.

(big breath) You still have the same moments where- you still have the guilt...you still have the sadness, but I don't blame myself the way that I did then...I understand the why you want to do whatever you can. Even though its, you know still an inside baby, you still want to do what you can, I still get that. But I've kind of released myself from the blame. Um, whe:n I think about it and when people experience it you feel it. I mean, you feel that pain in your heart of the 'ugh, I remember what that was like' ...it's never as raw as it was.

Knowing she will see the baby again helped Kiersten with the healing process.

I'm spiritual enough that I believe at some point, um, when I die and leave this world I will be- reunited...when people die I think of the, 'Hey...they're there and that's one more person that's with my baby, holding my baby.' And that was something that at first would make me

sob but as time went on it was important to me helping me heal.

The following example provides insight into Shannon's knowledge of time eventually healing pain, but not completely. Shannon told the oldest daughter of her participation in a study on early pregnancy loss and that she would have been the second daughter had the first pregnancy survived.

[Shannon referring to her daughter] "Wow! I could have been the middle sister." (Voice sounds like Shannon is smiling indicating a bit of joy at the realization). "Yeah you could have been the middle sister." And so it's a really weird sort of thing to think about what might've been. But with 15 years in perspective it's kind of interesting to go, "Huh, you could've been the middle sister." Whereas when you're going through it right now, all you need to know is that someday you're going to have perspective and you're going to be able to smile. And it's, it'll still hurt, but it won't hurt as much.

EPL experiences twenty-three years ago and beyond. Ginny recognized the EPL pain remains. "I look back on that now and I know, you know the pain is still there. You don't get rid of that pain. It's still there." Ginny mentions that talking about early pregnancy loss at the time of the interview brings up the pain again, and adds that the pain previously resurfaced when her own child experienced the pain of pregnancy loss.

It [talking] brings back...the pain that I had then. But it's been so long [37 years ago] that it's softened a lot. Until our son and his wife lost their twin boys. They were at five and six months I think... that brought it up again. (quiets) It was painful...for me (clears throat) for them to lose them, little boys.

Ginny shared the belief in reunion with the first EPL, the one believed to possess a soul.

I truly believe...all of the unborns [*sic*] or the, the babies that died, early, in pregnancy, that we'll see them...they have a soul...they're all with the Lord in Heaven right now anyway. And I know that we'll see that little one in Heaven someday.

Contrary to what Ginny stated about the experience of discussing the early pregnancy losses, Mary mentioned the ability to talk about anything because she was an

“open book.” She expressed that the twenty-three years since the EPL made talking about the EPL perfectly fine and that “time heals all wounds or wounds all heels. How does that work?” (Breathes out and laughs). Although Mary explicitly stated willingness to share the EPL story, the statement implicitly provides some indication that perhaps with healing, scars may remain.

The theme “time heals...it doesn’t erase,” demonstrates the majority of women in the study continue to experience the pain associated with EPL. Although emotions may ebb, dates or events associated with the loss and/or hearing stories of others’ EPL or later term pregnancy loss may trigger emotions. In addition, some women encounter random moments of re-experiencing guilt associated with EPL. Evident throughout the themes, women may adjust to the loss, but the memory remains.

The sub-story processing early pregnancy loss provides insight into a variety of ways women make sense of EPL experiences, including the influence of communication with others. Interactions where acknowledgment of EPL occurs assist women with making sense of and mourning EPL. With the memory of what was lost remaining long after physical healing, the potential lifelong need for emotional anchors exists should feelings associated with EPL resurface. With barriers to conversations of EPL existing both at interpersonal and societal levels women may continue to experience disenfranchisement of the grief. The time has come for society to take measures to move toward more open discussion and recognition of the frequent occurrence of EPL.

Chapter 4

Discussion

The objectives of this study were twofold. One objective explores how women implicitly and explicitly make sense of early pregnancy loss experiences. The second describes communication about early pregnancy loss. The thick descriptions (Geertz, 1973) of sense making and communication occurrences surrounding early pregnancy loss present in the lives of ten participants provide breadth and depth to understanding EPL experiences. The use of crystallization (Ellingson, 2009) allows both individual core narratives at the time of loss and sub-stories located across the entire interview data to strengthen EPL understanding. Three core narrative summaries tell more about each particular woman while concurrently providing commonalities of experience within the following convergent core narratives: (a) *conceptualization (what was lost?)* (b) *secret motherhood (disenfranchised grief)*, and (c) *anchoring emotions (talking helps)*. Two sub-stories occur throughout the data, *lost at sea* and *processing EPL*. *Lost at sea* consists of three themes: (a) *blindsided by the unexpected*, (b) *lack of acknowledgment within interpersonal interactions*, and (c) *EPL as marginalized by society*. *Processing EPL* consists of: (d) *cause of EPL*, (e) *emotional anchors*, and (f) “*time heals...it doesn't erase.*” The six themes indicate participants' shared reactions from the first moments of experiencing loss to current understandings of the EPL experience. The three core narratives symbiotically interact with the six themes to provide a coherent picture of the participants' early pregnancy loss experiences.

The core narratives and themes located within the participants' stories of EPL indicate sense making involves communicative events and describes communication

occurring within interpersonal and societal contexts. First, discussion of how the data provide understanding of sense making and communication in EPL by contributing support for and the extension of existing knowledge of disenfranchised grief and the power of the story in the context of early pregnancy loss occurs. Then, discussion of the practical implications addresses the relevance of the results for women with the experience of EPL and/or who may experience early pregnancy loss. The chapter closes with the presentation of limitations and a conclusion.

Sense Making and Communicating Early Pregnancy Loss

Making sense of early pregnancy loss and descriptions of communication surrounding early pregnancy loss often influence and inform one another. Results inform existing information on disenfranchised loss and support the call for understanding stories within the contexts of health related issues. Discussion of the two occurs in the following sections. The first section, grief of early pregnancy loss and disenfranchisement, provides insights regarding the women's grief experience and knowledge of societal and individual understanding of EPL as disenfranchised. The second section, the power of the story within the context of EPL, provides how stories impact the storyteller and hold potential to influence the listener.

Grief of early pregnancy loss and disenfranchisement.

My pain was not physical when he was born. It was emotional. The pain, I had no pain. I had no labor no pain at all. I was just 100% distraught... Maybe a month. I think a mother who loses the baby is going to grieve for a long time. I mean it's just, anyone who loves, being a mother is gonna grieve. Because part of them is gone. ~Ginny

Results offer understanding that often the pain of EPL loss remains despite efforts to alleviate the pain, as "*time heals...it doesn't erase*" indicates. The majority of women

in the study continue to feel and grieve the loss. Understanding women undergoing EPL often continue to feel the pain of EPL throughout life provides an understanding of the level of significance given to *what was lost*. All losses remain a part of the present life experience. The new normal, or current normal, for the women often exists as understanding and mourning the EPL; a child failed to join the family. The unrecognized grief associated with EPL leaves women feeling alone in the sorrow.

One of the overarching core narratives *secret motherhood (disenfranchised grief)* demonstrates women took on the role of mother the moment of confirming the pregnancy. Often the women reported carrying the role of mother to the lost pregnancy into the future. Contrary to parents in Lange et al.'s study (2011) focused on disenfranchised grief of couples experiencing perinatal loss, the women in this study held clear *conceptualizations of what was lost* during the EPL event. Most women continue to conceptualize the role of mother to a lost pregnancy at the time of interview, providing additional insight into the remaining experience of feeling disenfranchised in the grief when instances trigger thoughts of the loss years beyond the EPL occurrence.

The only exception, Ginny, failed to *conceptualize* the second loss as the loss of a child. Ginny understood the loss through medical explanation, a blighted ovum, which held no chance of growing into a baby. Ginny understood the medical explanation both at the time of EPL occurrence and the time of the interview. Ginny holds no ties to the second pregnancy. However, Ginny is convinced that she “gave birth” in the toilet to what looked like a baby. Ginny conceptualizes the first pregnancy loss as the loss of a child that she remains a mother to and will see again. Ginny holds two distinct understandings of *what was lost* and how she relates to the early pregnancy losses. For

the other women reasonable medical explanations of non-viable pregnancy at time of EPL were unsuccessful. The women conceptualize the EPL as the loss of a baby and still feel a mothering link to the lost pregnancies. Future investigations should further explore instances where women accept a medical explanation versus instances where women refuse to accept a medical explanation of a non-viable pregnancy. Such a study may include understanding how the explanation is communicated and how the woman experiences grief and interactions surrounding the EPL both at the time of loss and years later. Attempting to continue to make sense out of a situation that appears to hold no sense at all may only exacerbate the pain of EPL. The likelihood exists that if a woman understands the EPL as something for which no potential of a human connection exists, the sooner she may move forward in grieving the loss, potentially experiencing less internal turmoil over *what was lost*.

Societal. As stated in the first chapter, disenfranchised grief describes losses that are “not openly acknowledged, publicly mourned or socially supported” (Doka, 1989, p. 4). The participants’ stories demonstrate EPL grief as disenfranchised within societal contexts. All of the participant’s stories indicate understanding EPL as not publically mourned or societally accepted as a loss. While moments occur where women recognize large organizations working to acknowledge EPL (e.g. Angela’s story of the white cloth in the folder provided by the religious organization through her hospital), communication of expectations of available options for organizational acknowledgment is lacking. Lack of setting such expectations often catches women off guard when provided options for which women were previously unaware.

As Young and Zavatto (2008) state, in many instances social change begins with practices and behaviors present in hospital systems and/or religious organizations. Although a shift appears indicating healthcare and religious organizations working toward honoring EPL, a communication gap exists between organizations working to honor EPL and the expectations or common social knowledge of such offerings available to the woman who experiences EPL. With expectations and knowledge of the availability of ways to honor an EPL missing within the greater society, how women become informed of ways to honor EPL offered through hospitals and/or religious organizations warrants investigation. For example at what point in the EPL experience do organizations offer services to assist with acknowledging loss? Are pregnant women informed? What do the interactions include? What protocols exist at hospitals for honoring EPL? Are options common or rare in hospital systems across the country? Answers to these questions may assist in locating where failure to communicate expectations for options of honoring EPL occur and offer suggestions for improving information dissemination. Knowledge of organizations working together to recognize EPL is encouraging but fails to influence societal awareness at the present time.

Individual. Within interpersonal contexts EPL occurs as disenfranchised at varying levels. Some women lack a social network to talk to and employ a therapist to speak with. Others experience acknowledgment within a social network, but disenfranchisement from a doctor. Some women report feeling entirely alone in the EPL experience, expressing a sense of unresolved issues when individuals fail to acknowledge the loss, and express gratitude for a sole confidante, a counselor.

Particularly interesting data occurring within the results of this study lies within women sharing stories of societal disenfranchisement when asked to describe interpersonal communication occurring with healthcare providers and others (friends, family, etc.) No interview questions specifically focus on the societal handling of EPL, yet many responses express the need for society to openly speak about EPL and acknowledge EPL. Often women attribute the influence of societal views to an individual's inadvertent mishandling of and/or unconsciously incompetent (Howell, 1982) comments during interpersonal communication encounters surrounding EPL. More often than not, women grant individuals a "pass" because the individual's response fits within the larger understanding held within U.S. culture: EPL viewed as unimportant, "no big deal."

However, women became upset with healthcare providers who demonstrate insensitive and/or unconsciously incompetent behavior. Healthcare providers receive no "pass." Patients held healthcare providers working in settings (i.e. ER, OB-GYN offices, primary care provider offices) where the potential for working with patients experiencing EPL to higher standards. Women expect healthcare providers to possess more experience with EPL and therefore expect healthcare providers to possess an understanding of how to behave when communicating about EPL. By sheer chance a nurse participating in the study shares her own previous thoughts of EPL as "no big deal" until experiencing EPL. After attempting to believe prior thoughts of EPL the nurse's understanding eventually changes to "it's a big deal" because of personal experiences with EPL. The example may indicate a need for sensitivity training and educating healthcare professionals on attempting to understand EPL from the patient's perspective.

In contrast to Lang et al.'s (2011) study, which specifically focuses on the EPL experience existing as a disenfranchised grief, the results include moments and/or individuals in each woman's experience that acknowledge and support the woman's understanding of EPL. While great variation exists in women's experience of EPL as enfranchised in the current study, understanding the impact of acknowledging EPL and validating emotional responses to EPL assists in pointing to practical implications. Discussion of *anchoring emotions (talking helps)* and the *emotional anchors* present within women's stories of EPL occurs in the section regarding the power of the story, which precedes practical implications.

In summary, results of this study indicate the disenfranchisement of grief associated with EPL exists at the societal level with the indication of some church and hospital organizations making efforts to acknowledge EPL. Interpersonal interactions surrounding EPL demonstrate disenfranchisement exists for most within a majority of interactions. However, results also indicate acknowledgment of EPL existing within interpersonal communication, which leads to the second major understanding supported by the research, the power of the story.

The power of the story within the context of early pregnancy loss.

I had never cried that much about losing my babies, as I did when I talked to you. And it was really helpful and healing, for me, so, thank you again for that. ~Kim

Impact on the storyteller. Results demonstrate that making sense of EPL often occurs within conversations or in reaction to the lack of conversations with others. The inability to talk about one's story causes difficulty for women to work through the emotions of loss, essentially creating a barrier to moving forward. Regarding the lack of

conversation, EPL understood within the framework of disenfranchised grief provides knowledge of the lack of recognition many individuals exhibit regarding EPL. Often attempts to tell one's story fall on deaf ears. The inability to express emotionally disturbing or distressing experiences through language causes an individual to "continue to live with them [the emotionally disturbing or distressing experience]" (Pennebaker, 1997, p.103). The inability to speak of EPL may explain why the pain of EPL often remains.

The narrative process allows hearing the woman's voice, validating and acknowledging the story. Time and again women refer to the need for addressing the emotional pain of early pregnancy loss. *Talking helps with anchoring emotions* women associate with EPL experiences. Women experience varying levels of moments that allow the telling of the story within interpersonal interactions. Results support talking to other people facilitates adjustment and working through the difficulties associated with loss (Doka, 2002). The women's early pregnancy loss stories illustrate how the emotional anchors open up the women's ability to grieve. In addition, results indicate the need for validating and acknowledging emotions associated with EPL both at the loss occurrence and potentially throughout one's lifetime.

The resounding appreciation women express for the ability to speak of EPL occurs as particularly salient, especially within the context of healthcare. Participants talk of gratitude when "granted permission" to speak of EPL by counselors and therapists, expressing the importance of listening without judging in interpersonal interactions. Telling one's story offers a sense of acknowledgment of the EPL providing an *emotional anchor*. Stories of experiencing acknowledgment from healthcare providers indicate the

desire for empathic listening surrounding EPL. When healthcare providers (whether ER doctors, general practitioners, OB/GYNs, or nurses) truly focus, listen from a space of care, and provide information or explanation for the EPL in a sensitive fashion, the behaviors profoundly impact the woman's EPL experience. In all instances women report feeling validated in the grief response when provided the opportunity to openly speak of EPL. Often validation of EPL through conversation offers the woman the ability to express previously silenced emotions.

Although the idea of self-blame or guilt associated with EPL is previously identified within the literature on EPL (Bansen & Stevens, 1992; Crawford, Gask, Grinyer, & Wong, 2003; Mulvihill & Walsh, 2013), focus on communication within the context of EPL may provide new understanding surrounding guilt and blame. Some women report a release from self-blame or guilt after beneficial conversations with healthcare providers. Some women in this study refer to an individual's words *causing* feelings of guilt or blame for the EPL. Although some stories provide explicit communication of the woman being blamed for EPL, other stories reveal perceptions of others' communication implicitly refer to EPL as a result of the participant's wrongdoing. In some instances, whether or not self-blame or guilt for the EPL exists prior to the conversation remains unknown. Future work may explore the concepts of blame and guilt within the context of interpersonal interactions surrounding EPL, both within healthcare settings and family contexts. Specific focus on determining if blame derives from the influence of another's words may assist in determining how to better assist women experiencing the grief of EPL and may lead to revelations in better practices regarding what to say and what not to say to women undergoing EPL.

Potential impacts on individuals and society.

In addition to providing benefits to the individuals speaking about early pregnancy loss stories, hearing and/or reading EPL stories may assist individuals and society in a variety of ways. EPL stories serve as a representation for understanding the grief of loss, the diverse ways through which EPL occurs, and how women make sense of the occurrences and communication surrounding EPL. Hearing and/or reading EPL stories provide insights into communicative actions that may assist healthcare providers, friends, and family members responding to women experiencing EPL. For example, after hearing of an individual's EPL, the receiver of the message experiences uncertainty in knowing how to respond. Research provides clues for an appropriate response: "I'm sorry for your loss." While individually tailored statements assist each woman within the context of her specific life, across women's stories evidence of the value in and need for hearing "I'm sorry for your loss" exists. Similar to other experiences of grief with loss, the simple statement appears a safe item to say and is difficult to misconstrue. Other provisions of acknowledgment present in women's stories of EPL came in the form of comfort and empathy within a safe space to grieve and work through EPL.

Participants spoke of choosing to participate in the study in hopes of personal stories bringing forth change, if not at the societal level, hopefully for one nurse, doctor, friend, or family member. The stories tell of people with no experience of EPL often failing to recognize EPL as a significant loss. *Conceptualizations of what was lost* fail to align with how the woman experiences and understands the loss of a pregnancy occurring at twenty weeks in utero or less. This study points to how listening without judging serves as an excellent way to acknowledge a woman's EPL experience. From the stories

one may take away a deeper understanding of the variety of issues contributing to a woman's experience of EPL. Early pregnancy loss situations often become socially complicated. Beginning to understand the meanings women apply to EPL offers the listener or reader the opportunity to understand the woman's perspective. Attempting to understand from the woman's perspective provides potential for empathic response and demonstrates the acknowledgment of the EPL. Hearing the stories holds the potential to provide more than a window for viewing another's experience (Riessman, 2002). Hearing the stories provides the opportunity to create a footpath alongside the individual, offering the listener the chance to walk with and/or "feel with" the individual sharing an EPL story. In addition, individuals who experience EPL firsthand may benefit from hearing or reading others' stories of EPL, providing validation for their own experience (Baddeley & Singer, 2009). With the high incidence of EPL and EPL existing as a taboo topic of discussion, reading another's story of EPL allows silenced individuals to potentially feel less alone.

Practical Implications

The primary understanding gathered points to the need for an outlet to speak of EPL experiences and feelings associated with the loss. As the stories indicate, the need for conversations about EPL may continue years beyond the incident of loss, often because of the woman's inability to fully speak about the loss when EPL occurs. According to Pennebaker (1997) traumatic stories are difficult for individuals to hear. While not all EPL stories exist as traumatic, the difficulty in listening to such stories for the untrained ear may contribute to why so many women feel disenfranchised in EPL. Concurrently, individuals hearing of EPL may not understand EPL in the manner that the

woman conceptualizes her loss. Counselors and therapists trained in listening skills, who specialize in early pregnancy loss may provide the best option for creating a safe space for women to fully work through the emotions connected to loss. Healthcare organizations may need to create policies that support the need for EPL conversations to occur. As suggested by the nurse participant who only spoke of her losses with her mother and husband prior to the interviews, one meeting with a counselor after an EPL experience may make a significant difference in a woman's EPL experience. The nurse's recommendation of including a counseling session as standard practice within healthcare systems for women undergoing EPL receives support from many participant accounts. The suggestion may provide supportive direction for prior research findings where participants requested "formal follow-up plans" after miscarriage (Crawford, Gask, Grinyer, & Wong 2003, p. 697). Stories from women experiencing EPL years prior to the interview demonstrate the potential exists that women experiencing EPL in the near to distant past may benefit from the ability to tell the story of loss within a counseling session. Participants refer to the ability to tell the full story and feel completely heard as key to assisting in the continual story of life after EPL.

A second item points to the necessity for availability of information regarding (a) the possibility of EPL as an outcome of a pregnancy and (b) the resources one may utilize should EPL happen. With EPL occurring in up to one in four pregnancies (American Pregnancy Association, 2007) and about one-quarter of women experiencing a miscarriage sometime during their reproductive lives (Regan & Rai, 2000), the fact that women and society in general remain unaware of EPL until EPL hits home is dumbfounding. Women report feeling caught off guard by the situation indicating

communication meant to educate women about potential EPL is missing and/or occurs as an easily dismissed message. Women ought to possess knowledge of access to resources for working through EPL should EPL occur. Individuals experiencing EPL need supportive services within healthcare systems and society readily available. Further exploration into identifying where communication gaps exist in disseminating information regarding existing services may prove beneficial.

This study provides insights into potential scripts for individuals and healthcare providers when working with women experiencing and/or disclosing EPL. By definition disenfranchised grief indicates supportive communication as lacking. In both the sub-stories *lost at sea* and *processing EPL*, evidence of the need for validation of the loss (esteem support) and releasing emotional feelings associated with the EPL (emotional support) occur within the themes. The results indicate that having an individual, or individuals, present to listen (social network support) to the narratives of women who undergo EPL validates the loss. To communicate support upon hearing of an EPL, a statement of “I’m sorry for your loss” speaks volumes. Such a statement recognizes EPL as a loss worthy of bereavement, acknowledging EPL as a loss that held significance and provides the potential opening for further discussion. First, “I’m sorry for your loss” delivered with sincerity and/or compassion validates and acknowledges the pregnancy that no longer exists. Following the previous statement with, “Tell me what happened” or “I’m here to listen” and sitting down allows the sender of the message to understand opening up about the EPL is warranted. The receiver of the message needs to listen with the intent to understand the story from the perspective of the woman telling the story. Asking open-ended questions may assist in prompting invitation to continue the story,

allowing the woman to truly feel heard. Do not provide unsolicited advice, judgments or one's own perspective on the matter. Listen with the intent to connect and understand as if able to feel the other's emotions, providing an empathic response (Kuhn, 2001).

The time has come for EPL to exist as an open topic of conversation in our society. To work toward enfranchising women who feel disenfranchised in the EPL experience discussions surrounding EPL need to become mainstream. No woman needs to feel alone during such a crisis, nor should a woman feel ashamed of sharing the experience with others. A first step for educating the general public might include a national health campaign focusing on education and awareness regarding EPL. A carefully crafted health campaign holds potential to fulfill such a void in mainstream conversations of EPL. In the case of EPL, envisioning the possible may focus on the side of pregnancy that often goes unspoken; beginning with educating the public on the possibility that loss may occur and then understanding that women do hold the ability to move forward with life despite the incredibly deep pain most experience. Surviving such a breach in one's ideal expectations of pregnancy occurs, yet the pain may continue to exist and resurface throughout one's lifetime.

Limitations and Future Research

Although results indicate the majority of participants continue to experience pain associated with EPL even years beyond the occurrence, the possibility exists that only women who continue to feel a connection to the loss and the need to speak of EPL chose to participate. Whether or not this holds true points to a limitation. Future research may focus on recruiting individuals who self identify as having experienced the pain of EPL and indicate current resolve with the experience. Purposefully sampling women who

indicate resolve with EPL to understand their process of sense making and descriptions of communication surrounding early pregnancy loss may provide new insights for recommendations on handling EPL conversations within both interpersonal and societal contexts.

A second limit to the study exists in the demographics of the participants. The majority of women in the study identified as Caucasian. All held undergraduate degrees with a majority having education beyond the undergraduate degree. All women were financially stable. While data gathered from this group of women allows for rich understanding of EPL sense making and communication, the opportunity for rich data in groups less represented in research remains. Future work may focus on obtaining stories of EPL from women who are less educated, hold lower socio-economic status, and are from ethnic backgrounds less prominent in research. Data gathered from such work may allow for comparison of experiences, sense making and communication across various culture groups, providing a fuller picture of EPL experiences.

A final limitation presents in the study design, specific to data gathering. Although the protocol involves similar interview questions, gathering data over time versus in one interview session may impact the data. For example, all of the participants interviewed over time spoke to the impact participation in the research project held. Follow up interviews may provide room for reflection on the impact and experience of EPL encounters including within the interview, and thus may provide explanation for the implicit and/or explicit comments about participation in the process of the interview. The comments related to interview impact support the notion that processing EPL continues. What remains unknown is how or if the participants involved in one interview session

feel any change or impact from participation in the study. While intentional in design due to the constraints of timelines for data gathering, in hindsight the researcher may consider how future studies may benefit from longitudinal design to continue the line of research.

Conclusion

The purpose of this study was to gain knowledge of women's experiences of early pregnancy loss through solicitation of EPL stories. The two sensitizing foci of the project were sense making and communication surrounding EPL experiences. The research was influenced by Harter's (2013) new normal narrative framework for health communication, which calls for understanding how patients handle new health situations through the use of narrative to obtain a better understanding of the experience from the patient's perspective. This approach to understanding a sensitive health issue brought forth insights that support and extend existing literature on EPL experiences. The stories demonstrate a breadth and depth to the issue of early pregnancy loss with focus on how one makes sense of the new normal or current normal during and after the early pregnancy loss experience and communication surrounding EPL. In addition, this research contributes support for and extension of existing knowledge of disenfranchised grief and the power of the story in the context of early pregnancy loss. As stated in chapter one, prior scholars point to stories helping the narrator make sense out of disruptions in life. Results suggest that in situations of disenfranchised grief of EPL, the first step in moving toward working with and/or living in one's new normal is the ability to speak of the EPL.

The rich array of stories of early pregnancy loss present, allow the commonalities of experience to inform potential continual studies. The results provide a deep understanding of the emotional turmoil women experience at time of EPL and how the

emotions may resurface many years after the event. The new normal does not exist as a static event indicating one overcomes the EPL experience, but rather exists on a continuum. Women often continue to understand, live into, and with the unexpected early pregnancy loss years beyond the occurrence. Narrative inquiry contributes “a new sense of meaning and significance with respect to the research topic” rather than providing a “set of knowledge claims that might incrementally add knowledge in a field” (Clandinin & Connelly, 2000, p.42). The meaning and significance the accounts support is the reality that the pain of EPL may never go away. As demonstrated through participant’s stories, even though the pain remains the ability to create an alternative option to the original family plan (Keya’s story), and the ability to endure many losses and continue to move forward (Chelsea’s story) indicate adjustments made within the new normal, life after EPL.

As the data demonstrates, women experience communicative interactions that fail to acknowledge EPL and that acknowledge EPL. Often communication regarding early pregnancy loss is described as societally and interpersonally disenfranchised, silenced, dismissed, and not talked about. Apparent in the stories, the inability to acknowledge and talk about EPL within interpersonal and societal contexts detracts from a woman’s ability to work through the emotions that accompany such a blindsiding event. However, when interactions involve the acknowledgment of EPL, communication is described as anchoring, supportive, and assisting with coping with the pain of loss. Particularly salient to participants’ adjustment to the situation, or new normal, were the memorable moments where practitioners said or did things that positively impacted the participants’ EPL experience. Acknowledgment of EPL is demonstrated through and called for in the form

of (a) providing comfort, (b) providing the ability for women to talk about EPL and/or express emotions, (c) truly listening, and/or (d) expressing an empathic “I’m sorry.” Due to the variety of sense making evident in women’s stories the need for the acknowledgment to occur without judgment or unsolicited advice is implicitly understood.

While not all women may feel the need to speak about EPL loss or be ready to speak of EPL if prompted, participants’ stories indicate women benefit from telling stories of EPL. The stories remain present long beyond the loss occurrence, highlighting the potential need for more discussions to occur both with women recently experiencing EPL and women carrying the secret motherhood story years beyond the EPL occurrence. According to Pennebaker (1997) writing or speaking about experiences one still faces years after the event proves beneficial. Understanding “*time heals...it doesn’t erase*” may warrant further investigation of stories from women experiencing EPL and the need to provide discussion with an avid, empathic listener. Women may benefit from anchoring conversations whether the loss occurred recently or long ago.

Both Frank (2010) and Doka (2002) support gathering more stories to assist with understanding marginalized, silenced, and/or disenfranchised loss experiences. To better understand and serve individuals experiencing early pregnancy loss, additional stories need to be heard and continually listened to. Not all women resolve the pain associated with the loss of what was expected. As Angela mentioned at the end of her first interview, “the story continues.” For many a need may exist for the continual processing of life after EPL.

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Appendix A: Example of Scheduling Email Sent to Follow up Participants

Hello,

I am contacting you to set up a follow up interview per our recent conversation. In order to conduct the interview over Skype/phone, we will need you to have 30-45 minutes of uninterrupted time, preferably in a private location within your home or office where the Skype or phone call will not be dropped.

At the start of the interview, we will go over a verbal informed consent form, and review/update any needed demographic or history information. Questions asked will focus on a few follow up questions and include new questions regarding the impact the experience we have previously discussed has had on your life overall.

Again, thank you for your willingness to continue to participate in this study. Please let me know when the best time to reach you for a follow up conversation via Skype is.

Currently I'm interested in learning about your availability for any of the following:

Anytime

June 16, 17, 18, 19, (Monday through Thursday) or Sunday the 22nd

Anytime before:

5pm CST on Friday June 20th

Please reply with a date and time for our Skype/Phone conversation, and I will confirm. If any of these dates or times does not work for you we may look to future weeks.

My Skype address is JenmoreyXXXX. My phone number is 971-404-XXXX.

Thanks again.

Sincerely,

Jennifer

Jennifer Morey Hawkins
Doctoral Candidate
Department of Communication
University of WI- Milwaukee

Appendix B: Recruitment Message

Early Pregnancy Loss Narratives: Recruitment Message~

Hello,

I am conducting a study regarding communication occurring during and after early pregnancy loss. I am interested in interviewing women who have experienced a loss (or losses) of a wanted pregnancy prior to the 20th week (miscarriage, ectopic, chemical pregnancy, for example). The interview is meant to gather your stories of communication experiences within the healthcare setting and everyday interpersonal interactions, as well as your views of motherhood prior to and after loss. All information will be kept confidential.

- Participants will be interviewed for between 45 and 90 minutes.*
- Interviews will take place through July 2014 into the first week of August.*

If you are interested in participating please contact Jennifer Morey Hawkins to schedule an interview:

hawkinsj@uwm.edu, or 971-404-XXXX.

Thank you,

*Jennifer Morey Hawkins, Doctoral Candidate
Department of Communication, UW- Milwaukee*

Appendix C: Semi-Structured Interview Protocol – (Re)presenting Stories of Early Pregnancy Loss Through Narrative Analysis

Tell me about your view of motherhood and pregnancy prior to being pregnant.

1. What was/were your loss experience(s) like? (Prompt: What happened?)
2. Tell me about your view of motherhood and pregnancy after going through this.

Sub-Points- Follow Up Prompts to Organic Story:

Healthcare Provider Experience and Communication

1. (Can you tell me more about...or) Tell me about the experience of going to your healthcare provider.
 - a. How did you feel in that setting?
 - b. What items or systems were set up for your care?
2. How were you informed of your early pregnancy loss?
3. What were your conversations with healthcare providers like?
4. Were there any particularly helpful situations or interactions that occurred?
(Prompt: ...in the doctor's office/hospital?)
Follow up Prompt: How did that affect your experience of loss?
5. Were there any particularly unhelpful situations or interactions that occurred?
(Prompt: ...in the doctor's office/hospital?)
Follow up Prompt: How did that affect your experience of loss?

Communicating Early Pregnancy Loss with Others

1. (Can you tell me more about...or) Tell me about your experiences telling others about your early pregnancy loss (as). (Prompts: Whom did you tell? How did they respond?)
Follow up Prompt: How did that affect your experience of loss?
2. Who comforted you? Follow up: How did that make you feel?
3. Tell me about people that you intentionally kept this information from.
4. What is it like to communicate with others about your early pregnancy loss(es) now?
5. Are there any situations or conversations you experienced in the past or experience now surrounding early pregnancy loss that you wish you could change?
6. What would you say to another woman if you learned she recently experienced an early pregnancy loss?

(Additional) Impact and Present Understanding of the Experience

1. Are you changed as a result of your early pregnancy loss experience? (If yes, ask -How?)
2. What impact has this experiences had on your life?

3. Can you tell me how the experience impacted your relationship with your partner? (Prompts: Both at time of loss and now).
4. Did you, or do you continue to, do anything to recognize the loss? (If yes, ask – What?)
5. How do you think about your early pregnancy loss experience now?
6. How does it feel now to have gone through all of this?

Prior to ending this interview I want to see if there is anything else you would like to add regarding your experience. Please feel free to share that with me now.

Thank you!

Additional follow up prompts for more information:

What did they say? How did you react?

What do you mean by _____?

Can you tell me what was _____?

Can you tell me more about that?

What was the experience like for you?

Amended and approved June 11, 2014

Appendix D: Single Case Interview Guide

Interview Guide –

Introduction

Personal circumstances; relationship, children, age, religion

Prior thoughts on motherhood; expectations, initial reactions to the pregnancy

Early Loss experience; awareness, total losses

Communicating loss; supportive, non-supportive

Adjustments to thoughts regarding motherhood; behaviors, life plan

Current reactions to/viewpoints of the loss experience

Additional information/Input

Appendix E: Demographic and History Information

Demographic Information

1. What is your current age? _____
2. Are you?
 - a. Heterosexual
 - b. Homosexual
 - c. Bisexual
 - d. Other _____
3. What is your racial identity? (Circle all that apply.)
 - a. First Nation: American Indian or Alaska Native
 - b. Asian American
 - c. African American
 - d. Native Hawaiian or Pacific Islander
 - e. Hispanic or Latino/a American
 - f. Caucasian
 - g. Other _____
4. What is your religious affiliation?
 - a. Christian
 - b. Jewish
 - c. Muslim
 - d. Hindu
 - e. None
 - f. Other _____
5. What is your highest level of educational attainment?
 - a. Grade School
 - b. Middle School
 - c. High School
 - d. Associates Degree
 - e. Some College
 - f. College Degree
 - g. Masters Degree
 - h. Ph.D., J.D, or Ed.D.
6. What is your relationship status?
 - a. Married
 - b. Not married; In a committed relationship
 - c. Separated
 - d. Divorced
 - e. Widowed
 - f. Other _____

7. What is/was the length of the above relationship? _____
8. Is this relational partner the person you were with when pregnancy loss(es) occurred? (Yes/No)
9. What is your total household income?
 - a. 0 – 25,000
 - b. 25,001 – 50,000
 - c. 50,001 – 75,000
 - d. 75,001 – 100,000
 - e. 100,000 and above
10. What is your current occupation/position?

Background Information

1. Please indicate the types of losses you have had and the total number of each type. Include the point at which the pregnancy loss(es) occurred (and the age you were at time of loss (ex: miscarriage 8 weeks at 33, ectopic 9 weeks at 34, chemical pregnancy loss 2 days after positive test, 35).

Chemical Pregnancy (positive test result and then menstruation shortly after)

Ectopic Pregnancy

Miscarriage at or under 20 Weeks

Other (Please explain)

2. Have you ever had a successful pregnancy prior to or after your above noted loss(es)? If yes, please indicate at what point this occurred and your age at delivery. (Ex: miscarriage at 35, child at 37, ectopic 40)

**Appendix F: Semi-Structured Interview Protocol: Preliminary Exam –
Multiple Case Thematic Analysis of Early Pregnancy Loss Narratives**

1. Tell me about your view of motherhood and pregnancy prior to being pregnant.
2. What was/were your loss experience(s) like? What happened?
3. Tell me about your view of motherhood and pregnancy after going through this.
4. Tell me about the experience of going to your healthcare provider. (How did you feel in that setting? What items or systems were set up for your care?)
5. Tell me how you were informed of your early pregnancy loss. (How did you come to understand that you were experiencing a loss?)
6. What were your conversations with healthcare providers like?
7. Were there any particularly helpful situations or interactions that occurred in the doctor's office/hospital? (Please tell me.)
8. Were there any particularly unhelpful situations or interactions that occurred in the doctor's office/hospital? (Please tell me.)
9. Were you provided privacy at the doctor's office/hospital?
10. How were your interactions with other healthcare providers in this setting?
11. How did others respond when you told them about your early pregnancy loss? (Tell me about your experiences telling others in your life about the loss. Who did you tell?)
12. What about people that you intentionally kept this information from?
13. What is it like to communicate with others about your early pregnancy loss(es) now?
14. What experiences stand out that I may have not asked you about?
15. What would you say to another woman if you learned she recently experienced an early pregnancy loss?
16. Are there any situations/conversations/encounters you experienced or experience now surrounding the loss that you wish you could change?
17. Prior to ending this interview I want to see if there is anything else you would like to add regarding your experience. Please feel free to share that with me now.

Thank you!

Additional follow up prompts for more information:

What do you mean by _____?

Can you tell me more about that?

What did they say? How did you react?

What was the experience like for you?

Appendix G: Orange County Resources List

Resource List

Recommended Resources for Women who have experienced Early Pregnancy Loss

Early Pregnancy Loss

- **Share Pregnancy & Infancy Support, Inc.**

*<http://www.nationalshare.org/parents.html>

Site offers very detailed information about pregnancy loss including explanations of the different types of miscarriage, bereavement, and information packets specific to early pregnancy loss, all in a very sensitive, warm and professional manner. The following are links to PDFs of brochures on early pregnancy loss in Spanish and English taken from this site:

*http://www.nationalshare.org/Trifold_Espanol_EarlyPregnancyLoss_SAMPLE.pdf

(PDF in Espanol)

*http://www.nationalshare.org/Trifold_EarlyPregnancyLoss_SAMPLE.pdf (An excellent PDF on early pregnancy loss.)

- **March of Dimes**

*<http://www.marchofdimes.com/loss/pregnancy-loss.aspx>

Site offers information links to miscarriage, ectopic pregnancy, molar pregnancy, repeat miscarriages, and treatment after miscarriage.

- **OC Walk to Remember Organization**

*<http://www.ocwalktoremember.org/>

Note, this nonprofit works in many ways to support women and community members, including training healthcare providers in understanding pregnancy loss. Multiple resources may be found on this site. Also, they provide assistance via phone 1-800-714-9320 or email support@ocwalktoremember.org to help people locate needed resources such as support groups and/or therapists. There are many support groups, counselors, online chat boards, and other resources to help you through your grief.

In Person Support Group:

Hoag – Women’s Health Institute, Hoag Conference Center Newport Beach

Support Groups

As part of the Kendall Lauren Honig Pregnancy & Infant Loss Program, Hoag offers a weekly support group for parents and families who have experienced an early pregnancy loss, stillbirth or newborn death. The group provides a compassionate environment to allow parents and families the opportunity to heal and work through the grieving process. In addition, it provides support and sensitivity to families who have suffered a previous loss, while they consider a new pregnancy, or as they manage the feelings of being pregnant after a loss.

Hoag’s Pregnancy and Infant Loss Support Group is facilitated by a licensed clinical social worker with many years of experience in working with families who have experienced a loss. The group is open to anyone who has suffered a loss, including those whose loss did not occur at Hoag. Extended family members are welcome to attend with you. Parents who have experienced a loss after a difficult decision are also welcome.

Meetings are held weekly on Tuesdays at 6 pm at Hoag Conference Center, Newport Beach.

Session Topics may include:

- Understanding and Navigating the Waves of Intense Feelings
- Explaining Death of a Sibling to Young Children
- Marital Conflict / Learning to Understand Your Partner’s Style of Grief
- Dealing With Family and Friends
- Coping with the Holidays and Anniversaries

Drop-in attendance is accepted, however, registration is encouraged and appreciated. To register or for more information, please call 949/764-6864. To download a brochure with more information about the support group, including a map with directions, please see the website:

<http://www.hoag.org/Specialty/Womens-Health/Pages/Pregnancy-Infant-Loss/Support-Groups.aspx>.

Link to Support Group Brochure: http://www.hoag.org/Specialty/Womens-Health/Documents/3_InfantLossSupport.pdf

Online Support:

- **Share Pregnancy & Infancy Support, Inc.**

~Chat

<http://www.nationalshare.org/Chat.html>

The Bereaved Parent and Pregnancy After Loss chat rooms are open 24 hours a day, 7 days a week. There is a moderated bereaved parent chat from 8-9 p.m. CST on the first Tuesday of every month. This is a secured site with rules of conduct guidelines.

Please contact the National Share Office if you need someone to talk to at other times, or call 1-800-821-6819.

~Blog

<http://www.nationalshare.org/blog.html>

Provides option to read and respond to stories of loss.

Community Event:

**2014 10th Annual OC Walk To Remember
Memorial Service, 5K Walk and Celebration of Angels
October 4, 2014**

The District at Tustin Legacy

Saturday, October 4th, 2014 will be our 10th Annual Walk! Our Inaugural 5K Walk was at a local park with 100 participants who came to honor all babies lost to pregnancy and infant loss. Over the years we have grown into a multifaceted nonprofit organization. The flagship 5K Walk Event, which had 3,500 participants in 2013, is anticipated to host over 4,000 participants this year. Our organization has given support to thousands of Orange County families who have lost a baby to miscarriage, stillbirth, SIDS, pregnancy loss or infant death. OC Walk to Remember has educated hundreds of doctors, nurses, social workers, and other medical professionals on how to better care for families who are losing or have lost a baby. In 2014, OC Walk to Remember is undergoing a rebranding. Because we have grown to be much more than "just" a walk, our new name will be announced later this year. The new name will take effect by October 2014 and we have already adopted a new mission statement. Support, Education & Remembrance have become the organizations three pillars and we are very proud to continue OC Walk to Remember and the remembrance opportunity which it has brought to thousands of family members over the last decade. (See <http://www.ocwalktoremember.org/2014-walk>)

Appendix H: Field Note Guide Template (Stevens & Galvao, 2007)

Participant

how recruited –

appearance –

demeanor –

similar / dissimilar to researcher –

Environmental situation

Setting-

emotional atmosphere-

concurrent activities & others present –

Temporal context

time and duration –

fit in daily schedule –

fit in larger structure of life –

Nonverbal behaviors

body posture-

gestures –

facial expression –

emotional expression –

delivery of speech-

Rapport

open / guarded (content) –

ease / friction (process) –

Motives for participation

Explicit –

Implicit –

Power dynamics

direction / domination of interaction –

mutuality of exchanges –

interruptions –

silences –

Researcher's emotional reactions

your feelings during and after the interview –

Interview process

Success eliciting depth of description -

effectiveness of questions / probes –

procedural problems –

Additional Notes:

Appendix I: Narrative Summary Template

Title
Name (and time since last loss)

Brief history of losses with information on number of pregnancies, and where EPL occurred in the pregnancies experienced. If married more than 1 time and it relates to loss story, then any comments on how EPL or if EPL affected the marriage are included here (i.e. if they mention thoughts on divorce).

Thoughts on motherhood/pregnancy prior to being pregnant– then back story leading to the pregnancy

Early Pregnancy Loss Experience Described– OR if multiples Loss #1, #2 etc.

For the heading, add any description (medical term provided) for what the loss was called. For example a blighted ovum, ectopic pregnancy, or twins. For those where the woman did not receive a term to apply, use Loss Experience (if only 1) or Loss #2 etc. Include time of EPL for all. (5 weeks, 13 weeks, etc.)

Tell the story of loss the participant provided. Include mention overall re: communication.

Thoughts on motherhood and pregnancy now after going through “all of this.”

(Whichever “this” may mean depending on the story just heard).

Include entire family/children picture here as they story it.

Additional Instructions

Limit to 3 single spaced pages maximum.

Title of participant’s overarching theme to the story added after individual case analysis.

This goes above the participant’s name

Appendix J: Narrative Summaries

Unrelenting Hope: Unexplained Recurrent Early Pregnancy Loss Chelsea: (within the last few months)

Chelsea has become pregnant six times in the last year and a half. She has lost 5 pregnancies and is 6 1/2 weeks pregnant. She and her husband have unexplained recurrent early pregnancy loss.

Since childhood Chelsea looked forward to being a mother. Motherhood would be a part of life: Go to school. Get married. Have kids. However, she did not know what to expect of pregnancy. When she and her husband stopped using birth control, Chelsea became pregnant the first month. Chelsea instantly felt a strong, deep attachment to the pregnancy. She was a mother. At the 8 - week ultrasound Chelsea and her husband learned that they were having identical twins. Chelsea and the husband were pretty floored.

Loss #1 – 12 weeks: Twins

At the 12 -week ultrasound appointment Chelsea and her husband learned there was no heartbeat from either baby. She had no previous symptoms of miscarriage, was a healthy person and was shocked by the news. Although aware that twins did make the situation a higher risk pregnancy, Chelsea focused on positive thoughts. At the recommendation of her doctor, Chelsea scheduled a dilation and curettage (D&C), decided to be completely sedated and have the procedure at the hospital versus her doctor's office. Chelsea did not think she could handle being conscious for the D&C, nor did she want the doctor's office to be the place of D&C in her memory.

Chelsea describes communication with the doctor and medical providers surrounding the procedure as "pretty nice." The only negative experience was due to an overly friendly receptionist asking how her day was when checking into day surgery. At that point Chelsea felt so down it was all she could do to muster a positive response. Chelsea did recall a very helpful encounter with the woman who wheeled her from the recovery room to the regular hospital room. The woman shared with Chelsea her own story of pregnancy and early pregnancy loss. After losing two pregnancies, that woman had two early deliveries, but they were doing fine now and were healthy. Hearing someone else share an experience close to what Chelsea was experiencing provided Chelsea comfort.

Chelsea no longer felt like she was a mother after the miscarriage. She described feeling very alone after the first loss experience. Chelsea did not know anyone that had gone through miscarriage. No one spoke about early pregnancy loss.

Chelsea thought she might have caused the loss.

Loss #2 – 5 weeks

Exactly one week after confirming she was pregnant by an at home test, Chelsea started spotting. When she called the doctor's office Chelsea was informed that 5 weeks was too soon to do an ultrasound, the spotting could be nothing, the only option was to wait and see, but to be sure to call back if she had any heavy cramping or bleeding. Chelsea did experience pain and bleeding and took pain medication left over from the D&C. She bled for about a week and passed tissue but nothing that she recognized as a baby. Chelsea went in to the doctor's office where they monitored hormone levels to be

sure they were coming back down. Chelsea was thankful that the hormone levels did lower and no D&C was required.

After the prior experience with early pregnancy loss, Chelsea felt more mentally prepared for this loss. The doctor told Chelsea miscarriage happens in one out of every five pregnancies. So although she was hoping for smooth sailing, when the 2nd loss occurred Chelsea was more concerned that there could be something else wrong, causing the losses. Tests for blood clotting and to determine if she had thyroid issues came back normal. The sonohysterogram of the uterus came back normal. She and her husband proceeded to continue to try for a successful pregnancy.

Although the couple originally told the entire family they were pregnant with twins with the first pregnancy, after the first loss the couple determined to keep the information regarding subsequent pregnancies more private. Chelsea felt like a second miscarriage at twenty-five years old meant that there was something wrong with her. Chelsea felt like a failure.

Chelsea had been seeing a lot of medical professionals. Chelsea's mom and a sister-in-law, who had experienced miscarriage, were incredibly supportive throughout the process. At the time, a good friend offered the idea of going to see an acupuncturist. Although Chelsea never experienced alternative medicine before, at that point she felt it couldn't hurt. The acupuncture did help the mood and made her a little less anxious about trying again.

Loss #3 – 4 weeks

Chelsea felt and reacted differently to each loss and provided no further specifics regarding loss number three or four beyond how she felt about the loss afterward. She felt clear that the cause had to be due to a medical issue. This was no longer due to bad luck. The couple stopped trying to get pregnant for several months because Chelsea was terrified of pregnancy. Her obstetrician recommended Chelsea see a reproductive endocrinologist all the tests that they could do were exhausted, including genetic testing, and all of the results came back normal. Reflecting on the third loss, Chelsea explains that talking to her mother, sister-in-law, and husband helped.

Loss #4 – 5 weeks

Chelsea mentions feeling really discouraged about the whole situation. She was very upset and anxious after the fourth loss. Chelsea still wanted to keep trying to have a child of her own but recognized she was not in the right emotional place to start again. Chelsea went to see a therapist who specialized in an array of pregnancy issues including miscarriage. She saw the therapist for a few months and said therapy helped put her thoughts in order regarding how she was feeling about the whole situation. The tool the therapist suggested that really assisted with her emotional reaction to the experiences was writing a letter to the children she had lost.

Loss #5 – 5 or 6 weeks

With her fifth pregnancy Chelsea started on Prednisone, a steroid, to see if that may assist, but again had a loss. Chelsea felt optimistic with that one because she had just started seeing the new doctor who put her on new medication, which provided new hope. Chelsea was on a list to see one of the top reproductive endocrinologists in the nation who specializes in miscarriage and runs clinical trials regarding treatment for recurrent loss. Having options, things Chelsea can do to try and help the situation, provided a sense

of control over the situation. She has experienced so many things that are entirely out of her control, but Chelsea is not stopping until all of the options are exhausted.

Chelsea's husband has been the biggest comfort throughout this experience. He listens and hugs her when she cries. He's been right beside Chelsea through all of the medical decisions. Chelsea has had moments when she's felt guilty that her husband is stuck with this wife who has been unable to have any children. However, her husband has reassured her that he's happy with the two of them and if in the end that is how their family is defined that he'll be happy. This eases Chelsea's guilt.

Currently Chelsea is 6 1/2 weeks pregnant and notes that she is in a better emotional state about this pregnancy, and feeling pretty optimistic. Although not diagnosed with a clotting disorder, she is taking a blood thinner. She says the blood thinner appears to be doing well. She is still pregnant. As far as motherhood goes, Chelsea certainly will not take it for granted, stating that she has a deeper understanding of and appreciation for the miracle of life.

Chelsea explains that knowing that things can and often do get better help her remain optimistic. Yet, she makes a point to say that the pain of pregnancy loss does not necessarily go away. "I wanted (breathes out) I wanted that pregnancy. I wanted those babies. I, and I felt really upset that, they were gone." Chelsea adds that this is the first thing that she has really wanted that is entirely out of her control. No amount of effort on her part will guarantee a better outcome. Knowing the situation is out of her control has been difficult to deal with but having options for items to do to potentially assist with having a successful pregnancy helps. Although some tell Chelsea she is strong Chelsea does not see herself as strong, but admits to being stubborn, "I'm: going to keep trying since this is something that I really want, until, I have exhausted all my options."

Secret Motherhood: Disenfranchised Grief

Angela: just over 1 year ago

Angela was pregnant four times. Her three living children were born prior to her fourth pregnancy, which resulted in the loss of twins.

Angela was disinterested in motherhood. She assumed the role of mother for a sibling who was 14 years younger while growing up. She wanted to focus on herself.

After several years of marriage, she and her husband decided to have a family. Angela viewed pregnancy as a necessary means to an end. She and her husband successfully had three beautiful children. Although she had wanted more children, together she and her husband decided their family was complete with the three children they had. Angela was on birth control.

She took an at home pregnancy test due to wondering why she was so tired and could not get off the couch. Although an unplanned pregnancy, Angela was excited to learn she was pregnant. When she went to the doctor her blood work indicated she was anywhere from 7 to 12 weeks pregnant. She went in the next day for an ultrasound to determine how far along in her pregnancy she was.

Early Pregnancy Loss Experience - 6 weeks: Twins

Angela had been through routine ultrasound before, so she did not ask her husband to come along. During the ultrasound procedure she saw two embryo sacs on the screen but nothing in them. She asked the ultrasound technician if she was viewing the image the right way. The ultrasound technician did not say much other than, "oh well there looks like there are two. And there's one looks about six weeks and one looks about five weeks five days or something like that. But I can't really see anything. This should be right about the time we're seeing something. But that doesn't really mean anything." Angela did not know what to expect, but did not think that sounded good.

At her next appointment Angela saw the midwife because her doctor was occupied with another situation. The midwife said all that could be done was to wait and see and they would do another blood test. The midwife asked Angela if she had any questions and what she thought of the situation. Angela responded, "Well it sounds like you don't know but I have to come back but it doesn't look good." And the midwife said, "No, probably not." A day or two later Angela went back for the blood test and was told they would call her later that same day. Angela did not hear from them but had a voicemail that came at 5pm. When she called the next day she only contacted nurses who asked her to leave a message. She remembered the midwife had provided her number, so Angela called that number. To her surprise the midwife answered. The midwife found the results. Angela's numbers were going down, indicating lowering levels of pregnancy hormone in her blood. At this point Angela was still clinging to the hope that the pregnancy would be fine. The next time Angela went in she saw the midwife who asked her how she felt about her situation and told Angela it was ok to cry. Angela cried. Although she had been told there was no reason to keep her second ultrasound appointment, Angela decided to. Angela knew that having another ultrasound made no sense, but she decided she wanted the ultrasound anyway. She was hoping the results would be positive. No one told her to go. She went for herself.

After a week of tests and appointments, Angela learned that loss was inevitable. She followed the advice her midwife gave and attempted to wait out the miscarriage

naturally at home. A few days passed and she went in to see her OB who encouraged Angela to have a D&C. Trusting this doctor as she had trusted the midwife's advice, she determined to have the D&C since the natural way had not yet worked.

When Angela went into the hospital for the D&C, a male nurse prepping her for the procedure went out of his way to attempt to connect with her. "Oh I'm so sorry" and "this is such a sensitive topic," he said. Angela just wanted to have the procedure over with and was not interested in getting emotional with the nurse. She just wanted to focus on what she needed to do and would process the event later. Part of the male nurse's conversation with Angela included asking her questions she was not prepared for. He asked her what she wanted done with the products of conception. Did she want them to go to a funeral home or a communal burial site? Angela was completely unaware that a funeral was an option in this situation. Had she known to discuss this with her husband previously or had her husband been with her that day she may have opted for the funeral. She wanted to say yes, but because she did not know what the next step would be, she said no. She mentioned this conversation to her husband later, but they never really talked about the experience further.

Angela was upset. She did think recognizing or honoring the loss was a good idea, but was not prepared for the conversation regarding the potential for a funeral. She received a folder from her doctor that included information on grief and a business card for the early pregnancy loss coordinator. In that folder was a tiny- white square of material sewn together. On the back was an iron on with a note that offered the material for use to wrap up a baby for burial or to have as a keepsake to remember the loss. The keepsake meant a lot to Angela. Someone recognized her loss. She now had a physical item to remember her loss instead of just a memory.

Angela's husband was late picking her up that day. She told her husband she received a keepsake that was very special to her, but that she wanted to contact the organization and ask for a second piece to honor her loss because she lost two babies. She wanted to put the two pieces in a frame so that she could see them and remember.

She did not make that call. However a few days later, Angela did request a copy of the picture from her ultrasound to have something to remember her two children by.

Overall the news of her loss was intentionally kept quiet. Most people Angela told out of necessity: her boss and colleagues, and her mom who then shared the news with her brothers. Overall people were polite about the situation but brief. She had the impression that although people were into talking about what their living children did it was not usual for people to bring up stories of their children who died. She struggled between understanding that no one wanted to hear about her loss and wanting someone to acknowledge her loss when or if she wanted to talk.

She experienced difficulty discussing the issue with her husband who seemed unmoved by the loss. He did mention his difficulty connecting to the situation, and recognized the loss was significant to Angela due to her direct connection to the experience. Her husband focused on feeling lucky for what they had as a family. Angela really needed him to acknowledge that the family had lost something too. The lack of acknowledgement of loss made her feel like he thought the loss was a non-issue.

The place where Angela felt she could really let out all of her emotions regarding her loss was with her counselor who she already knew. Having someone listen to her and believe her provided a great release. Angela shares she was basically hysterically

questioning: “How am I ever not going to be like this again? ...How could this just go away? How could – how could you go on?” Her counselor did not try and make her feel better but offered that time would assist.

Angela was incredibly moved by a gesture from one friend she confided in. That friend left a card in her home mailbox. She wrote that she cared about Angela. There was a little penguin all by itself with a message to the effect of “I’m here to listen if you need to talk. I’m so sorry you’re going through this.” The card and message meant so much to Angela that she saved the card in the folder with the ultrasound picture and the small keepsake made of material.

Angela shares that she did not realize all of the risks that could occur in pregnancy due to her prior successful pregnancies. She is very appreciative of her health and the health of her three living children. However, their family is missing two pieces. Most see her as a mother of three, but she is a mother of five. No one else acknowledges the two babies. She is a secret mother to the twin babies she lost.

She mentions her sadness in the fact that her husband does not participate in or understand the loss in the same way she does. She and her husband do not talk about the experience. In hindsight, Angela wishes her husband had been with her the day of the D&C. She thinks his presence may have made the loss more real to him. Although she values and enjoys her relationship with her husband, she feels an unresolved piece exists. Angela holds a strong wish that her husband would acknowledge the losses and be a secret father with her. She would not be alone then. The secret would be shared.

Survivor

Kim: just fewer than 2 years ago

Kim's two early pregnancy losses occurred in between her 1st and 4th successful pregnancies.

Kim was always excited to be mom, which contributed to her excitement regarding pregnancy. She came from a family of eight kids and wanted eight of her own. A pediatric nurse by trade, she loved being around kids.

After their first baby, a honeymoon surprise, she and her husband held off trying to get pregnant for a few years. That first pregnancy was not so fun. Kim had a clotting disorder that increased pregnancy loss risk, so she took Lovenox while pregnant. The situation was rough, a lot more stressful than she originally anticipated. A completely different experience than the portrayals of beautiful, happy, women with beautiful baby bumps she saw in commercials and movies.

She and her husband tried to get pregnant again during a very stressful time of her life. Seven months later she was pregnant. She went in for an appointment and ultrasound showed the gestational sac. She was five weeks pregnant.

Loss #1 – 6 weeks

The day Kim arrived in San Francisco for a professional conference she started having cramps and a little bit of spotting. 'Oh this isn't good,' she thought. Then thought, 'spotting can be normal. It's okay.' The next day full-fledged bleeding began. 'Oh crap there's no way this is gonna survive.' She called her doctor, told her what was occurring, and then asked, "Is there anything that I can do?" The doctor responded, "No, it sounds like you're probably having a miscarriage. So take care of yourself and as soon as you get back come in and see me and we'll check it out." In a hotel room by herself, on the phone with her doctor, that was difficult to hear. For the next couple of days at the conference she knew what was happening but had nobody there. Her husband was not there and Kim could not go to the doctor. Alone, with no one to talk to, she dealt with her loss internally. Every night when back at the hotel she called her husband and cried.

When Kim came back home she saw her doctor right away. The encounter was anti-climatic. She was given a pregnancy test, which came back negative. The doctor told Kim she definitely had a loss, asked her if she was okay, and provided her time to grieve. Kim appreciated her doctor's acknowledgment and amazing support. The doctor told Kim she could wait to get pregnant or try again. "Talk to your husband and see what you guys want to do. But you have the green light if you want to try again. But if it's too hard emotionally... a lot of women need some time before that." Kim was thankful her loss was not brushed off with a let's move on to the next one kind of attitude. Kim felt comforted knowing her doctor understood. She provided Kim a space to be upset while listening to Kim.

That was it, however. Everything on her body was fine. Done. Over. Because the loss was early, Kim did not tell many people. She was very religious and knew that miscarriages happen. She thought, 'It wasn't meant to be, something must have been wrong with that baby or not the right time in our life that, that baby was not supposed to be here so it's no big deal. We'll try again.' She spoke with her husband and he inquired, "Well, should we keep trying?" She responded, "Yeah, we really want another kid." Six weeks later Kim was pregnant again.

Loss #2 – 8 weeks: Ectopic Pregnancy

Kim was attending a conference for work that was near her mom's home, so she went up the weekend prior for a visit. Her mom was going to watch her son while Kim attended the conference. Sunday afternoon Kim did not feel good. Her stomach was really upset, she felt really tired and gross. She told her mom "I need to take a nap." When she lied down she started getting really bad abdominal pain. She started self-diagnosing and thought her pain started out similar to appendicitis. She felt like her appendix had ruptured. In the middle of nowhere, nowhere near her doctor, she really did not want to go to the emergency room but knew something was not right. For an hour she laid there hoping the pain would go away. In denial that the pain could be anything related to the pregnancy, she thought, 'maybe I ate something bad?' Feeling worse she called the doctor and spoke with some random on-call OB nurse. Kim explained she was about 8 weeks pregnant and that her symptoms began at noon. "I'm not having any spotting or bleeding. I just have really bad abdominal pain." The nurse responded, "Well if you want to go into the doctor you could go into the ER, but if you feel like you could wait 'til tomorrow you could wait and go to see the doctor tomorrow." Kim was surprised by that advice because she was pregnant, had recently miscarried, and now had abdominal pain. Kim expected the nurse to tell her to go to the ER. That is what Kim would have recommended. Kim said, "Okay well I'll try and wait a little bit longer." She lied down for 30 minutes and the pain just kept getting worse. Kim got up and told her mom, "Mom, I think you need to take me to the emergency room. Something is not right." Something was really wrong.

Kim went to the little ER in central Minnesota, which she was not thrilled about. She preferred big medical institutions and feared little rural places. The ER took forever to figure out what was wrong. The hospital's healthcare providers were all on call. First, the ultrasound technician took an hour and a half to arrive. Then the radiologist was called in to read the scans. After the scans were read they called in the OB. Kim describes this as the longest period of time she ever waited. Overall, Kim felt the healthcare providers were pleasant and nice, but her main concern was the time taken for diagnosis to occur. What would have taken 10 minutes at Mayo Clinic to diagnose and have her in the operating room took seven hours. Kim was thankful her mother was with her during this time, but mentioned she did not have her husband or anyone else around.

While tests were run, Kim's brain shifted from denial that her pain was anything pregnancy related to realizing she was probably experiencing an ectopic pregnancy. Around a quarter to midnight, the doctor came in, and told Kim it was a ruptured ectopic pregnancy. Kim knew that meant the baby could not be saved or was already gone. The doctor was nice, but due to the emergency situation she did not counsel or comfort Kim. "We're gonna have to operate right away." Kim asked, "Like NOW right away or can I go back to Minneapolis?" The doctor replied, "no we need to do this now." Kim appreciated that the ER doctor's focus was saving her body from bleeding to death but would have liked a little more empathy or emotional support. To have a life-saving surgery in the middle of nowhere, at a hospital where she did not trust or know anyone made the situation very scary. Not knowing if the rupture occurred before she arrived at the ER, or if she ruptured while she was at the ER due to the five hours between her arrival and the scan being taken added to her concern.

Kim had so many emotions she did not know what to think or how to feel. She was very numb. There was no time to grieve or talk about anything. Terrified, she told her mom “I do not want to have the surgery here. I just, I do not.” Her mom replied, “Well you know you need to have it.” The doctor showed Kim the scan of all the internal bleeding, which explained to Kim why her whole abdominal cavity felt like ascites. The swollen feeling in her stomach was all blood from the rupture, so much blood that no organs were visible. Blood everywhere. Kim’s mom held her hand and cried with her. Kim was thankful she came to the ER instead of trying to sleep off the pain. She might not have woken up.

Laparoscopic surgery occurred around midnight. Incisions were made on her lower sides and in her bellybutton to take out Kim’s right fallopian tube. Kim lost a part of her body when she lost her baby. The ectopic pregnancy took part of her womanhood, adding another layer to her experience.

Kim felt comforted by her OB at her follow up appointment. Her OB sat down next to her, put her hand on Kim, showing care and concern. Although only a 15- minute appointment, those actions paired with asking open-ended questions like “tell me how you're feeling” instead of “are you doing okay?” helped Kim open up and talk. Having her second pregnancy loss occur so quickly and traumatically was difficult. Providing Kim the opportunity to talk and cry was really helpful.

People were somewhat aware of Kim’s second loss. She posted that she was having surgery on Facebook, “Please say some prayers. I’m about to have emergency surgery.” Many did not know she was pregnant or trying, but all responded with support. Although also helpful, those who knew of the loss focused conversations on how Kim was recovering from the surgery, not how she was recovering from the pregnancy loss. Kim’s father offered advice in response to hearing of the loss. “Oh you gotta slow down. You gotta take care of yourself.” Kim broke down upon hearing this and thought perhaps what happened may have been something she did, even though she did not drink or smoke, and did eat healthfully and exercise. No one, not a friend, family member, or her husband asked about the emotional healing that she needed. She wished someone had acknowledged the loss of a second baby.

Kim loves her number one job, being a mom. She always knew children were amazing blessings and miracles. Her pregnancy losses made her see even more how much of a gift a healthy, beautiful child really is. She believes everything happens for a reason. A missed opportunity always leads to a different path. She does not mean to dismiss the losses she had. Yet, believing the soul of a baby is there from the beginning, had she had one of those other babies, she would not have her infant son. She is so thankful that she and her husband kept trying. She could not imagine life without him. He is a beautiful gift from God. She holds her boys tighter every night, knowing that she is very fortunate and blessed that they exist and are healthy. Motherhood is an honor, a privilege, a joy, the most special thing in the entire world, and the toughest and the most rewarding job at the same time.

She remembers and will never forget her losses, but the memory is less traumatic. Time heals. Kim recognizes having a successful pregnancy after her two losses influences how she feels. Had she had another pregnancy loss, tried and was unable to get pregnant, or was no longer trying, her perspective today would be much sadder and filled

with more grief. Kim feels like a survivor. She can still have a baby after having half of her reproductive parts removed. She can still have children. The family will be okay.

Handle with Kid Gloves: Time Heals...it Doesn't Erase

Jenny: 5 years ago

Jenny lost her first pregnancy and went on to successfully give birth to two living children.

Jenny never experienced a time in her life where she questioned ever becoming or wanting to become a mother. Becoming a mother was part of her life plan. Her good upbringing provided her a positive view of motherhood, as did witnessing her brother's birth. Her mother gave birth to a 13- pound butterball turkey at home, which made her think, if my mom can do it, I can. She looked forward to sharing the motherhood experience with someone when ready. However, she always knew that getting pregnant would be difficult. Jenny had health issues that might require special preparation to assist with getting pregnant. She had irregular menstrual cycles growing up and knew she never was normal in that department. She went on birth control pills in college to regulate her cycles.

She and her husband decided that the first year after marriage she would go off birth control and focus on figuring out what was going on with her body prior to attempting to get pregnant. Never diagnosed as infertile, she considered herself proactive, describing her path to pregnancy as very clinical, very medical in nature. That first year was dedicated to getting to know her body, learning every single thing she could, to be armed with all the information when ready to try. For her, pregnancy never fit the fairytale idea of let's just try to have a baby. She was not ovulating, or if she was it was later or irregular. Sometimes she went three months without a period. A workup detected a slight issue of polycystic ovary syndrome (PCOS), which made her a little insulin resistant. Her OB put her on Metformin, a drug for diabetics, that balances out hormone levels and bring cycles back to normal. Jenny recorded her basal body temperature for months and saw that this medication was working. She was ovulating regularly.

After their first anniversary, she and her husband decided to try and get pregnant. Three months later they were 3 ½ weeks pregnant. She was in shock. She felt like she hit the lottery. After months of reading books, seeking information both online and with doctors, she was pregnant. She felt like a Mom instantly. With motherhood came empowerment and a strong sense of being protective.

Early Pregnancy Loss Experience – 6 ½ Weeks

Jenny started bleeding at around 4 ½ weeks pregnant. She was on hormone suppositories for about a week and then a week later had a massive bleed. She thought for sure she was losing the pregnancy. Her mom and her husband went and bought her favorite foods for comfort, her favorite ice cream and favorite dinner. When she called the doctor's office they said, "It's the weekend. Just put your feet up. Let's see what happens." So Jenny, her mom and her husband all sat on the couch. Jenny describes the experience as being very traumatic at the time.

Jenny went in for an ultrasound when she was 5 ½ weeks. That was her first time she and her husband met the doctor. She described the overall feeling of the people at the practice as very clinical and not comforting. The doctor mentioned that the chances of seeing a heartbeat prior to 6 weeks were very low. The trans-vaginal ultrasound showed a flicker. They saw a heartbeat!

A week later she and her husband went in for another ultrasound cautiously hoping to see the flicker going even faster. The embryo was still there, but no heartbeat. The doctor turned the lights back on after the ultrasound and saw Jenny lying there with tears streaming down the side of her face. The doctor's response was one of surprise "oh you're crying." Jenny was sad and could not believe the doctor would be surprised. They all had seen the flicker the week prior. The doctor's response made Jenny feel the doctor thought her loss was trivial. Jenny immediately felt anger toward her doctor.

Jenny was provided options to assist with the loss. One option would force a natural miscarriage, or she could wait it out to see if her body would expel the miscarriage naturally. She chose to attempt to wait it out naturally wanting to see what would happen prior to the use of any interventions. Nothing happened. Then she was offered the option of a D&C, which she opted for because she wanted the situation to be over. She had an ultrasound a couple days prior to the D&C to confirm the pregnancy was non-viable, and another ultrasound at the hospital just before her scheduled D&C. Preparation for the D&C that day included going to her OB two hours before surgery and having what looked like a giant matchstick shoved into her cervix. She understood that the device would start what was needed for the D&C: ripening the cervix to be able to get in and sweep the uterus. She and her husband walked across the hospital and waited for her scheduled surgery. The stick didn't hurt, but felt like a tampon that was kind of falling out.

Jenny's healthcare providers at the hospital were helpful and treated her with kid gloves. They knew what she was at the hospital for and understood that early pregnancy loss was a sensitive issue whereas her doctor's office clearly did not. The ultrasound technician Jenny saw prior to the D&C was very nice. She kindly said, "I think you know what we were expecting to see." Jenny agreed, "yeah." The anesthesiologist and the pre-op nurse did not say anything specifically about the pregnancy, but handled her in an extra sensitive way too, being careful with her and her feelings during the emotional time. The healthcare providers did not have to say anything. Jenny did not have to say anything. She just felt very cared for, handled gently, and calmed by them.

Jenny shares that her recovery was fine. However she felt empty. Nobody that she had ever known had gone through this. If they had, early pregnancy loss was never spoken of. Aware that somewhere around 1 in 4 pregnancies ended in miscarriage, she had not told many people she was pregnant because she did not want to have to un-tell people. She knew friends of hers screamed it from the moment they get the positive test because they preferred to have support around them if a loss should occur, but that was not Jenny's preference. Jenny felt truly alone.

Jenny turned to online message boards for information, support, and comfort prior to, during, and after her early pregnancy loss. She found the pregnancy loss message boards very helpful and appreciated the communication of strangers going through the same things at the same time. She used the boards to inform some of her medical choices about her early pregnancy loss situation. For example, she had read about how women experienced painful cramping when they chose the medicine that would assist with a natural miscarriage, so did not choose that route when that was provided as one of her options. She liked the anonymity of hiding behind her computer screen. She lurked more than chatting or posting and felt like she had a little home there. She adds that at that point, she did not have any kids to distract her.

The strangers on the pregnancy loss message board were her top source of comfort immediately following the loss. In that online space she did not feel alone. At home she felt alone. Being virtually with other females who were going through the exact same thing at the exact same time brought comfort. Jenny appreciated the real-time experience of the online community and appreciated that she did not have to be face to face with anyone. The online community brought comfort by letting her know she wasn't the only one. Even though she knew in her mind that she was not the only one, the experience makes a person feel as if they are the only one. She found the link to the pregnancy loss group in the margins of an online pregnancy community she was previously a part of. Jenny explains the pregnancy loss group as the club no one wants to be a member of. When she saw it in the margins she never wanted to go over there but when she did, due to her situation, that board was such a welcoming place to just be. Members of that group knew what to say and what not to say. In addition to visiting pregnancy loss board, she mentioned she taunted herself by going to the success after loss board, stating that that board provided her a glimmer of hope.

Jenny really felt she would never have a child and apologized profusely to her husband. She felt like she let him down. One side of her brain understood rationally that she did nothing wrong, while the other side of her brain told her she let her husband down. He was never going to be a father and she was sorry that her body would not let her have a baby. In response, her husband was very supportive. After all the work she put into getting pregnant before even trying, he learned not to make false promises. He knew not to tell her that “everything would be fine” or “we’ll get pregnant again” because those were triggers for her. He was really good at letting Jenny talk when she wanted to without trying to solve any problems. He became good at just listening and not solving. If he did say something that made Jenny angry, he retreated and eventually attempted to make it better by apologizing. Jenny’s husband told her he’d be happy if it were just the two of them forever, which comforted her. She felt like she had let him down the most. His reassurance that no matter what their future held their relationship would be okay helped, although she did not always believe that sentiment. Jenny says she was pretty unstable after the loss. Devastated. Her husband’s support made her feel validated. She would repeat herself over and over, saying the same thing over and over and he never made her feel like a nuisance. He never made her feel like she was annoying him by bringing up the same topic 48 times. He also gave her space when she needed. He did not question her. He did not pass the loss off as something that just happens and can happen to everyone. Her husband never made Jenny feel like what happened wasn’t a big deal. In his quiet, gentle way he validated Jenny’s feelings.

Jenny says her miscarriage really tainted her view of pregnancy, stripping her of the naivety and innocence she suspects a person not experiencing miscarriage would possess. She loved being pregnant, and would be pregnant for the rest of her life, except the anxiety experienced during subsequent pregnancies ate her alive. She mentions that due to this, they will probably not attempt to have more children. She would not want to put her husband through her being pregnant again and having to take care of their two children while also taking care of her.

The early pregnancy loss makes her even more grateful for the two little turkeys she and her husband have. She does not take them for granted. Time heals...it doesn't erase.

Acknowledgement and Healing: Circumventing Disenfranchisement

Kiersten: 8 years ago

Kiersten lost her first pregnancy and went on to successfully give birth to two living children.

Kiersten admits not really knowing what to expect regarding motherhood. She wanted to be a mother, and wanted to have kids. However, she never saw herself as a stay at home Mom. She had not really thought about what it would be like to be pregnant beyond the usual stereotypical occurrences; throwing up, and getting so big she could not see her feet.

She and her husband had been trying to get pregnant for a little longer than two years. She thought she might be pregnant so took a test, but it was negative.

Early Pregnancy Loss Experience –8 weeks: Ectopic Pregnancy

While in a city away from home Kiersten had shooting pains and bleeding that brought her to the ER. At first she thought she was starting her period. However, at the hospital a pregnancy test confirmed she was pregnant. A part of Kiersen was completely overjoyed. Anything she could do to protect the baby and better herself, she was going to do. She was happy and hopeful but also in a lot of pain. She admits being slightly in denial because something was inevitably not going well. Her level of pain combined with bleeding made nothing right about the situation and she felt panicked. Yet, a small piece of her held on to hope that the pregnancy would be viable.

Hormone levels in her blood indicated she was around 5 weeks pregnant, but the doctors could not find anything on the ultrasound. She was told seeing nothing indicated a threatened miscarriage and a possible ectopic pregnancy. She did not know what ectopic pregnancy was. Although she had a sense of what a miscarriage was, she did not really understand what threatened meant. When the ER doctor spoke to her he made it seem like ectopic pregnancies were due to a history of multiple abortions and/or an STD. He seemed judgmental. Kiersten took from his questioning that he thought there might have been something she had done to cause the situation she was in. He also left her in the ultrasound area and forgot to come back to release her. The experience was incredibly unpleasant. Everything about the setting was cold and nasty.

Upon returning home, she went to her doctor. Kiersten describes her doctor as very matter of fact and lacking compassion. The doctor focused on figuring out what was happening and how to avoid losing Kiersten's fallopian tube if this was an ectopic pregnancy. Over the next three weeks Kiersten had many blood draws and trans-vaginal ultrasounds. Her hormone levels fluctuated, up, then down, then up again. Kiersten spent that time trying to understand what was happening. She did not know anyone who had been through this type of experience. She was unaware of how severe an ectopic pregnancy could be. One day she experienced more pain and bleeding and her hormone levels dropped. At this point the healthcare became less about monitoring. The doctor hauled out a textbook and explained what was occurring. They thought she was 8 weeks pregnant, but could find nothing on the trans-vaginal ultrasound except for bleeding. They had no idea where the baby was. Kiersten felt pregnant, and was shocked doctors could not see the baby. Her doctor knew she did not want surgery, so suggested Methotrexate, but did not explain the drug in detail. The doctor ended the conversation

with, “My nurse will take you to oncology now.” Kiersten did not know what oncology was.

In shock, Kiersten did not say anything until arriving at oncology. She was stunned and frustrated that she did not have time to ask her doctor questions. The oncology nurse explained to her what Methotrexate would do. The nurse asked, “Did anyone explain anything to you?” and Kiersten said, “No.” The nurse questioned, “Do you even know what Methotrexate is, what it...” Kiersten interrupted, “I know nothing.” Kiersten recalls the nurse explaining how Methotrexate is used with tumors and with growths, what the injection would feel like, her restrictions, and how she would feel. Previously Kiersten never knew Methotrexate was something associated with cancer. The nurse described Methotrexate saying, “Basically what it does is it kills any living cell.” Hearing this made Kiersten concerned about the decision. She thought, ‘What if there was a slim chance for her pregnancy?’ The nurse offered a lot of sympathy, told Kiersten she was sorry, and hugged her. Kiersten’s husband was with her and did ask the oncology nurse some questions, but Kiersten’s mind was stuck on “this kills every living cell.” She kept wondering if she was making the right decision. She felt like she was essentially going in and killing the baby. She knew she had to do what was in the best interest of her health. Emotionally exhausted and scared Kiersten felt Methotrexate was the conservative route and went with that option versus surgery. She felt very guilty. She thought maybe there was something with her health, or something she did to cause the situation. She equally felt guilty that there was nothing she could do to stop what was happening. Kiersten recalls the nurses in the oncology area as the kindest to her throughout the entire experience. They had the most empathy and answered most of Kiersten’s questions.

After receiving the Methotrexate Kiersten continued to go for blood draws at the gynecologist’s office twice a week until her hormone levels reached zero, which took three weeks. Although Kiersten’s husband went with her every time she had an ultrasound appointment and when she went to oncology for Methotrexate injections, she was queasy about having blood taken so requested he not join her for blood draws. If she was not at home or work, she was at the gynecologist. She saw the same nice phlebotomist nearly every time. Kiersten consistently described her OB as very by the book, very official: a brilliant woman with very poor communication skills. Interactions were very clinical. The OB and her support staff never provided any sympathy or support. No one ever asked about the need for a follow up. No one ever spoke to the emotion side. No one spoke to the grief. No one spoke to the support. No one ever offered any assistance in that way.

While her loss experience was occurring, Kiersten expressed feeling like many members of her family dismissed her, which resulted in feelings of pure rage. Kiersten’s mother had experienced her own loss 30 years prior, but tended not to relate to Kiersten’s pain. Her mom was not insensitive, but seemed to have the view of “you go through it and you get through it.” Kiersten came to resent her husband’s family. Although she understood that they did not know what to do, she was infuriated by her in-laws’ attempts to be helpful and supportive. Her in-laws said things like, “everything happens for a reason” and “God has plans for you.” Kiersten explained that to tell someone who is losing a child that it is part of life or a plan is not helpful. Her response was short and blunt. “Um, you know, I’m pretty sure that God wouldn’t want my baby to be dead.”

While offline support was often lacking, Kiersten spoke of supportive experiences in an online community. Kiersten previously belonged to an online community whose members were trying to get pregnant. Ironically around the time of her loss, that same group formed a community around pregnancy loss. After her initial ER experience, and during those three weeks of blood work to determine what was occurring, she turned to this new online community. Although she did not know the people involved in the pregnancy loss discussion board, she thought she might be able to connect to similar people. Bound together by similar experiences Kiersten found it a helpful source for the emotional support she needed and a rich source of information. She mentions getting insider information from members of that forum regarding all types of things she did not know much about. She would talk to them in addition to talking to her doctor. Kiersten found it more helpful to talk to people going through the same thing than to just learn from her doctor, who literally pulled out a textbook to explain things. She found more clarification when she met up with people and talked to them online. Online members shared experiencing similar unpleasant encounters as she had experienced which offered some comfort during a time when it was hard to be comforted. No one in the community made what Kiersten called the stereotypical remarks: “God has a plan” and “well at least you know you can get pregnant.” She never had anyone in the online community say those types of things. Mostly people would listen, share their experiences, ask questions, or say simple things like “hugs.” The online pregnancy loss group was a very nice community, a place where she could go for a little bit of reassurance.

Kiersten expresses that pregnancy is scary; something she never wants to do again, and still makes her nervous. However, she is proud that her body overcame and was able to bring forth children. She appreciates what a body can do to sustain life. When she picks her girls up from school, she sees the children that are one year older and thinks, “WOW...that’s where my first child would be.” Although eight years ago this would have made her cry, she does not break down and cry now. Yet, she is still affected by her early pregnancy loss. She has never stopped thinking about it. The ectopic pregnancy does not leave her mind. Kiersten is always aware. Together with her husband she quietly acknowledges and remembers the ectopic loss. Each year they decorate their Christmas tree with ornaments for each of their children. A third ornament bears the name they would have named the baby. She also has a figurine given to her from her mother that stays out in their home. She and her husband do not discuss the loss in depth, but have these little reminders always present. Acknowledging the loss does not make it go away, but helps her heal, which to her is better than sweeping it under the rug. Kiersten says she was never upset with her marriage. Everything had to come together in kind of a certain type of acknowledgement for her. The fact that the acknowledgement was there, so the memory stays was important to her. Kiersten explains that she is spiritual enough to believe that when she dies she and her baby will be reunited.

Kiersten considers her view of motherhood different and complicated. Motherhood is not limited to those with the ability to biologically have children. She strongly protected her pregnancies, but previously strongly protected her dogs, which she also considered her babies. She protected and mentored her past students. Motherhood is instinctual and ever changing. Motherhood is teaching. Teaching empathy, gratitude, difficulty, and mistakes. Motherhood is about finding ways to bring out those lessons.

Motherhood is about a level of sacrifice, she had not previously considered. Nor had she thought she would be willing to make in this life. Motherhood is a great love.

Releasing Self from Blame: The Scarlet Letter of Early Pregnancy Loss

Keya: 13 years ago

Keya had two pregnancies that ended in loss. Both losses occurred during her first marriage. She thinks the losses and issues surrounding the losses may have been too much for her ex-husband to handle, but notes that he had already been mentally removed from the relationship. Her first son's adoption process began prior to the marriage ending. Keya chose to continue the adoption solo.

Keya was one who believed in the big princess story and per her grandmother's guidance waited until marriage to have sex. Keya could not wait to be a mother. She was excited to have the opportunity to do the opposite of what her own mother had done. Keya felt she learned from her negative experience what to do and say for her own children to ensure that they would be in better shape than she was at a young age. At 19 Keya was diagnosed with endometriosis, had a successful surgery, and everything was fine. She married at 28 and became pregnant within the first year of marriage.

Loss #1 – 6 to 7 weeks

Prior to her appointment with her doctor, Keya got her period. When she called the doctor's office instead of asking her to come as she expected, they told her they would cancel her appointment. She had expected to hear that she should come in to get some type of treatment. She was unaware that getting her period while pregnant meant she miscarried. She was told to watch out for excessive bleeding and provided other medical information. When she hung up the phone she realized she had miscarried. No specific language was stated to her that she no longer was carrying a baby. To be certain she understood what occurred she looked up information on the Internet. When she discovered that indeed she had miscarried she did not tell anyone due to feeling like she was at fault for the loss. She was embarrassed. Keya went in for an appointment with her doctor. He administered a pregnancy test and that came back positive. Her doctor explained that the positive result was just "some hormones in the urine" and indeed "she evacuated the pregnancy." She found that language to be rather cold for someone experiencing a loss.

At the time she did not feel really sad but did think about how happy her husband would have been about a baby. She had waited to tell him about the pregnancy until she confirmed it with a doctor. When she told her husband the negative news, he told her he thought something might be wrong with her body. He was not supportive of her regarding the loss. At that point she became aware that he had learned from his family that a baby was not a baby until it was born due to his mother experiencing some pregnancy losses.

Thinking that she was to blame for the loss of the pregnancy, she spent the next year attempting to get pregnant again. She researched all the things she could do to be healthier and spoke with her doctor about any questions she had when she went for a regular physical exam. She felt like all the workers at the doctor's small office knew that she was the one who lost a baby.

Loss #2 – 10 weeks

Keya was unaware she was pregnant. She began experiencing severe pains in her stomach and pelvic area at night. Earlier that day she broke up a fight between two boys

on the bus ride home from a school outing. Her husband was not home so she went to the emergency room (ER) alone. A very nice doctor gently confirmed that she had been 10 weeks pregnant, which at first excited her to know, but then he mentioned the excessive bleeding she experienced prior to coming to the ER was the loss of the baby and that he was sorry. Not again, she thought. The caring doctor asked Keya if she had any other family to stay with since her husband was out of town. Keya's good experience with the ER doctor helped her understand that the loss was not her fault. She no longer needed to feel like there was something wrong with her.

When Keya's husband returned, he again questioned what was going on with her body and mentioned perhaps the endometriosis was back. Or thought perhaps she should not be trying too hard with the urban kids.

At the time of loss when Keya shared what happened people would tell her "I'm sorry to hear that," but she got the impression that early pregnancy loss was no big deal. Keya admits that perhaps people just did not know what to say. She mentions however, that there is a point with loss when the person wants to talk about the loss but no one else does.

Keya explains her experience of early pregnancy loss as a Scarlet letter. Although not talked about openly, she experienced her situation as if everyone knew. She felt everyone knew she had miscarriages, everyone knew there was something wrong with her body, everyone knew Keya and Jamal were trying to have kids and were unsuccessful and everyone knew her first son was adopted. Shortly after her losses Keya and Jamal learned that the issues they were experiencing could be caused by an issue he had. He wanted that to remain a secret and Keya honored his wishes. Keya carried that mark as the object of blame and felt his aunts, mother, and extended family members talking about her behind her back at family gatherings. "That's the first assumption. 'Something's wrong with her body' ... 'She lost the baby.' She lost. She lost."

Keya found refuge in a counselor she sought to help her with her situation. She was provided many helpful tools to assist with coping through that counselor. However Keya explains that her own personal belief and understanding that she did not do anything wrong was what truly helped. The losses were not her fault. Letting herself off the hook, and realizing that she did not do anything wrong helped her. Keya told herself "it's your body, it's not you. You didn't do anything wrong. Some bodies hold babies. Some bodies don't. Your body is not holding a baby." She realized that this reality did not determine her value. Nor did it determine what she had to offer children or the world.

Today Keya is the mother of eight children. With her second marriage ten years ago came the blending of two families adding her husband's three girls. Additional children in the community were taken in to their home as needed on a regular basis, three of which became permanent members of the family. After attempts at getting pregnant in her second marriage failed, she and her husband adopted a son.

Only recently has Keya started to open up about her past loss experiences. Her close friends were shocked to learn that none of her children are biologically related to her. She mentions that talking about her losses, even when the purpose may be for comforting another woman, still bothers her. However, Keya is thankful for her journey

and so happy for the close –knit family she and her husband have created. Her house is full. It doesn't matter how they came.

Anchoring Emotion: Talking Helps

Shannon: 17 years ago

Shannon was pregnant three times. She experienced her pregnancy loss prior to her two successful pregnancies. All of the pregnancies occurred within her first marriage. Shannon notes the divorce was not directly impacted by the loss, but due to other issues.

Prior to meeting Joel, Shannon wanted to be a mother so badly that she had a pact with a male friend. If she were still single at 30 he would donate sperm so she could be a mom. Shannon was influenced by a strong line of women in her family who not only held strength through early losses of spouses, but who held good health living well into their late 90's. She was raised to have a strong opinion, and was told she could do anything, regardless if it was attributed to being something men did or women did.

She went on to law school right after college and then got married. When she and Joel chose to start a family, she did not have any trouble getting pregnant at age 27. She did not keep news of the pregnancy from anyone. As a high level executive close to the people she worked with, she chose to explain her morning sickness instead of trying to hide the pregnancy.

Early Pregnancy Loss Experience – 13 weeks

Upon arrival at the hospital ER, Shannon was taken to the Women's Center and then to ultrasound. She explained that the lack of communication from the ultrasound technician led her to believe the worst, resulting in tears. Once back in her ER room, it felt like quite some time had passed prior to the female doctor coming in and telling her of the impending loss. She described her loss experience as being lost at sea. She felt the way the doctor handled the situation made her feel adrift. Like she was lost in a sea of medical crap. When her doctor called and the ER doctor handed her the phone, she suddenly felt anchored. Her doctor offered to come in if she needed him. He also thoroughly explained the dilation and curettage (D&E) procedure she would be having the next day and expressed his sincere apologies that she was going through a loss. Talking to her doctor, a man she trusted, provided a medical anchor during a time where everything felt off and unexpected. Although she knew the situation was not going to get better, talking to her doctor provided her a sense of grounding. She would survive the experience.

Shannon described the strange experience and environment at length, noting that although the healthcare providers were professional the entire experience felt sterile and was reinforced by the surroundings. Although she was in a Women's Center ER, the space was far from the beautiful birthing suite she became familiar with when she had her daughter Megan just over 12 months after experiencing her loss. The room she was in was very white and very cold. She asked for a blanket due to how cold the room was. Throughout her story Shannon found the room both figuratively and literally isolating and distant. Her mother and grandmother experienced great difficulty locating the room due to how far into the hospital the room was located. When they arrived the lack of additional chairs in the room made the space additionally uncomfortable. Her mother and grandmother had to stand. Shannon felt very little effort could have improved the room, making it comfortable. However, it was clear to Shannon that whoever designed the room did not have comfort in mind. She went on at length about what improvements could be made to the room to assist in making it more comfortable. She added that through her

own experience of giving birth to Megan at that same Women's Center in a birthing suite just over a year later, she was fully aware that rooms could be created that were comfortable and sterilized. The stark, dichotomous difference between the room where losses occurred and the room where births occurred provided Shannon with a sense of what the Woman's Center held important.

That evening, the night before her D&E, she consoled her husband who demonstrated great remorse. Shannon attributed Joel's intense grief reaction to still being upset over the loss of his grandmother who was more like a mother to him due to his Mom's medical condition. She mentions that this is not what one would expect if creating a movie about pregnancy loss, referring to the fact that focus was given to her consoling her husband rather than her husband consoling her. She did note that mainly her mother comforted her during the ER experience, which provided her a sense of security allowing her to realize she would be okay. Although the entire situation felt chaotic to her, having her mom present for her let her know that once again there was someone there if she needed grounding.

The next day, Shannon chose to be fully under anesthesia when provided options by the anesthesiologist. She explained to him that her choice was due to not wanting to be present to experience the loss. When the procedure was over the anesthesiologist told her husband that he had to wipe her tears during the entire D&E procedure. Shannon overheard this conversation as she was coming out of the anesthesia.

Immediately after her loss experience, Shannon felt surrounded by support. Her coworkers sent plants and flowers and were kind to her upon her return to work. Her family was also very loving and supportive. All but mother-in law, were great, but that was to be expected from her mother in law. She felt that the acknowledgment of her loss by those around her was huge because no one discounted the loss. She attributed the response of family, friends, and colleagues to assisting her with coping with the loss. She realized that had no one acknowledged her loss she would have felt alone in her grieving.

Shannon did mention, however, that there came a point where it seemed most people including her husband encouraged her to get over the loss and move on. Three months after the loss while attempting to get pregnant again, she felt upset no one seemed to remember the loss occurred, or want to talk about it, not even her own husband. The exception that stood out was an Aunt who sent her a pin and a note that said, "I remember." She also noted that her mother was there for her throughout, but there was something special about her Aunt remembering.

Within the last year Shannon's oldest daughter Megan was killed in an accident. She misses both her daughter that she knew for 14 plus years and her lost pregnancy that she was excited about for 13 weeks, and adds how thankful she is for her daughter that is still with her. If she could have all three of her daughters together now she would. Shannon does not regret a single minute of the love that she gave and received from those children she lost. If she were offered the opportunity to erase the pain she feels but not reverse the losses, she would choose to keep the pain. The pain allows the fond memories of those girls and the love surrounding the experiences of each of the girls to remain present. Shannon reiterates the need for acknowledging early pregnancy loss, and includes the need for acknowledgment is similar with the loss of Megan. Pretending loss

did not happen is worse than acknowledging loss did occur. She adds that many people do not understand, it always hurts to talk about it, but it hurts more to not talk about it.

A Body's Betrayal: Guilt Lingers

Mary: 23 years ago

Mary was pregnant four times. She had two successful pregnancies while married to her first husband. Her loss occurred during her first pregnancy shared with her second husband. She had a successful pregnancy after that loss. Although Mary felt the loss put a strain on her relationship with her 2nd husband, she shared that her husband had other issues that ultimately ended their marriage.

From an early age Mary knew she wanted to be a mother. In her first marriage she and her husband chose to hold off from kids for a few years while they enjoyed life. But then they decided to have kids; Mary became concerned during the year it took to get pregnant because she was in her early 30s. They had two children without any trouble.

When attempting to get pregnant in her second marriage, she told her doctor of her intentions and he told her not to contact him or his office until she was four weeks late. During a visit to see her sister in Phoenix Mary discovered she was pregnant. Prior to driving home, she and her husband quarreled about how he mistreated her sister during the visit. Mary was very angry with her husband.

Early Pregnancy Loss Experience – 8 weeks

She started bleeding on the drive home from Phoenix. She remembered her doctor's words and realized that she was just one day less than four weeks late, so she really was unsure if she should contact her doctor. That night heavy bleeding occurred and she knew she had lost the baby. The next day she was exactly at four weeks but continued to question whether or not she should call her doctor, stating that she did not feel confident in calling his office. "Don't call until four weeks late." Her husband eventually convinced her to call the doctor and find out what was happening. Mary called on that 2nd day of bleeding.

Mary described the communication with all members at her doctor's office as business as usual and blasé. She went in to the office, they tested to see if she was pregnant, and told her that they would call her to let her confirm if she was still pregnant or had lost the baby. Two days later Mary received a call confirming she had been pregnant and lost the baby and was told to come in and get a RhoGAM shot. Her doctor did not get on the phone and say I'm sorry. Someone else coldly confirmed the information. During her appointment for the shot, Mary was told to wait a few months prior to attempting to get pregnant, to let her body heal. She explained the messages of "you'll get pregnant again" "don't worry about it" and "you already have your two children" made her feel that there was no concern for what had occurred or whether she would have another child. She was concerned about whether or not she would get pregnant again. Mary made a point to share that her statement of business as usual meant that she felt like once they knew that she was not pregnant, they were aware they were not going to make any money off of her. Compassion and empathy were lacking. She and her husband were shown no concern. No options for grief counseling were provided to her, even though she was noticeably depressed.

Mary did not call the office for two days because she kept thinking what she was experiencing may not really matter to them since she was only four weeks late. The communication of "don't call until you have already been four weeks late" combined with the business as usual treatment gave Mary the impression that early pregnancy loss

did not matter to that doctor. No explanation for her loss was provided beyond being told that, “this is something that can happen.”

At the time Mary felt both betrayed by her body and partially to blame for the miscarriage because of her fight with her husband. Another reason she did not contact the doctor at the time of bleeding was her guilt brought on by the fact that her 38- year old body that previously had two successful pregnancies was not allowing her 2nd husband to have a child of his own. She felt vulnerable, depressed and angry with herself. Mary was sad that her body had let her down. Mary explained that depression is anger turned inwards. She understood that her anger pointed at herself was due to her guilt regarding thoughts that she may have caused the miscarriage.

Mary was not a private person. She generally tended to surround herself with supportive people. Friends and family members that learned of her loss were supportive and provided positive feedback. No friend or family member was mean or snarky. At the time of miscarriage Mary’s husband was supportive and sweet reminding her of his love for her, not to worry, and that they would be able to have more children. He showed true concern and empathy for her at the time of the loss. Mary noted that although her second husband had awful qualities that eventually led to their divorce, his caring response was due to the fact that his mother had been a nurse. She also expressed the need for more empathy and compassion from the medical community and held concern that there should have been some sort of support available for her husband back then as well. He too was grieving over the loss of the baby.

Mary enjoyed being pregnant, liked being a mother and loved her kids even when she was a single mom. Mary states she loves being a mom. Mary notes that she has become pragmatic with age. She states that events happen that we do not know the reason. She’s become deeply religious in recent years and lives by the motto: it is what it is and what will be will be. She tries not to carry guilt regarding what happened.

What Was Lost? : Influence of Conceptualization

Ginny: Just under 38 years ago

Ginny was pregnant 5 times. Her two losses occurred between the births of her three living children.

Ginny always had the goal of being a mom. She dreamed of motherhood her whole life. Although she did graduate from college and for six years worked as a teacher, her focus was on becoming a mom. Once she had her first child she never went back to work. She and her husband experienced difficulty getting pregnant a 2nd time and tried artificial insemination, which did not work. Then Ginny described having a carbon dioxide test where carbon dioxide was shot up through her fallopian tubes, potentially clearing any blockages of the tubes and potentially contributing to her 2nd pregnancy. She, her husband, and all her friends were praying for a 2nd pregnancy. While working toward their 2nd pregnancy they considered adoption.

1st Loss – 18 to 20 weeks

She became pregnant and at just under 5 months, Ginny's first loss occurred. She felt a pressure at 2am and the need to use the bathroom. At that point the baby went into the toilet. Ginny noted that her pain was not physical when her son was born. The pain was emotional. Her husband collected the remains. Ginny, too distraught to look, said her husband thought the fetus was a boy. The doctor never did explain to Ginny what occurred. The baby's remains were never tested, and she never knew what happened to the remains. The entire experience lacked physical pain, but was filled with emotional pain.

Throughout the pregnancy and loss her experience with healthcare providers was pleasant, kind, and compassionate. However, she clearly remembered one unhelpful encounter with a nurse during her first loss. After going to the ER she was placed in a room and under a 24 -hour watch to ensure she did not experience life- threatening hemorrhaging. During that time, a nurse asked her why her eyes were so red. Ginny felt that was an uncaring and unnecessary question, adding that although the experience occurred just under 38 years ago, she could not forget what occurred. Both at the time of occurrence and the time of interview, Ginny was surprised that the nurse would not have understood her tears.

When Ginny returned home from the hospital, she was so distraught she could not go anywhere, not even to church. When she returned to church, around four weeks later, she found herself crying very hard during hymns. She left during the service and waited in the parking lot. In that church parking lot she met a woman who consoled her, was warm and compassionate, prayed with her, and shared her own pregnancy loss story with Ginny.

Throughout the time after loss, prayer with her pastor, friends and family assisted her through the grieving process, as well as the personal time she took to grieve. Ginny understood that first loss as a child that had a soul, and knew she would be reunited with him in Heaven. Seeing him in the future in Heaven and her strong faith in God's Providence assisted with accepting the loss. She found solace knowing that God knows what is best and that she will be reunited with her son in heaven some day.

2nd Loss – 5 to 6 weeks: Blighted Ovum

Ginny had two successful pregnancies following her first loss. However, in between the two, her second loss occurred at about 5-6 weeks pregnant. The loss passed into the toilet in her bathroom at her home. The doctor explained the loss as a blighted ovum. He told her losses due to a blighted ovum were quite common and added that the embryo never formed. The explanation led Ginny to internally question if what she lost had been a child. Although the second loss bothered her, she was not as devastated. She was not as affected by the blighted ovum as she was by her first early pregnancy loss.

Ginny expressed that she loved being pregnant, thoroughly enjoyed being a mom, and still does. She spoke of her relationship with her husband as being part of a team both then and now. She was thankful for the woman that had been there for her that day in the church parking lot who had shared her own loss. Ginny knew God sent that woman to her. To this day she and that woman continue to be friends. The two grew into family when her daughter married one of Ginny's sons.

Overarching Philosophy: God is in Control

Sherie: 40 years ago

Sherie was pregnant three times. Her loss occurred during her second pregnancy.

Sherie's heart's desire was to have a child after getting married. After watching her sister have babies over the years, Sherie felt pregnancy would be easy. From what her sister went through, Sherie thought the difficult part of pregnancy was juggling morning sickness while at work.

After three years of trying and not getting pregnant, Sherie and her husband went through testing. The tests showed that her husband had a low sperm count. Also Sherie had irregular periods that made knowing the right time to get pregnant difficult. She had two or three D&C surgeries to clean out her uterus and allow for a more normal menstrual cycle. To assist in attempts toward pregnancy she charted her temperature and recalled that trying to figure that all out was horrid. They were offered fertility drugs as an option but she and her husband felt doing that would be pushing God's hand. Believing that if He wanted them to have a child pregnancy would happen, they chose not to take fertility drugs and became pregnant within a month. Just within weeks of learning she was pregnant, Sherie's mother was diagnosed with cancer and given six months to live.

Early Pregnancy Loss Experience – 18 to 20 weeks

At her 20th week appointment, Sherie was told there was no heartbeat, she had lost her pregnancy and she needed to schedule a D&C. She described the communication as a little on the cold side. There was no "I'm so sorry" or a "this means that." Instead the doctor was just very matter -of -fact lacking any emotion or comfort in his delivery. Sherie mentions the difficulty learning this information without her husband or a friend being there with her. What occurred was unexpected. A few weeks prior she had some ankle swelling and light spotting, and had been told to take it easy by her doctor, but she was not expecting to hear what she heard at that appointment. All previous appointments had been fine. Encounters with healthcare providers also had been fine and mostly routine.

Sherie scheduled the D&C and her husband could not be there due to a new position he just started. He felt horrid that he could not be there for her. A dear friend dropped her off, went back to take care of Sherie's son and then picked her up from the surgery when it ended. When coming out of the dream state she was placed in for surgery, Sherie could not breathe and felt like she was dying. She was unsure if her reaction had anything to do with what was going on with her pregnancy. After the D&C Sherie asked the doctor if he could tell whether the fetus was a boy or a girl. He responded coldly, "It was just a bunch of tissue," and added that she "may not have even really been pregnant." That seemed odd to her after having several check ups that confirmed her pregnancy up to that point. However, she did not feel depressed or devastated and attributed that to her strong faith. Sherie was thankful she was not working at the time because she did not have to go to work and tell anyone about the miscarriage.

When Sherie returned home, her husband took good care of her when he came home from work. He made meals and took care of their son at night. This provided Sherie time to recover from the D&C. Her husband's loving acts made her feel very important to him. Sherie felt the early pregnancy loss experience drew her and her

husband closer. She was able to lean on him for support and was grateful for his tenderness. In addition he held strong faith and continued to draw Sherie back to her faith when she would have one of those moments.

At that same time Sherie was dealing with her Mom's cancer diagnosis and felt she could not get too upset over her early pregnancy loss. She understood that her life's plan was in God's hands. She placed her trust in God that if she were to have another child whether by adoption or pregnancy, that was up to Him. Sherie recognized that some Christians might still go into a deep depression over such a loss, but did not experience that herself. She was too busy taking care of her two-year-old son and visiting her mother. She felt that time spent wallowing in the early pregnancy loss or being upset with God would only take away precious time from the gift she had already been given, her first son. So instead she placed her trust in God.

Sherie and her husband were open people who shared sorrows or items of concern with others. They did not keep the loss from anyone. When they told the church group that they met with on a regular basis they received full support, comfort, and prayer. Beyond that group and close family they did not go out of the way to discuss the loss. Sherie knew that not wearing maternity clothes was an outward sign of the loss and that word of mouth would spread the news too. "She's not pregnant anymore."

Sherie's mother, father, sisters, and husband were the ones who provided comfort to her. They all subscribed to the same philosophy about life, God was in control. Messages of trusting in God, sorrow for her loss, and the love they held for her provided the empathy she felt had been lacking from the doctor. She noted that the empathy from family was much more important to her than getting it from her doctor. After all, the doctor was just a man that worked there.

Sherie loved being a mom and expressed her thankfulness for the way it all turned out in the end. After her loss, Sherie continued to be a mom through the adoption of a second son. Then eight years after giving birth to her first son, she became pregnant, which resulted in her third son. She does not take motherhood or pregnancy for granted and is so grateful that God gave her her three boys. Sherie's faith in God and Jesus Christ gives her peace and the ability to handle any difficulty that comes her way. She does not think of her early pregnancy loss that often. However, she does think that she really had been pregnant and she will see that little one in Heaven someday. She says she'll know for sure when she gets there.

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Education

- 2015 Ph.D. Communication
 University of Wisconsin – Milwaukee
 Health, Interpersonal, & Intercultural Communication
 Faculty Advisor: Mike Allen
 Committee Members: Nancy Burrell, Hayeon Song
 Patricia Stevens, RN, FAAN, and Sarah Morgan, RN
 Dissertation Title: *Understanding the Nature and Impact of Early
 Pregnancy Loss through Women's Stories*
- 2010 M.A. Communication
 University of Wisconsin – Milwaukee
 Health & Intercultural Communication
 Faculty Advisor: Renee Meyers
- 1995 B.A. Communication
 University of Wisconsin – Milwaukee

Professional History

- Spring 2015 *Adjunct Faculty*, Department of Communication Studies
 Chapman University, Orange, CA
- Spring 2015 *Part-time Lecturer*, Department of Communication Studies
 California State University - Long Beach, CA
- 2010-2014 *Teaching Assistant*, Communication Department,
 University of Wisconsin-Milwaukee, WI
- 2007-2010 *Academic Advisor*, School of Information Studies, University of
 Wisconsin- Milwaukee, WI
- 2004-2007 *Academic Advisor*, Division of Continuing Education,
 Adult Degree Program, Linfield College, Portland, OR
- 2004-2004 *Financial Aid Counselor*, Linfield College, McMinnville, OR
- 2002-2003 *Group and Charter Sales Representative*, Portland Spirit, Portland,
 OR
- 2001-2002 *International Educational Tour Consultant*, EF Educational
 Tours, Portland, OR

Publications

Hawkins, J. M. (In press). Thematic Analysis. In M. Allen (Sr. Ed.), *Encyclopedia of Communication Research Methods*. Thousand Oaks, CA: Sage.

Hawkins, J. M. (In press). Textual Analysis. In M. Allen (Sr. Ed.), *Encyclopedia of Communication Research Methods*. Thousand Oaks, CA: Sage.

Hawkins, J. M. (In press). Transcription Systems. In M. Allen (Sr. Ed.), *Encyclopedia of Communication Research Methods*. Thousand Oaks, CA: Sage.

Hawkins, J.M. (2015). Dying inside of me: Unexplained recurrent early pregnancy loss. In R. Silverman and J. Baglia (Eds.), *Communicating Pregnancy Loss: Narrative as a Method for Change* (pp. 211-224). In G.L. Kreps (Series Ed.) *Health Communication Series, Vol. 8*. New York, NY: Peter Lang.

Hawkins, J.M. (2015). Stunned: Ectopic pregnancy loss. *Health Communication*, 30, (4), 419-422. doi: 10.1080/10410236.2014.891454.

Allen, M., Bourhis, J., Burrell, N., Cole, A.W., Cramer, E., Dilbeck, K., England, N., **Hawkins, J.M.**, Maier, M., Mullane, R., Omachinski, K., Omori, K., DeCloedt Pincon, D., Victor, A., Willes, K.L., & Zmyslinski, A.N. (2013). Comparing communication doctoral programs, alumni, and faculty: The Use of Google Scholar. *Journal of the Association for Communication Administrators*, 32 (2), 55-68.

Teaching Activities

Department of Communication Studies, Chapman University

Spring 2015

Interpersonal Communication, Adjunct Faculty

Group Communication, Adjunct Faculty

Department of Communication Studies, California State University – Long Beach

Spring 2015

Intercultural Communication, Part-time Lecturer – Large Lecture

Department of Communication, University of Wisconsin – Milwaukee

Fall 2013, Winter Term 2014, & Spring 2014

Business and Professional Communication, TA- Stand Alone Instructor, Online

Fall 2012 – Spring 2013

Health Communication, TA- Stand Alone Instructor (Independently Designed)

Introduction to Interpersonal Communication, TA - Stand Alone Instructor

Fall 2011-Spring 2012

Introduction to Interpersonal Communication, TA - Discussion Instructor
Winter Term 2011

Public Speaking, TA - Discussion Instructor
Fall 2010 to Spring 2011, & Summer Term 2012

Public Speaking, TA - Stand Alone Instructor

The School of Information Studies, University of Wisconsin – Milwaukee

Summer Term 2009

- Study Abroad Assistant to South Korea and Japan.
- Guest Lecturer and Teacher for Korean students visiting the U.S.
 - *Ethnic Make Up of United States Citizens*
 - *Comparing and Contrasting Non-verbal Communication Between South Korea and the United States.*
- Facilitated English conversations in small groups and one-on-one

Publication In Review

Song, H., Omori, K., Kim, J., Tenzek, K., **Hawkins, J. M.**, Lin, W.Y., Kim, Y. -C., & Jung, J. -Y. (under review). Trusting social media as a source of health information: Comparison among U.S., Korea, and Hong Kong. *Journal of Medical Internet Research.*

Awards and Recognitions

Top Paper, Promotive versus preventive dietary practice and self-construal: Communicating healthful food choice. Health Communication Interest Group, Western Communication Association Convention, Reno, NV, 2013.

Top Student Paper, New directions for an old problem: Understanding the nature and impact of bullying through discourse analysis. Peace and Conflict Studies Division, National Communication Association Convention, Orlando, FL, 2012.

UWM Foundation Communication Graduate Student Research Award

To present research at the Organization for the Study of Communication, Language, and Gender (OSCLG) Conference in Houghton, MI, October 2013.

Graduate School Student Travel Awards

To present research at the NCA Convention in Chicago, IL, November 2014

To present research at the OSCLG Conference in San Francisco, CA, October 2014

To present research at the OSCLG Conference in Tacoma, WA, October 2012

To present research at the NCA Convention in Orlando, FL, November 2012

Recognition Award for service as the Liaison for the Bradley-Angle House (Domestic Violence Shelter) and the Portland Female Executives Business Organization, Portland, OR, 2004

Applied Research Projects/Collaborative Community Engagement

Winter Term and Spring Semester 2012

Participant Researcher - Wisconsin Center for Public Health Education and Training (WiCPHET) Joint Internship Experience through UW Madison's and UW Milwaukee's Schools of Public Health, Northeastern Wisconsin Area Health Education Center (NEWAHEC), and Manitowoc Wisconsin's Mental Health Task Force.

- Facilitated discussion regarding community mental health needs from a capacity building perspective
 - Facilitated collection of community information and creation of mental health resources database (Access Sub-Committee).
 - Trained the Education and Awareness Sub-Committee on health campaign messaging design

2009-2010

Practitioner Researcher (Invited)– Wisconsin Equity Transfer Study: A collaborative effort among the University of Southern California, Milwaukee Area Technical College, and the University of Wisconsin - Milwaukee

- Reviewed equity issues for non-white students transferring from Milwaukee Area Technical College to the University of Wisconsin-Milwaukee.
- Conducted focus groups and collaboratively analyzed the interview data, identifying themes.
- Presented the report to the larger team.

Public Presentation

Hawkins, J. M., Kamal, S., & Scarpita, A. (2012, May). Assessing the mental health environment in Manitowoc County. Presentation to Manitowoc County Mental Health Task Force and community members. Manitowoc, WI.

Conference Presentations

*Bold indicates presenter

Kim, S., Ahn, S., Cramer, E. M., Hawkins, J.M, & Song, H. (2015, April). Communicating healthful food choice: Cultural difference in regulatory focus. Paper presented at the Central States Communication Association, Madison, WI.

Hawkins, J.M. (2014, November). Early pregnancy loss: Women's narratives regarding healthcare interactions. Paper presented at the National Communication Association Convention, Chicago, IL.

Song, H., Omori, K., Kim, J., Tenzek, K., Hawkins, J. M., Lin, W.Y., Kim, Y. -C., & Jung, J. -Y. (2014, November). Trusting social media as a health information source: A cross-cultural Study. Paper presented at the National Communication Association Convention, Chicago, IL.

- Hawkins, J.M.** (2014, October). Experiencing a new normal: Narrative summaries of women's early pregnancy loss stories. Paper presented at The Organization for the Study of Communication, Language and Gender Conference, San Francisco, CA.
- Kim, S., Allen, M., Ahn, S., Cole, A., Cramer, E.C., Becker, K.A., Choi, C.S., Dilbeck, K.E., Gross, C.M., Hawkins, J. M., Jayroe, T.J., Kim, M., Mullane, R.R., Priddis, D.M., Smith, K., Victor, A.K., Willes, K.L., & Zmyslinski-Seelig, A.N. (2013, November). Testing the evidence effect of Additive Cues Model (ACM). Paper presented at the National Communication Association Convention, Washington, D.C.
- Hawkins, J.M.** (2013, October). Loss and trying again: Conversations during pregnancy loss and pregnancy after loss support groups. Paper presented at the Organization for the Study of Communication, Language and Gender, Houghton, MI.
- Hawkins, J.M.** (2013, October). Stunned: One woman's ectopic pregnancy loss experience. Presented at the Organization for the Study of Communication, Language and Gender, Houghton, MI.
- Hawkins, J.M.** (2013, April). Ethical issues in hidden communities: Alternative contexts and methods. Central States Communication Association, Kansas City, MO.
- Kim, S., Lim, T., Song, H., Herrman, A., Omori, K., Hawkins, J. M., Ota, H., Kim, H., Kim, J., Kim, J., England, N., Tenzek, K., Cramer, E., Grimes, D., & Dilbeck, K. (2013, April). The impact of self-construal on weight estimation and health practice: A cross-cultural study. Paper presented at Central Sates Communication Association, Kansas City, MO.
- Kim, S., Lim, T., Song, H., **Hawkins, J.M.**, Herrman, A. R., Kim, H., Ota, H., Kim, J., Kim, J., England, N., Tenzek, K., Cramer, E., Omori, K., Grimes, D., & Dilbeck, K. (2013, February). Promotive versus preventive dietary practice and self-construal: Communicating healthful food choice. **Top Paper** in the Health Communication Interest Group presented at the Western Communication Association Convention, Reno, NV.
- Song, H., **Hawkins, J.M.**, Kim, J., Omori, K., Tenzek, K., Kim, S. & Lim, T. (2013, February). Health information seeking online: An experimental study focusing on Internet skills. Paper presented at the Western Communication Association Convention, Reno, NV.
- Hawkins, J.M.**, & DeCloedt-Pinçon, D. (2012, November). New directions for an old problem: Understanding the nature and impact of bullying through discourse analysis. **Top Student Paper** in Peace and Conflict Studies Division presented at the National Communication Association Convention, Orlando, FL.
- Kim, S., Lim, T., Song, H., England, N., Herrman, A., Hawkins, J.M., Kim, H., Ota, H., Kim, J., Kim, J., Tenzek, K., Omori, K., Cramer, E., Grimes, D., & Dilbeck, K. (2012, November). What's healthy? Community perceptions of healthy food. Paper presented at the National Communication Association Convention, Orlando,

FL.

Kim, S., Lim, T., Song, H., Cramer, E. M., Tenzek, K., England, N., Herrman, A., Hawkins, J.M., Kim, H., Ota, H., Kim, J., Kim, J., Omori, K., Grimes, D., Dilbeck, K. (2012, November). Integrating cultural worldviews into health self-assessment and behavior when a family member is ill. Paper presented at the National Communication Association Convention, Orlando, FL.

Hawkins, J.M. (2012, October) Helpful and hurtful enacted support messages experienced by women regarding early pregnancy loss. Paper presented at the Organization for the Study of Communication, Language and Gender, Tacoma, WA.

Hawkins, J.M. (2012, October) Negotiating pregnancy loss. The Organization for the Study of Communication, Language and Gender, Tacoma, WA.

Hawkins, J.M. (2012, May). Folk beliefs' impact on HIV/AIDS communication in rural South Africa. Paper presented at the Eighth International Congress of Qualitative Inquiry, Urbana-Champaign, IL.

Joosten, T., Al-Budaiwi, D., England, N., Hawkins, J.M., McNallie, J., Stache, L., & Allen, M. (2011, November). Student response systems: impact of clicker technology on learning. Paper presented at the National Communication Association Convention, New Orleans, LA.

Hawkins, J.M. (2011, October). Recurrent early pregnancy loss: Grief, uncertainty, and coping: Dichotomous voices intersecting at narrative. Paper presented at the Organization for the Study of Communication, Language and Gender, Evanston, IL.

Hawkins, J.M. (2011, September). Support for the culture-centered approach to HIV/AIDS prevention education in rural Native American tribes. Paper presented at the Western Michigan University Medical Humanities Conference, Kalamazoo, MI.

Joosten, T., Allen, M., Al-Budaiwi, D., Benoit, E., England, N., Glocka, J., Groppi, J., **Hawkins, J.M.**, Hoffman, A., Hong, H., Immerman, J., Li, J., McNallie, J., & Stache, L. (2011, April). Student response systems: Impact of clicker technology on learning. Paper presented at Central States Communication Conference, Milwaukee, WI.

Joosten, T., Allen, M., Al-Budaiwi, D., Benoit, E., England, N., Glocka, J., Groppi, J., Hawkins, J.M., Hoffman, A., Hong, H., Immerman, J., Li, J., McNallie, J., & Stache, L. (2011, April). Student response systems: Analysis of UW System data. Paper presented at the UW Systems President's Conference on Education, Madison, WI.

Hawkins, J.M. (2010, February). Adult, non-traditional, and veteran student experience and improving service. Access to Success Campus Conference, University of Wisconsin- Milwaukee, Milwaukee, WI.

Professional Service

2013 to 2015

- Elected to serve as Student Representative on the Executive Board of the Organization for the Study of Communication, Language, and Gender (OSCLG)
- OSCLG Outstanding Undergraduate Paper or Creative Project Award Committee

Fall 2014

- Reviewer, Western States Communication Association (WSCA) Convention 2015 Health Communication Interest Group
- Volunteer, Exhibitor Check-in: National Communication Association Convention (November, 2014), Chicago, IL

Spring 2013

- Reviewer, National Communication Association (NCA) 2013 Peace and Conflict Studies Division

Fall 2011

- Reviewer, Central States Communication Association (CSCA) 2012 Conference: Health Communication & G.I.F.T. Divisions
- Volunteer, Reception Guide: International Society for Scholarship of Teaching and Learning (ISSOTL) Conference (October, 2011), Milwaukee, WI

University of Wisconsin - Milwaukee Service

Department of Communication

Fall 2012 to Present

- Peer Mentor to New Graduate Student (1st Year Ph.D. Student), Communication Department

Spring 2012

- Volunteer: Potential Ph.D. Student Outreach

Fall 2011 to Spring 2013

- Member, Communication Graduate Student Council (CSCG)

Summer 2011

- Member of the New Organization Committee - Assisting with Communication Graduate Student Council (CSCG) becoming an official Student Organization on Campus transitioning from what was previously called the Student Graduate Advisory Committee (SGAC); Assisted with drafting of the Organizational Charter

Fall 2010, Fall 2011, & Spring 2011

- Public Speaking Showcase Volunteer: Timer, Extra Credit Checker & Volunteer Judge

Fall 2010 & Fall 2012

- Student Graduate Advisory Committee, Ph.D. Representative for Faculty Council Meetings

Campus-wide Community

August 20, 2012

- Invited Presenter: Fall 2012 Campus-wide Teaching Assistant Orientation Program. “Learning from Experience: Discussions with Experienced TAs”

March 2, 2012

- Participant: Realigning for Inclusivity: Reframing Diversity at UWM-strategic planning event, facilitated by Dr. Caesura McDowell

Spring 2011

- Volunteer Marshall at the Capitol in Madison on behalf of the Milwaukee Graduate Assistant Association (MGAA)

2010 – 2011

- Member, Milwaukee Graduate Assistant Association (MGAA)

2010

- Invited Consultant, Milwaukee Area Technical College’s IT Development Advisory Committee
- Invited Member, Outreach and Recruitment Team, University of Wisconsin-Milwaukee
- Invited Member, Transfer Orientation Team, University of Wisconsin-Milwaukee

2009

- Preparing and Learning for Success (PALS), Curriculum development team, University of Wisconsin-Milwaukee.

2008- 2010

- Invited Member, Adult, Transfer, Non-Traditional and Veteran Student Working Group, University of Wisconsin-Milwaukee
 - Member, Web, Marketing and Online Communication Sub-Committee
 - Member, Transfer Student Sub-Committee
 - Member, Degree Completion Sub-Committee

Linfield College Service

2007

- Staff Development Day Planning Committee

2006-2007

- Oregon Women in Higher Education Conference Planning Team Member
2007 Conference: Portland, OR
 - Led Book Club break out session: Reading Lolita in Tehran
 - Organized and implemented and all member Networking Session designed to bring together Administrators and Faculty

2004-2007

- Leadership Team Member, Consortium of Higher Education Colleges, Portland, OR

Community Service

2011

- Volunteer: Dining out for Life Ambassador- The Eatery, Milwaukee, WI, Benefiting One Heartland, Milwaukee, Camp for Youth affected by HIV/AIDS
- Suicide Prevention Art Installation Project at Pride Fest, Milwaukee: "Step Away from Suicide." Involved with Karina Willes in creation of an interactive art installation, invited attendees to participate, Milwaukee, WI.
- Volunteer: Registration Table, Party with Heart Auction, Milwaukee, WI, Benefiting One Heartland, Camp for Youth affected by HIV/AIDS
- In collaboration with Kaori Yamada and Kiko Omori, led Communication Department Fundraiser for Japan in response to Earthquake and Tsunami
- Volunteer: WI Donor Network; Office help
- Volunteer Member, LGBT Suicide Prevention Program Development Team

2010

- Volunteer Judge: Milwaukee Debate League

2008

- Volunteer: Cyclic Vomiting Syndrome Association Run/Walk
- Volunteer: Peace Learning Center, Milwaukee, WI – assisted in training students on peaceful solutions to conflict resolution

Professional Development and Certifications

November 19, 2014

- National Communication Association Convention Pre-Conference: Early Careers and Scholarship in Health Communication

May 15, 2013

- Change Your Mind Change the World 2013 Attendee: Conversations on Global Health and Well-being. Panel discussion featuring the Dalai Lama Co-hosted by UW-Madison's Center for Investigating Healthy Minds at the Waisman Center and the Global Health Institute

May 17, 2012

- Qualitative Inquiry Congress Pre-Conference: Grounded Theory Methodologies for Social Justice Research: Kathy Charmaz

July 29, 2011

- Qualitative Methods in Social Science Research Workshop, University of Wisconsin – Milwaukee Center for Addiction & Behavioral Health Research

May 24, 2011

- "Make your HIP Hop: Designing your High Impact Practice for High Outcome Performance," a one-day retreat designed to learn to develop the skills and habits that will enhance students' experience of learning and prepare them for success throughout their first year. Sponsored by the First Year Learning Center at the University of Wisconsin, Milwaukee.

April 6, 2011

- Central States Communication Association (CSCA) Pre-Conference: "Finding a 'HOME' for Your Scholarship: The Do's & Don'ts, Ins & Outs of

Publishing and Securing Funding for Communication Research.

Spring 2011

- HIPPA for Researchers Training, University of Wisconsin-Milwaukee, Certified

Fall 2010

- Science and Research Integrity Graduate School Professional Development Series, University of Wisconsin – Milwaukee, Certificate received

2009

- Safe Space Training (Part 2), University of Wisconsin-Milwaukee
- Wisconsin Academic Advisors Association (WACADA) pre-conference Transfer Workshop- Successful Transitions: Building Supportive Networks for UW Transfer Students
- University of Continuing Education Association's Marketing Seminar

2008

- Dialogue on Racism, University of Wisconsin-Milwaukee

Professional Affiliations

Lifetime member	The Organization for the Study of Communication, Language and Gender
2013 – present	Organization for Research on Women and Communication
2012 – present	Western States Communication Association
2010 - present	Central States Communication Association
2009 - present	National Communication Association
2007-2010	Southeast Wisconsin Education Consortium
2005-2010	University of Continuing Education Association
2004-2010	National Academic Advisors Association
2004-2007	Consortium of Higher Education Colleges, Portland, OR

International Travel Experience

Canada, France, England, Ireland, Australia, Costa Rica, the Netherlands, South Africa (Study Abroad Student), South Korea & Japan (Study Abroad Assistant)