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A PHENOMENOLOGICAL INVESTIGATION OF WOMEN'S INFERTILITY
AND MISCARRIAGE GRIEF EXPERIENCES

by

Tristan D. McBain

A dissertation submitted to the Graduate College
in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
Counselor Education and Counseling Psychology
Western Michigan University
August 2019

Doctoral Committee:

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Tristan D. McBain

A PHENOMENOLOGICAL INVESTIGATION OF WOMEN'S INFERTILITY AND MISCARRIAGE GRIEF EXPERIENCES

Tristan D. McBain, Ph.D.

Western Michigan University, 2019

Infertility and miscarriage are reproductive losses that often produce grief reactions in affected women. This phenomenological study investigated the grief experiences of infertility and miscarriage through the ambiguous loss and disenfranchised grief frameworks in order to better understand both the obscurity of reproductive loss and how the resulting grief may be invalidated.

Sixteen women volunteered to participate in this study and each fell into one of the following three categories: women affected by infertility without miscarriage (4); women affected by miscarriage without infertility (4); and women affected by infertility and miscarriage (8). A phenomenological hermeneutic approach was utilized to uncover the meaning of the participants' grief experiences related to infertility and miscarriage and the themes that emerged were the result of a recursive process of thematic analysis. Themes that related to the ambiguity of the loss included: (a) loss of normative life experiences; and (b) a more personal loss. Themes that related to how the grief is disenfranchised included: (a) stigma leads to silence; (b) a lack of clear grieving rituals; and (c) elements of insensitive encounters. Finally, themes that related to improving counseling services for affected women included: (a) further training; (b) increasing access to appropriate resources; and (c) characteristics of validating support.

Participants indicated that most people acknowledge that reproductive loss produces grief, however; what they believe can be improved is how other individuals understand the pervasiveness of their pain. Implications for the counseling profession and areas for future research are discussed.

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CHAPTER I

INTRODUCTION

Overview of the Study Topic

Infertility and miscarriage are reproductive losses that often have devastating emotional effects. Women who experience infertility and miscarriage have grief reactions (Adolfsson, Larsson, Wijma, & Bertero, 2004; Bell, 2013; Daniluk, 2001; Hutti & de Pacheco, 1998; Johansson & Berg, 2005; Lee et al., 2010; McCarthy, 2008; Meaney, Corcoran, Spillane, & O'Donoghue, 2017; Swanson, Chen, Graham, Wojnar, & Petras, 2009) but little is known about the lived experience of the grief itself. Grief practices for infertility and miscarriage do not necessarily follow societal grieving norms, thus leaving the door open for the grief to be unacknowledged by others or society as a whole (Doka, 1999, 2002). Disenfranchised grief occurs when grief is not or cannot be acknowledged openly, publicly mourned, or socially sanctioned (Doka, 1989, 1999, 2002). When grief is disenfranchised, there is a greater sense of isolation, being misunderstood, and more complicated grief (Doka, 1989, 1999, 2002). It is important to recognize the grief and respond with sensitivity in order to promote healing and best meet the needs of the women who have experienced the arduous losses of infertility and miscarriage.

Infertility

Infertility is a disease of the reproductive system that prevents the conception of a pregnancy after at least one year of unprotected sexual intercourse for women under the age of 35 (Centers for Disease Control [CDC], 2018; Resolve, 2018b; World Health Organization [WHO], 2018a). The time frame is decreased to six months of unprotected sexual intercourse for

women aged 35 and older to account for the decline of fertility as a woman ages (CDC, 2018; Resolve, 2018b). In the United States, 12.1% of women aged 15-44 have impaired fecundity (CDC, 2016), which refers to “difficulty getting pregnant or carrying a pregnancy to term” (CDC, 2018).

Conditions that may contribute to female infertility include, but are not limited to, ovary or ovulation disruption (e.g., polycystic ovary syndrome [PCOS]), ovarian age, obstruction of one or both fallopian tubes, or abnormal physical characteristics of the uterus (CDC, 2018). One in five couples are diagnosed with unexplained infertility (Resolve, 2018b), which is no apparent cause for the infertility. Some women elect to pursue medical intervention in their quest to have a child. Treatments for infertility include medication (e.g., Clomid), surgery, intrauterine insemination (IUI), or assisted reproductive technologies (ART) such as in vitro fertilization ([IVF]; CDC, 2018). The percentage of non-donor ART cycles that led to a successful birth in 2015 was 38% for women under the age of 35. That number decreases with age, with the percentage being 23% for women between 38-40 and 3% for women older than 44 years (CDC, 2018). Twelve percent, or 7.3 million women aged 15-44, have utilized some form of infertility service (CDC, 2016).

Miscarriage

Miscarriage occurs when a fetus dies in the womb at or before the 19th week of pregnancy (CDC, 2017b, 2017c; March of Dimes, 2017; National Institutes of Health [NIH], 2018). The exact number of miscarriages is unknown because many happen before a woman is aware that she is pregnant (March of Dimes, 2017; NIH, 2018). Approximately 10-15% of known pregnancies end in miscarriage (March of Dimes, 2017). The majority of miscarriages occur in the first trimester, with 1-5% of all miscarriages happening in the second trimester

(March of Dimes, 2017). The cause of miscarriage varies and is not always known. Possible causes of miscarriage include chromosomal abnormalities, uterine or cervical problems, certain infections, or chronic diseases (March of Dimes, 2017; NIH, 2018). The physical recovery of a miscarriage can last from several weeks to over a month. The emotional recovery is often longer, because of the grief and loss associated with the death of the fetus (March of Dimes, 2017).

Disenfranchised Grief

Disenfranchised grief can be experienced when one suffers a loss that “is not, or cannot be, openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p. 4). The theory of disenfranchised grief acknowledges that the attachment and sense of loss a person may experience does not necessarily match typical societal norms, or “grieving rules” (Doka, 1999). In Doka’s original conception of disenfranchised grief (1989), three reasons disenfranchised grief may occur were identified: When the relationship is not recognized, when the loss is not recognized, and when the griever is not recognized. Two other reasons were later identified: When the death is disenfranchising, and when the way an individual grieves is not validated (Doka, 1999, 2002). Infertility has been identified as a hidden loss (Lindsey & Driskill, 2013), thus categorizing infertility as a loss that is not recognized within the framework of disenfranchised grief (Doka, 2002). Miscarriage may also be considered an unacknowledged loss (Doka, 2002).

Ambiguous Loss

Ambiguous loss is an unclear loss that remains unresolved (Boss, 1999, 2007). There are two types of ambiguous loss (Boss, 2016). The first is when there is a physical absence with a psychological presence. Examples include divorce or a missing body (e.g., murder, plane crash, military MIA) (Boss, 1999, 2007, 2016). Infertility and miscarriage would also fall under this category. There is a physical absence of a pregnancy, but a psychological presence of the desire

for or loss of a fetus. The second type of ambiguous loss is when there is a psychological absence with a physical presence, such as when a loved one has dementia or an addiction. Ambiguous losses are traumatic because they are often painful, immobilizing, and incomprehensible to the extent that effective coping is blocked (Boss, 1999, 2010). The pain of an ambiguous loss often persists for years (Boss, 2010), largely because of the impossibility of resolution (Boss, 2016).

Focus of the Study

Statement of the Problem

There is evidence that general help-seeking patterns for counseling services of women with infertility is low (Boivin, Scanlan, & Walker, 1999; Greil & McQuillan, 2004; Hammarberg, Astbury, & Baker, 2001; Kahlor & Mackert, 2009). Patterns of help-seeking behavior of women who have endured a miscarriage are less known, although there is evidence that women would like counseling either during their next pregnancy or after another miscarriage (Musters et al., 2013; Musters, Taminiau-Bloem, van den Boogaard, van der Veen, & Goddijn, 2011). Women with infertility tend to rely on family and friends for support before more formal professional counseling resources (Boivin et al., 1999; Gibson & Myers, 2002; Greil & McQuillan, 2004; Kahlor & Mackert, 2009). For example, results from a study by Kahlor and Mackert (2009) revealed that the 567 infertile women in their sample had higher rates of relying on friends (89%), partner or spouses (88%), and family (77%) than on counselors (32%). Another study by Greil and McQuillan (2004) revealed that of 123 subfecund women with intent to conceive a pregnancy, 66% had discussed fertility with family or friends while only 8% consulted with a mental health provider. The authors suggested that low pursuance of formal support suggests an unmet counseling need exists, while high reliance on informal supports underlines the importance of social networks during help-seeking (Greil & McQuillan, 2004). However, there is evidence

that both informal and formal supports have been disenfranchising to women suffering from grief related to perinatal death (Hazen, 2003; Lang et al., 2011; Mulvihill & Walsh, 2014). It is likely that this disenfranchisement also happens to women with infertility, meaning that both forms of support may invalidate their grief experiences.

There are also functional considerations that impact the utilization of counseling services. Practical concerns such as scheduling difficulties and deficient information offered on infertility support services have been cited as the most important reasons counseling was not sought (Boivin et al., 1999; Read et al., 2014). In a study by Souter, Penney, Hopton, and Templeton (1998), only 14% ($N = 761$) of infertile women surveyed said they had been offered counseling by their outpatient clinics, although 57% said they would attend infertility counseling if it was offered. Similarly, Hammarberg et al. (2001) found that most of the women in their sample thought counseling should be an ongoing aspect of having IVF, but only a small number of women utilized counseling themselves. Regarding miscarriage, Musters et al. (2011) found that many of the 15 women with recurrent miscarriage that were interviewed spoke to the importance of being offered counseling, even if it was not needed at the time. These studies point to the necessity of improved visibility and access to counseling services for women affected by infertility and miscarriage. Researchers have highlighted ways that counselors can meet the needs of infertile women and highlight the need to improve counseling resources (Boivin et al., 1999; Bray, 2015; Bryson, Sykes, & Traub, 2000; Dancet et al., 2013; Gibson & Myers, 2002; Peterson et al., 2012; Raque-Bogdan & Hoffman, 2015; Sundby, Schmidt, Heldaas, Bugge, & Tanbo, 2007; Wischmann, Scherg, Strowitzki, & Verres, 2009), but the degree of counseling satisfaction is less known.

Another problem is a dearth of literature on the grief experienced by women related to infertility or miscarriage in the field of counseling. Most of the available information on the lived experiences of miscarriage and infertility is published in journals within the medical field, such as nursing (Cunningham & Cunningham, 2013; MacWilliams, Hughes, Aston, Field, & Moffatt, 2016) or women's reproductive health (Adolfsson et al., 2004; DeBackere, Hill, & Kavanaugh, 2008; McCarthy, 2008). Publications on the lived experience of infertility expand to include journals related to women (Bell, 2013; Parry, 2004), couples (Benasutti, 2003), sociology (Greil, Slauson-Blevins, & McQuillan, 2010), and counseling (Watkins & Baldo, 2004). Additionally, the aforementioned research includes a mix of qualitative and quantitative studies and literature reviews. Unfortunately, there is even less literature that focuses on the grief experience alone. Most qualitative research on infertility describes all or parts of the journey of infertility, from diagnosis to living with infertility (Benasutti, 2003; Ferland & Caron, 2013; Parry, 2004) and adjusting to life with involuntary childlessness (Bell, 2013; Daniluk, 2001), or after failed fertility treatment (Johansson & Berg, 2005; McCarthy, 2008; Wirtberg et al., 2007). Qualitative research on miscarriage generally focuses on the experience of the miscarriage itself (Adolfsson, 2010; Adolfsson et al., 2004; Meaney et al., 2017) and the impact on future implications for pregnancy and having children (Côté-Arsenault & Morrison-Beedy, 2001). However, while these descriptions often include accounts of grief and loss, they lack thorough investigation of the lived experience related specifically to the grief.

Finally, there is a lack of consistency for grief training in graduate counseling programs. Despite evidence that teaching grief counseling is of perceived importance (Humphrey, 1993; Ober, Haag Granello, & Wheaton, 2012), there are no standardized guidelines for how to incorporate grief training into counselor education programs (Council for Accreditation of Counseling

and Related Educational Programs [CACREP], 2016). The delivery of grief counseling education therefore occurs in a variety of ways (Low, 2004), such as infusion with other program curricula (Hannon & Hunt, 2015; Humphrey, 1993; Ober et al., 2012). In a qualitative study by Breen (2010) that described practices of 19 grief counselors, only two stated they accessed information about grief through their formal training and that the information provided did not translate well to applied settings. Given the inconsistency in their own training, it is possible that faculty may not be prepared to provide grief education (Eckerd, 2009; Hannon & Hunt, 2015). Counselors primarily acquire grief training through continuing education credits such as workshops or seminars (Breen, 2010; Wass, 2004). They rely on the grief theories with which they are the most familiar (e.g., Stage Theory [Kübler-Ross, 1969]), and not necessarily grief theories that have been empirically validated (Breen, 2010; Ober et al., 2012).

Purpose Statement

Given the identified problems of low help-seeking behavior for counseling, the lack of available literature on infertility and miscarriage grief experiences, and the inconsistencies in grief training in counselor education graduate programs, the purpose of this study is to examine the infertility and miscarriage grief experiences of women to better understand both the ambiguity of their loss and how their grief may be disenfranchised. This study will expand the current research by exploring the perceptions, beliefs, and lived experiences of grief for women who have weathered infertility or miscarriage within the context of ambiguous loss and disenfranchised grief. Studying these experiences will divulge a greater understanding of how to recognize and validate the losses, increase effective psychosocial support, and promote healing in counseling.

Significance of the Study

This research is important to the field of counseling for several reasons. First, there is room to improve utilization of and access to counseling services for women experiencing infertility and miscarriage grief. There is some research to suggest that women who experience perinatal loss, such as miscarriage or stillbirth, also experience disenfranchised grief from family or friends, partners or spouses, health professionals, and the workplace (Hazen, 2003; Lang et al., 2011; Mulvihill & Walsh, 2014). Mulvihill and Walsh (2014) revealed their participants had experienced disenfranchised grief through the language that professionals used, insensitive comments, and a lack of social support regarding their perinatal loss. Counselors must genuinely understand the loss while preventing minimization, assumptions, and false hope (Raque-Bogdan & Hoffman, 2015; Watkins & Baldo, 2004). This study will build upon previous research and provide information that will be useful to counselors and other medical professionals in having a greater understanding of how to validate rather than disenfranchise infertility and miscarriage grief experiences. Counseling interventions can then be better tailored to the needs of these women, and counselor response can more appropriately address the loss ambiguity, and thus minimize the disenfranchisement of the grief experience. Given that these results could also be useful to other medical professionals, such as infertility doctors or nurses, this study will also contribute to better integration of care, an issue that has gained attention regarding infertility treatment (Boivin et al., 2012; Boivin & Gameiro, 2015; Cunningham & Cunningham, 2013; Dancet et al., 2013; Peterson et al., 2012).

Another area of significance is in regard to the current training practices for preparing counselors to address grief and loss. Many counselors are most familiar with stage and task models of grief (Breen, 2010; Ober et al., 2012), despite movement within the profession toward

a more individualized and contextual view of the grieving process (Doughty, 2009; Horn, Crews, & Harrawood, 2013; Martin & Doka, 2000). Breen and O'Connor (2007) suggest that grief education could be improved by attending to the contextual nature of grief, which will allow greater sensitivity to and recognition of the diversity of experiences. This study will explore infertility and miscarriage grief through the context of the participants' lived experience, thus providing a resource for educators, students, and counselors to learn more about how to provide grief counseling that is modified to the specific needs of a particular client.

Previous studies have recognized the lived experience of women regarding infertility and miscarriage and encompassed accounts of grief and loss. However, there are limited studies that have examined those grief experiences from both the perspective of disenfranchised grief and ambiguous loss. A dissertation by Gonzalez (1988) examined the lived experiences of infertility and identified five themes that described the meaning of infertility. The results were consistent with the popular view that infertility is a significant loss to be grieved, but questioned whether resolution truly happens thus challenging the use of traditional grief models (Gonzalez, 1988). A more recent dissertation published in 2010 by Rosenzweig examined the disenfranchised grief experience of miscarriage. This quantitative study confirmed the hypothesis that unsupportive social interactions predicted problematic grief while social support did not (Rosenzweig, 2010). This current dissertation is a qualitative analysis of infertility and miscarriage grief experiences from the framework of ambiguous loss and disenfranchised grief and will build on this previous literature and expand the knowledge of practical and effective grief counseling methods for infertility and miscarriage.

Definition of Terms

Ambiguous Loss – A traumatic, unclear loss that remains unresolved (Boss, 2010).

Disenfranchised Grief – Grief that “cannot be openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p. 4).

Infertility – The inability to achieve a pregnancy after at least one year of unprotected sexual intercourse (CDC, 2018; Resolve, 2018b; WHO, 2018a).

Miscarriage – The loss of a pregnancy at or before the 19th week of conception (CDC, 2017b, 2017c; March of Dimes, 2017; NIH, 2018).

Polycystic Ovary Syndrome (PCOS) – A condition that causes women not to ovulate, and the most common cause of female infertility (CDC, 2018).

Primary Infertility – When a woman has never delivered a viable child, either due to the inability to achieve pregnancy or carry a pregnancy to a live birth (WHO, 2018b).

Secondary Infertility – When a woman is unable to deliver a child, either due to the inability to achieve pregnancy or carry a pregnancy to a live birth, after a previous successful birth (WHO, 2018b).

Stillbirth – The loss of a pregnancy at the 20th week of pregnancy or later (CDC, 2017b, 2017c).

Subfecundity – Difficulty conceiving or carrying a pregnancy to term (King, 2003).

Summary

Women experience grief reactions to infertility (Bell, 2013; Daniluk, 2001; Johansson & Berg, 2005; Lee et al., 2010; McCarthy, 2008) and miscarriage (Adolfsson et al., 2004; Hutti & de Pacheco, 1998; Meaney et al., 2017; Swanson et al., 2009). Several studies have identified low help-seeking behaviors of women with infertility to pursue counseling (Boivin et al., 1999;

Greil & McQuillan, 2004; Kahlor & Mackert, 2009), and even less is known about help-seeking for women who have endured a miscarriage. Women with infertility are more likely to rely on social supports rather than formal supports (e.g., counseling) (Boivin et al., 1999; Gibson & Myers, 2002; Greil & McQuillan, 2004; Kahlor & Mackert, 2009), and practical concerns such as cost or scheduling have been identified as barriers (Boivin et al., 1999; Read et al., 2014).

There is agreement that grief counseling is an important part of counselor preparation (Humphrey, 1993; Ober et al., 2012), however there is a lack of standardization in how counselors are trained to address grief (CACREP, 2016) and many counselors acquire grief training through continuing education credits (Breen, 2010; Wass, 2004). Research on infertility and miscarriage typically includes accounts of significant grief and loss, but to date few studies have been done that thoroughly examine the grief experiences through both the ambiguous loss and disenfranchised grief frameworks. This study aims to explore the ambiguity of the grief experiences related to infertility and miscarriage and how those grief experiences have been disenfranchised by others.

This chapter provided a brief introduction to infertility, miscarriage, ambiguous loss, and disenfranchised grief. The problem statement outlined existing issues regarding help-seeking behavior for women affected by infertility and miscarriage, a dearth of literature investigating the grief experiences of these women, and a lack of consistency in grief training for counselors. The purpose of the study was defined, which is to examine women's infertility and miscarriage grief experiences in order to better understand the loss ambiguity and disenfranchisement of their grief. Lastly, the study significance delineated the potential for this study to improve counseling services, better prepare counselors to address grief and loss, and contribute to a gap within the counseling literature. In Chapter II, the literature review will be presented. The existing research on infertility, miscarriage, disenfranchised grief, and ambiguous loss theory within the counseling

profession and other relevant fields will be discussed. In Chapter III, the research methodology selected for this study will be divulged. Chapter IV will present the findings of the data analysis. Chapter V will interpret the results, discuss the implications for counseling, and make recommendations for areas of further research.

CHAPTER II

LITERATURE REVIEW

Introduction

The purpose of this study is to examine the infertility and miscarriage grief experiences of women in order to better understand the ambiguity of their loss and how their grief is disenfranchised. While it has been well established within the literature that women experience feelings of grief and loss as a result from infertility and miscarriage, there are currently few studies that have explored the lived experience of the grief itself. The goal of this study is to provide a deeper understanding of the grief experience so that the losses can be better recognized and validated, and effective psychosocial support can be improved.

The relevant theoretical and empirical research related to infertility and miscarriage grief is presented in the following literature review. The research conducted on infertility and miscarriage are the first two sections that begin the discussion. Both sections start with current definitions and statistics and are followed by a review of the sociocultural context, psychological implications, aspects of the lived experience, and trends in counseling. Then, an overview of grief within the field of counseling is explored, which includes a description of clinical diagnoses, counselor training, and counselor ability to work with grieving clients. A brief discussion of ambiguous losses and disenfranchised grief within the infertility and miscarriage literature concludes this section. Finally, the last two sections provide a more specific examination of disenfranchised grief and ambiguous loss theories. This review includes quantitative and qualitative research in order to capture an inclusive understanding of the current literature and

support the need for the present study. Diversity issues are addressed through the identification and exploration of experiential differences amongst gender, race, and socioeconomic status.

Infertility

Definitions and Statistics

Infertility is generally defined as a disease or condition affecting the reproductive system that prevents the conception of a pregnancy after at least one year of unprotected sexual intercourse for women under the age of 35 (Centers for Disease Control and Prevention [CDC], 2018; Resolve, 2018b; World Health Organization [WHO], 2018a, 2018b). For women who are age 35 and older the time frame is reduced to six months of unprotected intercourse (CDC, 2018; Resolve, 2018b) to account for the natural decline of fertility with age. Some infertility definitions include the presence of miscarriage. For example, the demographic definitions of infertility of the WHO (2018b) are “an inability of those of reproductive age (15-49 years) to become *or remain* pregnant within five years of exposure to pregnancy” (p. 3), and, “an inability to become pregnant *with a live birth*, within five years of exposure based upon a consistent union status, lack of contraceptive use, non-lactating, and maintaining a desire for a child” (p. 4) (italics added for emphasis). Resolve, a national non-profit organization that provides support and community resources for men and women diagnosed with infertility, include the suffering of multiple miscarriages in their definition of infertility (2018b). In addition to using the term infertility to refer to the inability to get pregnant after one year of trying for women of reproductive age, the CDC (2018) also uses the term impaired fecundity, which is “difficulty getting pregnant or carrying a pregnancy to term” (p. 2).

In addition to the above terms, infertility research includes other vocabulary that is more inclusive of the vast array of situations in which women attempt to conceive but do not meet the

above criteria of infertility definitions. The term *involuntary childlessness* more accurately captures women who use assisted reproductive technology (ART) but are not infertile (Bell, 2013), such as in the case of women who undergo assisted reproduction as a result of male factor infertility, women in lesbian relationships, or women without a diagnosable explanation for their childlessness. The term also legitimizes the *voluntary* choice to remain childless, allowing for a broader range of roles for women and men (Bell, 2013). Several studies (Bell, 2013; Lechner, Bolman, & van Dalen, 2007; McQuillan, Greil, White, & Jacob, 2003; Miall, 1994; Scherdtfeger & Shreffler, 2009) have used *involuntary childlessness* to describe infertility.

There are two major subtypes of infertility. Primary infertility is when a woman has never birthed a child, either due to the inability to achieve pregnancy or the inability to carry a pregnancy to a live birth (WHO, 2018b). Women who spontaneously miscarry, or whose pregnancy results in a stillborn child, or who have never been pregnant would present with primary infertility. Secondary infertility is when a woman is unable to birth a child due to the inability to either become pregnant or carry a pregnancy to term, following the live birth of a previous child (WHO, 2018b). Women who repeatedly miscarry or bear stillborn children or are unable to conceive a pregnancy following a previous ability to produce a healthy child would present with secondary infertility.

In 2016, the most recent year for which data are available, 12.1% of women aged 15-44 met criteria for impaired fecundity in the United States (CDC, 2016). African American women have the highest infertility rate at 7.2%, followed by Hispanic or Latina women (6.1%) and Asian women (5.6%) (Chandra, Copen, & Stephen, 2013). Even after adjusting for socioeconomic status, marital status, and risk factors such as age, Black women have a significantly higher likelihood of having ever experienced infertility than White women (Wellons et al.,

2008), who have the lowest infertility rate at 5.5% (Chandra et al., 2013). The results of a cross-sectional survey of physicians conducted by Ceballo, Abbey, and Schooler (2010) revealed that 82% ($N = 155$) incorrectly believed that European American women were the racial group most at risk for infertility. Only 16% correctly identified African American women, indicating that many physicians are unaware of racial demographics for infertility risk (Ceballo et al., 2010). Infertility affects both women and men, although there is some variation among prevalence estimates. Some approximate one third of infertility is attributable to female factor, one third to male factor, and the remaining cases attributable to issues in both partners or unexplained infertility (Resolve, 2018b; Shapiro, 2009). The CDC (2018) approximates issues in both partners for 35% of couples with infertility, but only 8% attributed to male factor only. This dissertation study will focus only on female factor infertility.

There are a variety of causes for infertility in women. The CDC (2018) breaks down potential (but not exhaustive) causes for infertility by conditions of the ovaries, fallopian tubes, and uterus. The following paragraphs describe these conditions and treatments as explained by the CDC (2018). First, ovulation is disrupted when there is dysfunction of the ovaries or due to ovarian age. Polycystic ovary syndrome (PCOS) is a condition that leads to irregular or no ovulation and is the most common cause of female infertility. Dysfunction of the hypothalamus and pituitary glands in the brain can lead to irregular ovulation, as these glands produce hormones that maintain ovarian function. Other issues are diminished ovarian reserve, a situation in which fewer eggs remain in the ovaries than usual, and premature ovarian insufficiency, a situation in which the ovaries fail before the age of 40. Menopause, while an expected phase of a woman's life, is also a decline of ovarian function. Next, fallopian tube obstruction may occur whether the tubes are open, blocked, or swollen. A history of conditions such as endometriosis (when uterine

tissue grows outside the uterus), certain sexually transmitted infections ([STI], e.g., gonorrhea or chlamydia), abdominal surgeries, ruptured appendicitis, and pelvic infection are all risk factors for obstructed fallopian tubes. Finally, abnormal physical characteristics of the uterus may impact fertility. An example is the presence of fibroids, which are benign tumors that grow in and around the uterus. Further risk factors for female infertility are age, smoking, excessive use of alcohol, extreme weight loss or gain, and excessive stress (CDC, 2018).

Treatments for infertility include medication, surgery, intrauterine insemination (IUI), and ART. Examples of medication that may be prescribed are Clomid or Femara, which are often used to stimulate ovulation in women with PCOS or to increase the production of mature eggs. Surgeries may be performed that remove uterine fibroids, polyps, or endometriosis tissue. Intrauterine insemination is also known as artificial insemination and is sometimes used alongside medication. This treatment is often utilized in circumstances of male factor infertility or unexplained infertility. Fertility treatments in which both eggs and embryos are managed outside the body are considered to be ARTs and these methods may at times use donor eggs, donor sperm, or donor embryos. Factors including the clinic, the infertility diagnosis, and the age of the woman impact ART success rates. In 2015, the percentage of non-donor ART cycles that led to a live birth was 38% for women under the age of 35. As the age of the women increased, the percentage of successful ART cycles decreased. For women aged 38-40 the percentage was 23% and for women 43-44 the percentage was 7%. Women aged 45 and older had a 3% chance for an ART cycle that led to a live birth. The most common and effective ART is in vitro fertilization (CDC, 2018).

Twelve percent, or 7.3 million women aged 15-44, have received infertility services (CDC, 2017a). These infertility services as identified by the CDC (2017a) are advice (6.3%),

medical help to prevent miscarriage (5.4%), tests (5.2%), ovulation drugs (4.2%), and artificial insemination (1.4%). The age group of women that received the highest percentage of infertility services were those aged 40-44 years at 23.7% (CDC, 2017a). Despite the aforementioned statistics, infertility does not inevitably equate to childlessness. In fact, many women who experience infertility at one point in their lives go on to have either biological or social children (Bryson, Sykes, & Traub, 2000; McQuillan et al., 2003; Sundby, Schmidt, Heldaas, Bugge, & Tanbo, 2007).

The Study of Infertility

Sociocultural context. Motherhood is often considered to be a central life role for women (Ferland & Caron, 2013; Johansson & Berg, 2005; McQuillan, Greil, Shreffler, & Tichenor, 2008; Reitzes & Mutran, 2002), with the socialization of taking on a nurturing role often beginning in childhood (Ferland & Caron, 2013; Shapiro, 2009). Many individuals feel a strong commitment toward having children (Rittenour & Colaner, 2012; Thornton & Young-DeMarco, 2001), and personal aspirations for motherhood may stem from life expectations that are long-standing (Bell, 2013; Berer, 1999; Ferland & Caron, 2013; Shapiro, 2009). As referenced by Miles, Keitel, Jackson, Harris, and Licciardi (2009), Margaret Mead (1962) wrote that ‘it is very hard to separate a woman’s desire to have children from society’s expectation of her role as chief caretaker’ (p. 862). Indeed, women today are still often faced with a societal pressure to become pregnant and have children (Ferland & Caron, 2013; Gray, 1996; Imeson & McMurray, 1996; Miles et al., 2009; Morell, 1994) and abide by the philosophical motherhood mandate (Ceballo, Graham, & Hart, 2015; Russo, 1976). The ideology that womanhood equates to motherhood (Bell, 2013; Ferland & Caron, 2013; Miall, 1994; Morell, 1994) is reinforced by societal expectations but also socially constructed individual beliefs. In their review of over 150

pieces of literature on infertility, Greil, Slauson-Blevins, and McQuillan (2010) noticed that the social context in which infertility is framed is gaining attention in research. Due to the personal, familial, and cultural denotations assigned to motherhood in Western society, infertility cannot be fully understood without consideration for the larger sociocultural framework.

Childbearing often both validates identity and authenticates the establishment of a family unit (Gold, 2012). Without deliberate disclosure by the woman of her fertility struggles, other people may not explicitly know about her infertile status and her desire to birth a child but have the inability to do so. Women tend to perceive their infertility as more stressful when faced with the societal pressure to achieve motherhood (Miles et al., 2009), which is further complicated by the fact that women without children are viewed as less warm and more emotionally troubled (Koropecyk-Cox, Copur, Romano, & Cody-Rydzewski, 2018). Although a rising number of women are choosing not to have children (Berer, 1999; Gillespie, 2003; Gold, 2012), it is still considered controversial to go against cultural norms and voluntarily forgo motherhood (Bell, 2013; Berer, 1999; Gold, 2012; Koropecyk-Cox et al., 2018; Morell, 1994). For these reasons, infertility carries a social stigmatization (Read et al., 2014; Shapiro, 2009; Slade, O'Neill, Simpson, & Lashen, 2007). Bell (2013) interviewed 28 involuntary childless Australian women in her qualitative exploration of their experiences and need for support as related to the use of ARTs. The participants spoke to personal choice and pronatalist societal pressure as strong forces propelling the urge to have children. Some of the women thought that other people made assumptions that they were voluntarily childless after being directly asked about their absence of children. Many felt an inference that they were being selfish and choosing careers or wealth over childbearing. Participants described positive reactions from friends and family members, as well

as unsolicited advice, offensive comments, and otherwise intrusive questions regarding their childlessness (Bell, 2013).

It is assumed that women with primary infertility, who have never birthed a child, experience social pressure to procreate to a higher degree than women with secondary infertility who have at least one child. Raque-Bogden and Hoffman (2015) explored well-being among 119 women with primary infertility and 53 women with secondary infertility. The authors found that the women with primary infertility had greater association with fertility-related social concerns. These participants reported a higher sensitivity to comments about their childlessness, were more often reminded of their status as childless, and proclaimed greater levels of social isolation and alienation from family and their peers. No differences were found among levels of subjective well-being and global infertility-related stress between the two groups of women. These results were similar to an earlier study conducted by Newton, Sherrard, and Glavac (1999), which revealed that women with primary infertility reported higher levels of social concern and global fertility-related stress. Such findings highlight the need to incorporate the social context of expectations for procreation in how infertility, particularly primary infertility, is understood (Raque-Bogden & Hoffman, 2015).

There are some aspects of infertility that allow for it to be socially constructed in a unique way (Miall, 1994). Greil et al. (2010) discussed the social construction of infertility as a process, in which individuals label their inability to have children as a problem, identify the nature of that problem, and construct an action plan. Greil et al. (2010) noted four ways the social construction of infertility is remarkably different from other conditions. First, those that do not desire the social role of parenthood are unlikely to define themselves as infertile and seek treatment, regardless of whether they fit within the medical definition. Second, infertility is typically perceived as a

condition that affects the couple, regardless of which partner is identified as infertile. Therefore, negotiations of how to define oneself as infertile encompass the individual and the medical professional, but also the partnership and perhaps larger social networks. Third, infertility is characterized by an absence of a desired event rather than the presence of pathology. Fourth, alternative treatments exist, such as adoption, changing partners, or re-defining as voluntarily childfree, which leaves the door open for a range of possibilities instead of only one path to a cure (Greil et al., 2010).

Additionally, social class makes a difference when it comes to how women understand their diagnosis of infertility. Bell (2014) interviewed 58 infertile women of diverse class backgrounds in the United States in order to learn more about the differences in understanding, interpretation, and outcome of diagnoses. Results indicated that many women sought a diagnosis but the meaning that was placed on to the diagnosis differed. Women from lower socioeconomic status (SES) who knew they could not afford treatment wanted a diagnosis that explained their fertility problem, and higher class women wanted a diagnosis that would bring treatment. Without the prospect of medical intervention, women of lower SES relied more on other pathways to resolving their childlessness. They are also frequently excluded from research on the psychology of infertility and help-seeking because recruitment for these studies often comes from medical clinics (e.g., see Anderson, Sharpe, Rattay, & Irvine, 2003; Gibson & Myers, 2002; Hammarberg, Astbury, & Baker, 2001; Monga, Alexandrescu, Katz, Stein, & Ganiats, 2004; Oddens, den Tonkelaar, & Nieuwenhuys, 1999; Schmidt, Holstein, Christensen, & Boivin, 2005; Slade et al., 2007). Understanding the influence of social class on infertility diagnostics provides a more comprehensive view of women's infertility experiences (Bell, 2014).

Psychology of infertility patients. There is very little dissension in the literature that those with ongoing infertility experience higher rates of distress (Anderson et al., 2003; Fekkes et al., 2003; McEwan, Costello, & Taylor, 1987; McQuillan et al., 2003; Miles et al., 2009; Monga et al., 2004; Oddens et al., 1999; Wischmann, Scherg, Strowitzki, & Verres, 2009; Wischmann, Stammer, Scherg, Gerhard, & Verres, 2001). Infertile women have reported higher levels of anxiety (Anderson et al., 2003; Galhardo, Pinto-Gouveia, Cunha, & Matos, 2011; King, 2003; Lechner et al., 2007; Oddens et al., 1999; Wischmann et al., 2001), depression (Bryson et al., 2000; Datta et al., 2016; Galhardo et al., 2011; Lechner et al., 2007; Oddens et al., 1999; Schwerdtfeger & Shreffler, 2009; Volgsten, Svanberg, Ekselius, Lundkvist, & Poromaa, 2008; Wischmann et al., 2001, 2009), complicated grief (Boivin, 2003; Lechner et al., 2007), and adjustment disorder (Sbaragli et al., 2008) when compared with other groups. In a study of 2,363 women, Greil, McQuillan, and Sanchez (2014) reported that African American women indicated lower levels of fertility distress than White women, but that the intention of pregnancy mediated these results. The authors concluded that African American women were less likely to think of themselves as actively trying to conceive, and not that they felt infertility distress to a lesser degree (Greil et al., 2014).

Approximately 39% – 57% of all women with infertility choose to seek medical intervention (Datta et al., 2016; Greil & McQuillan, 2004; Resolve, 2018a) in their quest to have a child. The literature on women's emotional well-being before engaging in treatment is mixed. Verhaak et al. (2007) found in their systematic literature review that the women who were just starting in-vitro fertilization (IVF) emotionally differed only slightly from norm groups, whereas Sbaragli et al. (2008) proclaimed that a portion of infertile Italian patients had already developed a psychiatric disorder by the time of their first fertility treatment. Similarly, Fekkes et al. (2003)

revealed that not only do young men and women who are planning fertility treatment show more short-term social and emotional problems than comparison groups, but that irrational cognitions about parenthood accounted for a large part of the scores participants reported on quality of life measures. The Irrational Parenthood Cognition scale used in this analysis was developed by the authors and included items such as ‘Having a child is the most important thing in life’, ‘You start hating your body when you cannot have children’, and ‘Not having children causes lifelong suffering’ (p. 1543). These irrational cognitions may help explain the problematic psychosocial functioning of young individuals entering into fertility treatment (Fekkes et al., 2003).

Several studies have examined emotional distress and psychopathology of women and men undergoing IVF treatment (Galhardo et al., 2011; Holter, Anderheim, Bergh, & Möller, 2006; Miles et al., 2009; Schmidt et al., 2013; Verhaak, Smeenk, van Minnen, Kremer, & Kraaimaat, 2005; Verhaak et al., 2007; Volgsten et al., 2008). Galhardo et al. (2011) found that of three groups of couples (couples without fertility problems, couples with infertility and pursuing treatment, and couples with infertility and pursuing adoption), the infertility and pursuing treatment group scored higher in measures of depression, anxiety, external shame, internal shame, and self-judgment than the other two groups. Self-judgment, and external and internal shame were also significant predictors of depression (Galhardo et al., 2011). Social support has been discovered to have a protective effect, leading to lower distress in people undergoing fertility treatment (Gibson & Myers, 2002; Mindes, Ingram, Kliever, & James, 2003; Verhaak et al., 2005). Conversely, Lechner et al. (2007) found minimal evidence that social support is a protective factor. The writers speculated that these differences could be due to how social support is experienced at different stages of treatment (Lechner et al., 2007).

Fertility treatment can be a positive part of women's lives, providing a sense of pride and stronger feelings of self-esteem (Bryson et al., 2000; Johansson & Berg, 2005). Nevertheless, not all medical interventions are successful. The emotional reactions evoked after treatment are dependent on whether or not a pregnancy is conceived; women who fall pregnant tend to see their negative emotions disappear immediately (Verhaak et al., 2007), whereas women who do not achieve pregnancy report an increase in emotional and psychological problems (Bryson et al., 2000; Holter et al., 2006; Verhaak et al., 2005). Responses to the failure of fertility treatment include depression, anxiety, anger, isolation/denial, and even bargaining and acceptance (Lee et al., 2010; Verhaak et al., 2005), and the negative emotional impact may remain present for months or years after treatment failure (Bryson et al., 2000; Johansson & Berg, 2005; Verhaak et al., 2005, 2007). With time most women are able to adjust after unsuccessful treatment (Hammarberg et al., 2001; Sundby et al., 2007; Verhaak et al., 2005, 2007), although the emotional pain may never go away (Ferland & Caron, 2013; McCarthy, 2008; Parry, 2004). Sundby et al. (2007) conducted a follow-up study with 66 infertile Norwegian women who had undergone IVF between 9 and 10 years prior. Most of the women acknowledged that infertility had been a painful time of their lives but that they had been able to cope with that period of their lives and find a meaningful way to move forward. The majority of the sample (83%) perceived their current health as fair to good and many of them had biological or adopted children at the time of study. It is not certain how much, if at all, having children impacted their ability to adjust to life after IVF treatment. Additionally, 17% stated they had permanent complications from their infertility, which included depression, grief, and feelings of inferiority. Most of the women indicated that at some point over the previous 10 years infertility made them depressed or sad

(Sundby et al., 2007), indicating that while overall adjustment can be achieved, infertility still has lasting effects.

Satisfaction ratings of fertility treatment are mixed, with some studies reporting high satisfaction levels (Schmidt et al., 2003; Souter, Penney, Hopton, & Templeton, 1998) and others reporting satisfaction levels closer to 50% (Malin, Hemminki, Räikkönen, Sihvo, & Perälä, 2001; Sundby et al., 2007). Achieving a pregnancy or becoming a parent after treatment is one of the most common and highly rated outcomes linked to a positive experience with infertility care (Malin et al., 2001; Schmidt et al., 2003). Hammarberg et al. (2001) reported in their follow-up study of IVF experiences that the women who did not conceive were more critical of the clinic and treatment; however, they did not regret having tried IVF. The women who had gone on to have children had a more positive recollection of their treatment, indicating that effectiveness of treatment is highly valued. Malin et al. (2001) reported that respectful, empathic, and personal care from her doctor was the most positive treatment experience for Finnish women. The above findings have been corroborated by Dancet et al. (2013), who found effectiveness, patient-centered care, and also safety, to be the top three quality indicators for different dimensions of infertility care.

An earlier study by Souter et al. (1998) reported a high satisfaction rate (87%, $N = 1366$), but also highlighted where improvements in fertility treatment could be made. Nearly as many participants (86%) felt they had not received enough help for the emotional aspects of infertility. Much higher numbers of respondents indicated that some forms of desired care (e.g., counseling, written information) were not offered than were offered. Poor encounters with medical professionals appear to have a large influence over whether the treatment experience is perceived as dissatisfactory (Malin et al., 2001). Women have described medical staff as disinterested or too

busy to listen to them (Souter et al., 1998; Sundby et al., 2007), unable to provide explanations for the cause of infertility or why treatment was not successful (Souter et al., 1998; Sundby et al., 2007), and frequently insulting, insensitive, or impersonal (Ferland & Caron, 2013; Malin et al., 2001; McCarthy, 2008). Physicians are expected to be the most compassionate toward infertility (Ferland & Caron, 2013), leaving women to feel dehumanized and isolated when they show a lack of empathy (Malin et al., 2001; McCarthy, 2008).

Ultimately, there are some women who never become mothers. Women who remain childless report higher distress (Bryson et al., 2000; McQuillan et al., 2003; Schwerdtfeger & Shreffler, 2009) and lower life satisfaction (Bryson et al., 2000; Daniluk & Tench, 2007; Hammarberg et al., 2001; McQuillan, Stone, & Greil, 2007) when compared with population norms and women with infertility who have subsequently conceived or adopted. In addition to lower life satisfaction, less marital satisfaction, less sexual satisfaction, and lower self-esteem were four factors that consistently related to poorer adjustment to biological childlessness over time in a study by Daniluk and Tench (2007). Other factors that contributed to a more difficult transition to biological childlessness were believing there were none or few other options besides producing their own biological child, receiving no or little support from significant others or medical professionals in adjusting to their infertility and childlessness, and those who relied on emotion-focused rather than problem-focused coping strategies (Daniluk & Tench, 2007). Another study by Schwerdtfeger and Shreffler (2009), using a representative sample of American women from the National Survey of Fertility Barriers, examined the long-term psychological outcomes of 2,894 mothers and involuntary childless women. The childless women who had endured pregnancy loss or inability to conceive reported the highest levels of depression and the lowest life satisfaction. Women who had experienced both events reported the most distress

related to their fertility (Schwerdtfeger & Shreffler, 2009). Overall, there is unison in the infertility research that unresolved infertility contributes to significant distress, and that the stress may persist long-term if the woman remains childless.

Methodological issues within infertility research have been noted and may even be partly attributable to inconsistent findings (Greil, 1997; McQuillan et al., 2003; Wischmann et al., 2009). Many studies draw their samples from fertility clinics but given that not all individuals facing infertility seek treatment (Datta et al., 2016; Greil & McQuillan, 2004; Resolve, 2018a) and previously described issues with defining who is infertile, data may be incomplete and difficult to generalize (Greil, 1997; Greil et al., 2010). Since treatment seekers are more likely to be White and have a higher educational, occupational, and socioeconomic status (Bell, 2014; Ceballo et al., 2010; Datta et al., 2016; Greil & McQuillan, 2004; Greil, McQuillan, Shreffler, Johnson, & Slauson-Blevins, 2011), women who do not fit these demographics are less likely to receive infertility services and are often left out of research. This phenomenon has been described as “stratified reproduction” (Ceballo et al., 2015; Ginsburg & Rapp, 1995), whereby the fertility of high-income, married, White women is more valued than the reproduction of less desirable babies belonging to Black women (Roberts, 1997) and other women of color. Ceballo et al. (2015) highlighted how stratified reproduction in the policies that are created for the deserving White mother undermines the needs for poor and racial minority women. Thus, the absence of non-majority women in infertility treatment and research can be attributed to larger systemic racial inequalities.

Details about poor and racial minority women regarding infertility treatment have been identified. In response to the simultaneous overrepresentation of women of color among those with infertility and underrepresentation of their presence in treatment, Greil et al. (2011) used

path analysis in order to examine racial/ethnic differences among infertile women and those who receive medical services among 2,162 Black, White, Hispanic, or Asian American females. Their results revealed that when compared to White women, Black and Hispanic women receive fewer medical services, which was partly explained by less access to treatment, but also because they were less likely to have primary infertility. They were also less likely to have thought of themselves as actively trying to conceive, had less encouragement from family and friends to pursue treatment, placed less value on motherhood as an identity, and had greater ethical concerns about treatment for infertility (Greil et al., 2011). Regarding socioeconomic status, women with lower class backgrounds may avoid diagnosis altogether out of fear that a diagnosis will decrease their hopes of ever having a child (Bell, 2014). Schmidt et al. (2003) found that when lower class women do engage in fertility treatment, they tend to be more satisfied with their care than women of other social classes. The authors interpreted this finding as the clinic staff possibly being able to meet the needs of patients with fewer social resources or viewing medical staff with more reverence (Schmidt et al., 2003).

In order to understand a more encompassing picture of the psychology of infertility patients, inequalities in both treatment and research should be considered (Datta et al., 2016; Greil et al., 2010). A few studies have attempted to address issues with study design. Greil and McQuillan (2004) used a random sample of US women and identified 196 of the 580 with subfecundity, a term which the authors stated they used interchangeably with infertility. The sample was then divided further into subfecund women with intent to conceive and those without intent to conceive (Greil & McQuillan, 2004). Random sampling and delineating women who wanted to get pregnant from those who did not allowed the authors to capture voices from women who did not pursue treatment. Other studies (King, 2003; McQuillan et al., 2003, 2007;

Schwerdtfeger & Shreffler, 2009) have used non-clinic samples, allowing for a more representative glimpse at infertile women. Additional methodological concerns include questions of who should form the control groups (e.g., parents, voluntarily childless couples, or infertile couples never in treatment) and how attrition should be handled when couples drop out of treatment due to pregnancy or finances (Greil, 1997; Monach, 2003; Wischmann, 2008).

Lived experience of infertility. The cyclical emotional cost that infertility creates is often termed an ‘emotional roller coaster’ within the literature (Daniluk, 2001; Gray, 1996; Imeson & McMurray, 1996; Parry, 2004; Shapiro, 2009; van den Broeck, Emery, Wischmann, & Thorn, 2010; Watkins & Baldo, 2004). This metaphor describes the hope that is built up every month with the possibility of pregnancy, only to be shattered with disappointment by menstruation, which then resets the cycle (Imerson & McMurray, 1996; Johansson & Berg, 2005; Parry, 2004; Shapiro, 2009; van den Broeck et al., 2010; Watkins & Baldo, 2004).

A plethora of other emotions have been documented, including profound grief and loss, sadness, and pain (Daniluk, 2001; Johansson & Berg, 2005; McCarthy, 2008; Shapiro, 2009). An element of self-blame may be present, consisting of guilt, shame, or self-judgment (Bell, 2013; Ferland & Caron, 2013; Galhardo et al., 2011). Many women expect that they will be able to have children once they make the decision to enter into motherhood, resulting in a feeling of powerlessness or a lack of control over their situation (Bell, 2013; Imeson & McMurray, 1996). Johansson and Berg (2005), Daniluk (2001), Benasutti (2003), and McCarthy (2008) all reported women describing emptiness or that they felt incomplete, with one woman in Benasutti’s study using “horrible”, “awful”, and “humiliating” (p. 61) to describe her reaction to her infertility. Daniluk (2001) identified several components of her participants’ experience after deciding to end attempts at producing a child, which included futility and hopelessness, depletion, failure

and despair, ambiguity and dread of the future, and marginalization and isolation. In fact, isolation has been reported in other studies (Benasutti, 2003; Ceballo et al., 2015; McCarthy, 2008; Wirtberg, Möller, Hogström, Tronstad, & Lalos, 2007), with many women feeling displaced from normative social exchanges with other women (McCarthy, 2008). Some emotions even involve comparing oneself to others, such as experiencing inferiority compared to other women (Wirtberg et al., 2007) and feeling envious of people with children (Oddens et al., 1999).

Qualitative research on the lived experience of infertility for African American women has been limited; however, Ceballo et al. (2015) conducted a seminal qualitative investigation on the infertility experiences of fifty African American women, with a mean age of 37 and a range of educational backgrounds, occupations, and socioeconomic status. Silence and isolation was a salient theme for the participants, with 98% of the sample referring to silence or isolation in relation to her infertility at some point in her interview. While acknowledging the complexity of interacting factors, the authors offered five possible explanations for the women's sense of loneliness, isolation, or silence:

- (a) feelings of shame and personal failure; (b) a sense that other people would not understand; (c) cultural expectations about privacy in the African American community; (d) the cultural myth about African American women's strength, self-reliance, and ability to overcome challenges; and (e) the internalization of stereotypes promoting "Black sexuality with abundant fertility. (p. 507)

They also speculated that African American women are impacted by stereotypes of sexuality and fertility for Black women and images of infertility as a White woman's problem, to the extent that they end up contributing to their own marginalization and silence. Regardless of their demographic differences, the data revealed that African American women had similar experiences across all three domains formulated from the data: stereotypes/discrimination in medical settings (26%), gender identity related to the motherhood mandate (32%), and silence/isolation (98%)

(Ceballo et al., 2015). The first author later expanded on this study in an examination of her personal journey of conducting the research (Ceballo, 2017). Considerations for participants and researchers were discussed in regard to sensitively exposing emotionally challenging topics (Ceballo, 2017).

Much of the qualitative research on the lived experience of infertility describes the process or stages of the infertility journey (Benasutti, 2003; Ferland & Caron, 2013; Parry, 2004), living with involuntary childlessness (Bell, 2013; Daniluk, 2001), life after failed fertility treatments (Johansson & Berg, 2005; McCarthy, 2008; Wirtberg et al., 2007), and patient-centered fertility care (Cunningham & Cunningham, 2013). Generally speaking, the stages of infertility encompass the transitions that women encounter after learning of their condition. Ferland and Caron (2013) named the three stages they identified in their study as *finding out*, *living with it*, and *coming to terms*. Parry (2004) described four stages of the infertility journey that were shared by 30 infertile Canadian women. The first was *recognition of the problem*, in which the women explained how they found out and their reactions to their fertility issues. Most of the women described feelings of anger, frustration, anxiety, sadness, and disappointment. Next was *cautious optimism*. This stage consisted of decisions surrounding medical treatment and the resulting emotional ups and downs. The third stage was recognized as *the turning point*, during which one of two circumstances occurred: conception, or the realization that conception was impossible. If conception was deemed impossible, the women began the process of resolving their infertility, through shifting their perceptions of self-identity. Some women found relief during this time. Lastly, *forging new paths* was identified. During this stage, women explored new paths toward parenthood and broadened their definitions of family. Some women found ways to accept their childless status and seek other fulfilling avenues. Each woman went through the stages at

differing lengths of time depending on her unique experience and all of the women indicated there was a long-term impact that had in some way changed her forever (Parry, 2004).

Stages have also been described as women are moving toward adjustment to childlessness. Daniluk (2001) conducted four semi-structured interviews with 37 couples at 10-month intervals starting two months after they stopped trying to conceive. Four meta-themes of the transitional process were identified. The first, *hitting the wall*, consisted of the time when couples decided to end their attempts to have a child. Couples felt a mix of relief and profound grief, and uncertainty about the future. Next the couples began *reworking the past*, where they focused on making sense of the lost years and emotional and tangible costs of pursuing parenthood. The third stage was *turning toward the future*, where couples started to envision their lives without biological parenthood. Many couples were able to direct attention to themselves and their relationship, and described finding a sense of balance, control, and hope that a life without biological children could bring fulfillment. The last stage was *renewal and regeneration*, characterized by a heightened state of comfortability with themselves and their relationship, and a greater ability to see what they had gained. Couples were able to integrate infertility into their self-structures and create meaning of their experiences (Daniluk, 2001).

Involuntary childlessness resulting from failed fertility treatments remains a central theme in the lives of the affected women (Johansson & Berg, 2005; Wirtberg et al., 2007). McCarthy (2008) described women's infertility as an existential paradox, consisting of opposing perceptions such as both opportunity and loss, emptiness and fulfillment, and infertility as a "present absence" (p. 320). Infertility was thus determined to challenge a woman's sense of self, personal identity, and life meaning because it is a life-defining experience (McCarthy, 2008). The anticipated trajectory of family life is disrupted (Shapiro, 2009), leaving many men and

women out of sync with their peers throughout years of childbearing, parenthood, and eventual grandparenthood (McCarthy, 2008; Wirtberg et al., 2007). Finding meaning in the creation of a new self-identity can facilitate the long-term adjustment to infertility (Daniluk, 2001). This may include finding other ways to mother, especially children (Ferland & Caron, 2013; Parry, 2004), identifying a greater purpose in their infertility (Daniluk, 2001), accepting the state of being a non-parent (Matthews & Matthews, 1986; Wirtberg et al., 2007), and re-envisioning themselves as childfree (Parry, 2004; Wirtberg et al., 2007).

Gender differences, partner relationships, and sexual functioning. Gender differences in how men and women experience infertility have been documented. Given the societal pressures and gendered expectations for motherhood that are placed onto women, it is not surprising that women experience higher levels of stigma (Slade et al., 2007) and distress related to infertility than their male counterparts (Anderson et al., 2003; Galhardo et al., 2011; Lechner et al., 2007; McEwan et al., 1987; Monga et al., 2004; Peterson, Newton, & Rosen, 2003; Slade et al., 2007; Wischmann et al., 2001). Gender-biased assumptions that fertility issues must be the fault of the female place more of the burden on women than men (Bell, 2013, 2014; Galhardo et al., 2011; McEwan et al., 1987). Women feel guilty or blame themselves for not being able to get pregnant (Ferland & Caron, 2013), with lower class women more concerned that an infertility diagnosis will lead to her partner leaving the relationship (Bell, 2014). Some women take responsibility for the infertility, even if their infertility is unexplained or related to male-factor infertility only (Hlatshawyo, 2004; McEwan et al., 1987). In South Africa, it is rare for men to even have their infertility confirmed, as Hlatshawyo (2004) pointed out in an article about the infertility of Black South African women. For the women of this area of the world, infertility carries such stigmatization and humiliation that they may be coerced to enter into polygamous relationships or be

forced into sexual intercourse with other men to protect her husband's honor (Hlatshawyo, 2004). Women also tend to take on the responsibility for infertility treatment, including initiating treatment, making appointments, tracking ovulation, and buying medication (Daniluk, 2001; Shapiro, 2009). Concerning coping strategies in managing infertility stress, women have been found to use more confrontative coping, accepting responsibility, seeking social support, and escape/avoidance, whereas men use more distancing, self-control, and problem solving (Gibson & Myers, 2002; Peterson, Newton, Rosen, & Skaggs, 2006).

Issues that had a negative impact on the partner relationship have been identified as conversations being dominated by talk of having children and getting pregnant (Sundby et al., 2007), women feeling that their partners did not pay as much attention to infertility issues as they did (Sundby et al., 2007), miscommunication between partners (Read et al., 2014), incongruence of their appraisal of infertility-related stress (Peterson et al., 2003), and issues pertaining to adoption (Daniluk, 2001). Infertility and IVF can have a lasting negative impact on the relationship, even up to 10 years after ending treatment (Sundby et al., 2007). Some women (Bell, 2013; Benasutti, 2003; Ferland & Caron, 2013; Wirtberg et al., 2007) have implicated infertility as being the direct reason for their divorce or separation. All twelve participants in Ferland and Caron's (2013) qualitative analysis were married at the time they found out they were infertile, but by the time of their interviews 5 women were divorced. They each cited infertility as a major factor in their divorce. However, all of the 7 women who remained married stated that infertility had strengthened their marriage. They felt closer and more committed to their spouse than other couples they knew (Ferland & Caron, 2013).

Interestingly, there are several studies that document the positive effects that infertility can have on the couple relationship (Benasutti, 2003; Daniluk, 2001; Ferland & Caron, 2013;

Hammarberg et al., 2001; Peterson et al., 2003; Schmidt et al., 2005; Sundby et al., 2007). There is evidence that women show better adjustment to infertility and fertility treatment when they have an entrusting marital relationship (McEwan et al., 1987; Schmidt et al., 2003). Women have reported feelings of closeness and support from their partner, as well as an overall sense of a stronger relationship for having weathered the challenges of infertility and fertility treatment (Benasutti, 2003; Daniluk, 2001; Ferland & Caron, 2013; Hammarberg et al., 2001; Holter et al., 2006).

Descriptions of sexual functioning do not fare as well. Complaints about the negative impact on sexual functioning include the focus of sex shifting toward pregnancy (Daniluk & Tench, 2007; Imeson & McMurray, 1996; Sundby et al., 2007), sex on demand or being too scheduled (Benasutti, 2003; Daniluk & Tench, 2007; Ferland & Caron, 2013; Imeson & McMurray, 1996; Oddens et al., 1999; Sundby et al., 2007), sex feeling mechanical (Benasutti, 2003; Imeson & McMurray, 1996), sex being associated with failure (Daniluk, 2001), and sex is no longer fun or satisfying (Benasutti, 2003; Ferland & Caron, 2013; Oddens et al., 1999). Participants in a study by Wirtberg et al. (2007) discussed their lives 20 years after unsuccessful infertility treatment. All but one of the 14 Swedish women interviewed said that both their sexual life and sexual desire had been negatively affected by their infertility and fertility treatment. Four of the participants stated they later regained sexual desire, but nine stated their sexual life and desire were lost forever (Wirtberg et al., 2007). Sundby et al. (2007) reported that 10% of their participants ($N = 66$) said that infertility still had a negative influence on their sex life 10 years after IVF treatment. It is likely that sex problems are exacerbated by the challenges of transitioning to biological childlessness for those who have had unsuccessful fertility treatments (Daniluk & Tench, 2007).

Help-seeking and counseling. The infertility literature is full of recommendations that promote counseling and psychosocial services for those afflicted. However, despite the potential for psychosocial intervention to decrease depression, anxiety, and psychiatric morbidity for involuntary childless people (Boivin, 2003), numerous studies have demonstrated that help-seeking patterns of counseling services for infertile individuals are low (Boivin, Scanlan, & Walker, 1999; Ferland & Caron, 2013; Greil & McQuillan, 2004; Hammarberg et al., 2001; Kahlor & Mackert, 2009). For example, in Slauson-Blevins et al.'s (2013) study, the highest proportion of the sample ($N = 1,352$) did no help-seeking than pursued other methods (34%). Only 3% of the women ($N = 66$) in Sundby et al.'s (2007) study had professional counseling to deal with the emotional problems connected to their infertility, and none of the 12 participants in Ferland and Caron's (2013) qualitative analysis sought out professional counseling, despite many having endured life-long grief. Some studies have shown that a higher number of infertile patients would be open to counseling services if they were offered. The majority of 19 Canadian couples in a study by Read et al. (2014) said they wanted some form of psychosocial support, but only 9 couples actually sought counseling. Souter et al. (1998) stated that 57% of the 761 infertile women surveyed said they would attend infertility counseling if it was offered, but only 14% said they had been offered counseling by their outpatient clinics. It appears that women recognize the potential benefits of counseling, however a disparity exists between interest in counseling and actual use of services.

Women with infertility rely more on informal supports such as family and friends, before more formal support services like professional counseling (Boivin et al., 1999; Gibson & Myers, 2002; Greil & McQuillan, 2004; Kahlor & Mackert, 2009). Interestingly, Greil and McQuillan (2004) and Boivin et al. (1999) both documented 66% of their samples having discussed

infertility with family or friends, while 8% reached out to a counselor or therapist. Kahlor and Mackert (2009) reported slightly different numbers, with 32% of their sample of 567 infertile American women relying on counselors for infertility information and support. Informal supports were more utilized, with friends at 89%, partner or spouse at 88%, and family at 77%. Boivin et al. (1999) proposed two potential explanations: The possibility that individuals do not consider themselves to be distressed enough to require counseling services, and the possibility that individuals do not know how to initiate counseling. Both explications compel further discussion below.

First, while a smaller number of highly distressed infertile patients may benefit from counseling, the majority can likely cope effectively with the use of informal sources (Boivin, 1997). For them, less intense services such as written information, using the Internet, or confiding in family or friends, may be preferred (Boivin et al., 1999; Greil & McQuillan, 2004). In one study, participants reported high satisfaction with patient-centered care without any counseling, psychotherapy, or other professional psychosocial services, suggesting that it is possible to meet the needs of those with infertility without formal psychotherapy (Schmidt et al., 2003). It may be enough for some individuals and couples to know that psychosocial services exist, even if they never use them (Boivin et al., 1999; Wischmann et al., 2009).

Second, practical considerations have been identified as the most important reasons a counselor is not sought (Boivin et al., 1999; Read et al., 2014). These practical concerns include scheduling difficulties, potential cost, not knowing whom to contact, and a lack of information offered on support services for infertility (Boivin et al., 1999; Read et al., 2014). Ultimately, more diverse methods of helping infertile individuals can be introduced in order to meet their needs (Boivin et al., 1999; Read et al., 2014; Schmidt et al., 2003; Souter et al., 1998; Wirtberg et al., 2007). This may include developing models of counseling that foster empowerment and

strengthening personal resources (Wirtberg et al., 2007), providing more written information (Souter et al., 1998), or promoting peer mentorship, a person who would provide practical information in addition to emotional support (Read et al., 2014).

The suggestions for when counseling should be offered are varied. Some studies have recommended counseling be offered from the time women begin fertility treatment (Ferland & Caron, 2013), with acceptance rates rising up to 80% when counseling is integrated early (Emery et al., 2003). Wischmann et al. (2009) suggested that written information or video presentations on common emotional and psychosocial reactions to infertility, coping with infertility, and typical issues in infertility counseling should be administered at the start of treatment. Moreover, the authors stated that a low-threshold counseling offer of two sessions could be given at any stage of treatment, consisting of discussions related to infertility stress and providing information about additional psychological help, if necessary (Wischmann et al., 2009). A few studies have recommended that professional help should continue after treatment ends, particularly if it had failed in order to assist people to accept their involuntary childlessness (Daniluk, 2001; Lechner et al., 2007; Verhaak et al., 2005). Daniluk (2001) asserted that women were most in need of emotional and psychological support during the *hitting the wall* stage, when they were in the early process of adjusting to the permanence of their infertility. Another study did not specify when treatment should occur, instead asserting that counseling should be offered at any time during fertility treatment, not only when it failed (Wischmann et al., 2001).

Various counseling approaches appropriate for helping women and couples with infertility have been presented in the literature. One strategy proposed infertility counseling as a step-wise process, comprising of patient-centered care, infertility counseling, and psychotherapy (Peterson et al., 2012). The Heidelberg Fertility Consultation Service has also been identified as

a framework for counseling individuals and couples with specific considerations regarding infertility (van den Broeck et al., 2010). Peterson and Eifert (2011) used Acceptance and Commitment Therapy (ACT) to treat one couple with infertility stress following a failed IVF procedure in a single case study. Through mindfulness, acceptance strategies, and value-directed action, this preliminary study revealed that ACT shows potential to treat infertility stress after failed treatment and maintain therapeutic gains one-year post-therapy (Peterson & Eifert, 2011).

Other researchers have described useful techniques and interventions for infertility counseling. Several authors have discussed methods for addressing specific cognitions in psychotherapy related to stigma or childlessness (Fekkes et al., 2003; Slade et al., 2007; Verhaak et al., 2005). Another study encouraged action-oriented, problem-focused coping strategies for women coping with permanent childlessness (Daniluk & Tench, 2007). Bray (2015) recommended several explicit therapeutic techniques that counselors can implement with affected clients. These techniques included storytelling and narrative therapy, the empty chair approach, journaling and letter writing, expressive arts, and externalizing the problem, among others. Externalizing the problem has been noted elsewhere, along with creating an alternative dominant discourse and use of culturally based rituals as therapeutic tools (Burnett, 2009).

It is important for counselors to take cultural considerations into account when working with infertile women (Burnett, 2009; Peterson et al., 2012). Culturally sensitive assessments and interventions for infertility will provide more effective therapy to women and couples seeking treatment (Burnett, 2009). Raque-Bogden and Hoffman (2015) assert that a systems-based framework would be helpful in further research to examine the role of cultural expectations, and help women deconstruct social concerns and stigmas of infertility. The social stigma surrounding infertility is often compounded by the stigma of mental health (Read et al., 2014). Some women

may use the Internet as a means to avoid the stigma of infertility (Bunting & Boivin, 2007; Slauson-Blevins et al., 2013), since in recent years with technological advances, the Internet (Greil & McQuillan, 2004; Kahlor & Mackert, 2009; Slauson-Blevins et al., 2013) and telephone counseling (Barlam & McLeod, 2000; Wischmann, 2008) have become viable sources of support and information.

Finally, a recent paradigm shift in infertility care involves integration between medical and mental health professional services (Boivin et al., 2012; Boivin & Gameiro, 2015; Cunningham & Cunningham, 2013; Dancet et al., 2013; Peterson et al., 2012). Born from recognition of the challenges that patients face during treatment and limitations of current psychological interventions, collaboration is intended to create new psychosocial patient supports (Boivin & Gameiro, 2015). Boivin et al. (2012) proposed an integrated approach to infertility care, which targets three treatment sources for integration. These areas are the patient, the medical treatment, and the clinical environment (Boivin et al., 2012). Cunningham and Cunningham (2013) proposed a relational model of infertility care, connecting the patient to different dimensions of the personal and social contexts, relationships in which they live, and the role of clinical practice. However, despite the movement toward integrated care, Monach (2003, 2013) notes that there is much room for advancement regarding the inclusion of counselors on multidisciplinary teams.

Miscarriage

Definitions and Statistics

A miscarriage is the loss of a fetus at or before the 19th week of pregnancy (CDC, 2017b, 2017c; March of Dimes, 2017; NIH, 2018). Medical terminology may also refer to miscarriage as spontaneous abortion (NIH, 2018). At the 20th week of pregnancy and beyond, the loss of a

fetus is considered a stillbirth (CDC, 2017b, 2017c). Stillbirths are further categorized as early (fetal death that occurs between 20 and 27 weeks gestation), late (between 28 and 36 weeks gestation), and term (between 37 weeks gestation and birth) (CDC, 2017b). This dissertation will focus only on miscarriage experiences, and thus only on fetal loss that occurred at or before the 19th week of gestation.

The exact number of miscarriages is unknown because many miscarriages occur very early in the pregnancy, before the woman is aware that she is pregnant (March of Dimes, 2017; NIH, 2018). It is estimated that up to half of all pregnancies end in miscarriage, but of known pregnancies, approximately 10-15% end in miscarriage (March of Dimes, 2017). The majority of miscarriages occur in the first trimester, before the 12th week of gestation (March of Dimes, 2017). A miscarriage during the second trimester, which is between 13 and 19 weeks gestation, occurs in 1-5% of pregnancies (March of Dimes, 2017). According to the March of Dimes (2017) repeat miscarriages, or recurrent pregnancy loss, occurs when a woman has two or more miscarriages in a row. Approximately 1% of women have repeat miscarriages.

The etiology of miscarriage is not always known. Potential causes of miscarriage can be attributed to chromosomal abnormalities (March of Dimes, 2017; NIH, 2018), uterine or cervical problems (March of Dimes, 2017; NIH, 2018), infections such as STIs or listeriosis, a type of food poisoning (March of Dimes, 2017), and chronic diseases such as PCOS (NIH, 2018). Of the women who have repeat miscarriages, about 75% have an unknown cause (March of Dimes, 2017). Risk factors for miscarriage include two or more previous miscarriages, age, smoking, alcohol or drug use, and certain health conditions such as autoimmune diseases, obesity, pre-existing diabetes, thyroid issues, and some prenatal tests (e.g., amniocentesis) (March of Dimes, 2017).

Signs and symptoms of miscarriage include vaginal bleeding or spotting (March of Dimes, 2017; NIH, 2018), cramping (March of Dimes, 2017; NIH, 2018), severe abdominal pain (March of Dimes, 2017; NIH, 2018), and the vaginal passing of fluid or tissue (NIH, 2018). Recommended treatment for a miscarriage may involve medicine or a dilation and curettage procedure, also known as a D&C, to remove any remaining tissue in the uterus (March of Dimes, 2017; NIH, 2018). When the miscarriage occurs early in the pregnancy treatment is usually not required (NIH, 2018). Physical recovery from a miscarriage can range from a few weeks to over a month. Many women have a menstrual cycle within 4-6 weeks after a miscarriage (March of Dimes, 2017). The emotional recovery is often longer because of the strong feelings of grief and loss after the fetal death (March of Dimes, 2017). The point at which a woman decides to begin trying for another pregnancy varies based on her own physical and emotional recovery, but many women who have a miscarriage go on to deliver healthy babies in the future (March of Dimes, 2017; NIH, 2018).

The Study of Miscarriage

Sociocultural context. The majority of American men and women view fatherhood and motherhood as a fulfilling endeavor (Thornton & Young-DeMarco, 2001) and women often put a great amount of effort into planning their pregnancy and preparing for the new arrival (Adolfsson, 2010). A variety of cultural rituals may take place; for example, pregnancy is often socially celebrated with baby showers or gender reveal parties. These events are ordinarily planned especially if it is a woman's first pregnancy and represent important rites of passage (Layne, 2000, 2013). Lindemann (2015) noted a rise in middle-class women making entire projects out of their pregnancies, including reading books (e.g., *What to Expect When You're Expecting*), visiting pregnancy or mommy blogs, and participating in prenatal yoga. During

pregnancy, the transition to motherhood begins as the woman adopts her new maternal identity (Mercer, 2004) and starts constructing the personhood of her would-be child (Layne, 2000, 2013; Lindemann, 2014, 2015; Mullin, 2015). She may engage in behaviors such as following the physiological development of the fetus, acquiring items for the “baby”, giving the fetus a name or nickname, talking to the fetus, and attempting to inspire personality by playing music (Layne, 2000). She may envision her delivery within the well-established cultural script of beautiful pregnant women who give birth in a loving, supportive setting to babies who are healthy and ready to bond and nurse with the mother (Layne, 2003). A miscarriage defies the cultural expectation and disrupts this process of creating maternal and fetal identity, leaving the woman abruptly excluded from the social status as a pregnant woman (Carolan & Wright, 2017; Corbet-Owen & Kruger, 2001; Layne, 2000; Lindemann, 2015).

Pregnancy is a socially constructed event and has different meanings to different women based upon the significance that they attach to it (Corbet-Owen & Kruger, 2001). How a woman experiences her pregnancy—and therefore how she experiences her miscarriage—is influenced by factors such as whether the pregnancy was known or unknown, planned or unplanned, and wanted or unwanted (Corbet-Owen & Kruger, 2001; Flink-Bochacki, 2017; Shreffler, Greil, & McQuillan, 2011). Gerber-Epstein, Leichtentritt, and Benyamini (2008) revealed that women described the first weeks of a planned pregnancy with “excitement, optimism, and delight” (p. 10). It was a time when reality and fantasy began to come together to form the new family and future that a baby would bring. In order for the devastation of a miscarriage to be fully comprehended, an understanding of the joy and anticipation that engulfed the first few weeks of a planned pregnancy is necessary (Gerber-Epstein et al., 2008).

The impact of the miscarriage is comparative to the desire for the pregnancy (Gerber-Epstein et al., 2008), such that women who miscarry wanted pregnancies face greater distress than women who miscarry unwanted pregnancies (Corbet-Owen & Kruger, 2001; Neugebauer et al., 1992; Shreffler et al., 2011). The eight South African women who participated in Corbet-Owen and Kruger's (2001) qualitative study experienced their pregnancies on a continuum from wanted ($n = 5$) to unwanted ($n = 3$). The women who miscarried wanted pregnancies described pregnancy as "normal, natural, and an inevitable part" (p. 416) of being female and a dutiful partner, and consequently felt marginalized and inadequate when the pregnancy was lost. Pregnancies that were not wanted left the women feeling desperate and uncertain, and resulted in relief when the pregnancy ended. However, positive feelings were also sullied by regret and shame, which the authors speculated could be related to cultural taboos about negative attitudes toward pregnancy. Irrespective of where the women placed themselves on the continuum, their immediate needs after the miscarriage were similar (Corbet-Owen & Kruger, 2001). The context that surrounds the pregnancy is an important component to how the woman experiences her miscarriage.

Increased medicalization over the last several decades has shifted perceptions of pregnancy and childbirth from a natural state to one that requires constant surveillance of maternal behavior and the fetus (Fordyce, 2013; Lupton, 2012; Ross, 2015). Pregnant women are encouraged to engage in some behaviors (e.g., getting extra sleep, monitoring mental health and prenatal care) and to avoid others altogether (e.g., consuming caffeine, lying on her back) in order to preserve the health of the unborn would-be child (Fordyce, 2014; Lindemann, 2015; Lupton, 2012). This rhetoric implies that women have and should take individual control over their own body and pregnancy (Layne, 2003; Lindemann, 2015; Lupton, 2012) and bear the responsibility

for the well-being and development of the fetus (Bell, McNaughton, & Salmon, 2009; Fordyce, 2014; Lupton, 2012). One hundred and seventy-two narratives of miscarriage thematically analyzed by Simmons, Singh, Maconochie, Doyle, and Green (2006) revealed that many women attempted to create the ideal environment when planning their pregnancies. These efforts included a vitamin regime, limiting alcohol and tobacco intake, monitoring healthy eating, and even avoiding cats, chickenpox infection, and discontinuing anti-depressant medication. Women also emphasized the importance of a long-standing relationship, adequate home and income, and intentions to decrease work hours and associated stress. Those who had planned for pregnancy considered themselves to be deserving of motherhood, while women who did not used their lack of preparation as reasoning for the miscarriage (e.g., “I had not been taking any extra care with diet or alcohol or caffeine intake as I had with pregnancies which were successful” [Simmons et al., 2006, p. 1940]). These narratives demonstrate the responsibility women feel for fetal health, which consequently puts them at risk for maternal blame and self-blame when something goes wrong (Abbound & Liamputtong, 2002; Layne, 2003; Lindemann, 2015). Even the terms ‘lost pregnancy’ or ‘failed pregnancy’ place personal agency onto the woman because it is implied that the pregnancy was lost by someone (Reiheld, 2015). Furthermore, Simmons et al. (2006) identified from the narratives a sense that motherhood is a sort of personal right—that “if you really want a child you should be able to have one” (p. 1939). Increased medicalization and breakthroughs with ARTs have redefined traditional expectations of motherhood and propels the notion that anyone can have a baby (Lupton, 2012; Simmons et al., 2006). Many women expect that their pregnancies will go smoothly (Layne, 2003; Simmons et al., 2006) and believe that miscarriage itself is a rare event (Bardos, Friedenthal, & Williams, 2013).

An over-reliance on medical technology (Klier, Geller, & Ritsher, 2002) may prompt many women to expect to receive a reason for what caused the miscarriage, and lead them to search for an explanation when one is not provided (see, e.g., Abboud & Liamputtong, 2002; Adolfsson, Larsson, Wijma, & Bertero, 2004; Corbet-Owen & Kruger, 2001; Simmons et al., 2012). Abboud and Liamputtong (2002) and Adolfsson et al. (2004) both conducted phenomenological studies which revealed that when a medical explanation is not given, women will develop their own causal beliefs about why the miscarriage occurred. Adolfsson et al. (2004) noted specific rationalizations which included emotional stress, smoking, too much or too little physical exercise, lifting heavy items at work, and one woman who claimed she inhaled exhaust fumes due to car trouble. A woman from Abboud and Liamputtong's (2002) study claimed that she had been blamed for the miscarriage by others so extensively that she eventually developed a belief that she had killed her baby. Similarly, the eight women interviewed in Corbet-Owen and Kruger's (2001) study discussed the empowerment that came with explanations from their doctor and the converse tendency to self-blame when there was no apparent reason for the miscarriage. Women furthermore described feeling inadequate, defective, and heartbroken (Corbet-Owen & Kruger, 2001). These accounts describe the implications of having or not having a medical explanation for the loss, which proves to be a defining aspect of the miscarriage experience.

Despite pregnancy loss being a relatively common occurrence, a cultural, interpersonal, historical, and academic silence remains (Layne, 2013; Miller, 2015), and no explicit scripts exist that delineate the social roles and interactions to take place after a miscarriage (Carolan & Wright, 2017; Layne, 2013; Reiheld, 2015). For example, sympathy cards may be sent to someone who lost a loved one or even a pet, but no such acknowledgment or support is sanctioned when one suffers a pregnancy loss; it is simply "not *customary* to do so" (Layne, 2013, p. 69,

italics included in original text). Women may refrain from telling others about their pregnancy before the end of the first trimester in order to avoid relaying news of a miscarriage (Abboud & Liamputtong, 2002; Layne, 2013; Ross, 2015). When early pregnancy is disclosed, women may eschew telling wider social networks beyond immediate family or may qualify the news with an acknowledgement that a full-term pregnancy is not guaranteed at this point (Ross, 2015). Miscarriage is poorly addressed by society because of the liminal nature that imbues the fetus and pregnant woman (Layne, 2013; Miller, 2015; Reiheld, 2015). Liminality represents transition from one social role to another and is a metaphorical, ambiguous place that wavers betwixt and between two worlds (Beech, 2011; Carson, 2002; Turner, 1967). The affected woman finds herself in a murky space of both having procreated and not having procreated; she is both a parent and a non-parent to the child who was lost (Reiheld, 2015). This is a markedly dissimilar experience to that of infertility, in which the would-be child or parental status has not yet been established (Reiheld, 2015).

Miscarriage is closely tied to taboo topics such as sex (Murphy & Merrell, 2009) and death (Murphy & Merrell, 2009; Reiheld, 2015), and the overlapping dimensions of miscarriage with the stigmatized subject of abortion (Layne, 2013; Miller, 2015; Reiheld, 2015) make it sticky territory for open discussion. Miscarriage and abortion are often entangled through language (e.g., spontaneous abortion, Hahn et al., 2015; Jacob, Polly, Kalder, & Kostev, 2017; NIH, 2018), legislation (*Mississippi v. Buckhalter*, 2012), issues regarding fetal abnormalities (Keefe-Cooperman, 2005; Ross, 2015), and medical procedures (e.g., D & C, Reiheld, 2015). Miller (2015) outlined two possible reasons for miscarriage silence. One is based upon the ease that miscarriage can be entrapped within abortion politics. Conversations around personhood may grant the fetus a moral standing that makes feminists and other groups that support women's

interests hesitant to enter into discussions about miscarriage in order to avoid inadvertent support of anti-choice efforts. Comparably, Berg (2017) suggested that if those who oppose abortion and believe life begins at conception were to focus their efforts on preserving life through the prevention of miscarriage (which ends pregnancies at a much higher rate than abortion), it would actually shift attention away from abortion because miscarriage would, in theory, be a much bigger public health crisis. Thus, parties on both ends of the pro-life and pro-choice spectrum may have an interest in evading conversations about miscarriage. The second reason for miscarriage silence purported by Miller (2015) is because miscarriage is difficult to conceptualize and categorize, which makes ethical boundaries hard to navigate. In other words, the liminal nature and ‘inbetweenness’ of miscarriage sustains the culture in which miscarriage is to remain a silent and invisible event (Miller, 2015).

Psychological reactions. Women who experience a miscarriage have reported higher rates and risk of depression (Ambriz-Lopez et al., 2018; Beutel, Deckardt, von Rad, & Weiner, 1995; Broen, Moum, Bödtker, & Ekeberg, 2006; Jacob et al., 2017; Klier, Geller, & Neugebauer, 2000, Klier et al., 2002; Kulathilaka, Hanwella, & de Silva, 2016; Lok & Neugebauer, 2007; Lok, Yip, Lee, Sahota, & Chung, 2010; Mutiso, Murage, & Mukaindo, 2018; Neugebauer et al., 1992; Neugebauer & Ritsher, 2005; Sham, Yiu, & Ho, 2010; Swanson, 2000), anxiety (Ambriz-Lopez et al., 2018; Broen et al., 2006; Cumming et al., 2007; Geller, Kerns, & Klier, 2004; Jacob et al., 2017; Lok & Neugebauer, 2007), adjustment disorder (Jacob et al., 2017), and post-traumatic stress disorder (Engelhard, van den Hout, & Arntz, 2001; Farren et al., 2016) in the weeks and months following the loss when compared with other groups of women. Quantitative research on the relationship between miscarriage and mental health began to rise in the 1990s (Radford & Hughes, 2015), when implementation of controlled studies began (Klier et al., 2002). This early

research used control groups consisting of pregnant and/or women from the community (Beutel et al., 1995; Neugebauer et al., 1992; Thapar & Thapar, 1992) and revealed an elevated likelihood for symptoms and caseness of depressive disorder (Klier et al., 2002).

The immediate days and weeks after miscarriage are a sensitive and vulnerable time for women. Mutiso et al. (2018) conducted a cross-sectional analysis of exposure to miscarriage and the outcome of depression among 182 women who were recruited from the gynecology center of a Kenyan university teaching hospital. Fourteen days post-miscarriage, a prevalence of depression was found in 34.1% of the sample, with the authors noting that this finding was among the highest in recent literature. Of those women, about one-third had thoughts of self-harm. While the women indicated that these thoughts were rare, the authors asserted that any thoughts of self-harm are concerning and warrant further research (Mutiso et al., 2018). Another recent study conducted in Mexico by Ambriz-Lopez et al. (2018) consisted of 120 patients taking the Hospital Anxiety and Depression (HADS) scale within 10-14 days after a miscarriage that required surgical treatment of either MVA (manual vacuum aspiration) or D&C (dilation and curettage). Anxiety or depressive symptoms were present at some degree for 41.7% of the sample. This study and others (Broen, Moum, Bodtker, & Ekeberg, 2005, 2006; Lok et al., 2010; Neugebauer et al., 1992; Neugebauer & Ritsher, 2005; Séjourné, Callahan, & Chabrol, 2010) suggest that the time immediately following a miscarriage is crucial for women. The first follow-up visit within six weeks of loss may be an appropriate time to screen for signs of depression (Klier et al., 2000) and general mental health well-being.

Distress tends to decrease as time goes on after the loss with most women showing rates of depression and anxiety comparable to that of controls or the general population between six and twelve months after the miscarriage (Broen et al., 2005, 2006; Farren et al., 2016; Lok et al.,

2010). Lok et al. (2010) looked at 280 women with miscarriage and 150 non-pregnant women with the 12-item General Health Questionnaire (GHQ-12) and the Beck Depression Inventory (BDI). Immediately after the miscarriage, the percentage of participants who scored high on the GHQ-12 was 55% and 26.8% on the BDI. These scores remained statistically significant at 3 months (25% for GHQ-12 and 18.4% for BDI) and 6 months (17.8% for GHQ-12 and 16.4% for BDI). The numbers became non-significant after one year, at which they were comparable with controls at 10.8% for the GHQ-12 and 9.3% for the BDI (Lok et al., 2010). In one long-term study, women reported statistically significant levels of anxiety and depression ten days after miscarriage, but at six-month, two-year, and five-year follow-up evaluations, their scores were not different from general population comparisons (Broen et al., 2006).

An important study by Farren et al. (2016) revealed that PTSD was more prevalent and persisted longer than either depression or anxiety. A cohort study of 186 women was created in order to better understand psychological morbidity after loss so that appropriate support can be provided. There were 128 women with early pregnancy loss of either miscarriage or ectopic pregnancy who were evaluated at one month and 3 months post-loss, and 58 women with ongoing pregnancies who served as the control group. At one month, the women who had suffered a pregnancy loss reported rates of psychiatric morbidity for depression at 16%, anxiety at 32%, and probable PTSD at 28%. At three months, the rates for depression and anxiety had decreased (5% and 20%, respectively), but PTSD persisted and grew to 38%. The majority of women who did not meet full criteria for PTSD still indicated experiencing all symptom clusters and deficiency in social and occupational functioning. No women in the control group met criteria for PTSD and only 10% met criteria for depression and anxiety (Farren et al., 2016). This reporting

of PTSD after pregnancy loss is higher than what has been found in previous studies (Engelhard et al., 2001; Sham et al., 2010).

Certain risk factors place women at a higher likelihood to develop mental health disorders. Childlessness (Lok & Neugebauer, 2007; Neugebauer et al., 1992), low social support (Lok & Neugebauer, 2007; Swanson, 2000), and a history of mental health (Lok & Neugebauer, 2007; Sham et al., 2010) and fertility problems (Sham et al., 2010; Shreffler et al., 2011) have been commonly identified. Additionally, a variety of other risk factors have been established, such as high personal significance attached to the miscarriage, lower emotional strength, use of passive coping strategies, lower income, no further pregnancies or births by one year after the loss (Swanson, 2000) and being younger in age (Sham et al., 2010). Shreffler et al. (2011) reported characteristics that were associated with higher distress after pregnancy loss, including a current desire for a baby, placing a strong value on motherhood, and knowing the cause of the miscarriage. This last finding surprised the authors and is counter to qualitative accounts that women long for answers when a medical explanation is not given (Corbet-Owen & Kruger, 2001; Simmons et al., 2012). Shreffler et al. (2011) postulated that knowing the cause might still lead women to blame themselves even if the loss was not within their control, a finding that is similar to some results of infertility research (Greil, 1991; McEwan et al., 1987).

While the aforementioned studies provide important information about the psychological and psychiatric impact of miscarriage on women, there are precarious methodological problems within miscarriage research that complicate generalizability and make studies difficult to compare (Klier et al., 2002). The first is how mental health disorders are measured; some studies report the rate of disorders after miscarriage (see, e.g., Jacob et al., 2017; Lok et al., 2010; Neugebauer & Ritsher, 2005; Sham et al., 2010), whereas others report the level of psychiatric symptoms or

distress (see, e.g., Ambriz-Lopez et al., 2018; Neugebauer et al., 1992; Shreffler et al., 2011). Klier et al. (2002) asserts that reducing emotional anguish to caseness implies a diagnostic dichotomy (one either has a disorder or they do not) while ignoring the continuum upon which emotions are experienced. A miscarriage may have been distressing and significant even if the person did not meet specific diagnostic criteria, so while quantitative investigation on both psychiatric symptoms and disorders is essential, the results do not equate exactly (Klier et al., 2002).

Second, research has administered evaluations for women at varying lengths of time after the miscarriage, including four weeks (Neugebauer et al., 1992), three months (Sham et al., 2010), six months (Klier et al., 2000), and one year (Jacob et al., 2017; Lok et al., 2010). This variation in timing also poses challenges in comparing results (Klier et al., 2002). Third, selection of participant samples and control groups has been a concern. Corbet-Owen & Kruger (2001) noted that many samples might be biased due to self-selection. They surmised that women who chose to participate in studies had a significant miscarriage experience, meaning that women who were not impacted negatively by their miscarriage are not as represented. Shreffler et al. (2011) noted that many samples in pregnancy loss research come from clinics or are otherwise non-representative of all women. They attempted to remedy this in their study by using a nationally representative sample of 1,284 women (Shreffler et al., 2011). Regarding control groups, a major concern is how to define and select them to appropriately match women who have had a miscarriage so that comparisons can be made (Jacob et al., 2017). Previous studies have used pregnant women (Jacob et al., 2017; Kulathilaka et al., 2016), non-pregnant women (Lok et al., 2010), and women who have elected to have an abortion (Broen et al., 2005; Keefe-Cooperman, 2005) as comparison or control groups.

Lastly, research studies and miscarriage literature have used an assortment of inconsistent definitions (Klier et al., 2002) that pose challenges for generalizability and transferability. Scholars have used fetal death at or before 16 weeks (Adolfsson, 2010; Adolfsson et al., 2004; Hutti & dePacheco, 1998), 20 weeks (Farren et al., 2016; Jacob et al., 2017; Musters, Taminiau-Bloem, van den Boogaard, van der Veen, & Goddijn, 2011; Swanson, 2000), 22 weeks (van den Akker, 2011), 23 weeks (Sham et al., 2010), 24 weeks (Jacobs & Harvey, 2000; Lok et al., 2010; Meaney, Corcoran, Spillane, & O'Donoghue, 2017), and 28 weeks gestation (Klier et al., 2000; Kulathilaka et al., 2016; Neugebauer et al., 1992; Neugebauer & Ritsher, 2005) as definitions of miscarriage and cutoff points for recruitment criteria in quantitative and qualitative research and literature reviews. While some of this variation may be due to international and cultural differences in how miscarriage is conceptualized and defined, even studies conducted in the United States vary from the medical definition of miscarriage as fetal loss at or before 19 weeks of gestation (Klier et al., 2000; Neugebauer et al., 1992).

Lived experience of miscarriage. Some qualitative accounts of miscarriage begin with descriptions of attitudes toward the pregnancy. Whether the pregnancy was planned or unplanned, women felt happy, excited, in control, and content that their dreams were becoming actualized (Abboud & Liamputtong, 2002; Gerber-Epstein et al., 2008). The absence of healthy pregnancy signs (e.g., sickness, food cravings, tender breasts, tiredness) may be the first indicator that something is wrong (Adolfsson et al., 2004; Simmons et al., 2006). Physical symptoms of abdominal pain or cramping and vaginal blood loss may appear and have been recorded in many women's stories of their miscarriage experience (Adolfsson et al., 2004; Adolfsson, 2010; Leach, Wojnar, & Pettinato, 2014; Murphy & Merrell, 2009; Radford & Hughes, 2015). All of the 13 Swedish

participants in Adolfsson's (2010) interpretive phenomenology could describe with vivid detail the exact location they were at the moment they realized they were losing the pregnancy.

Upon the recognition that they are in need of medical attention, women are then admitted to the hospital so that they can undergo an examination or ultrasound scan (Adolfsson, 2010; Leach et al., 2014; MacWilliams et al., 2016; Murphy & Merrell, 2009). The confirmation of the miscarriage diagnosis is important to the women (Murphy & Merrell, 2009) and allows them to move past denial that the loss occurred (Adolfsson, 2010). This trip to the hospital is a central part of the miscarriage experience because it denotes the ending of the previous identity as a pregnant woman (Murphy & Merrell, 2009). Unfortunately, many women have described negative aspects of the medical visit, primarily related to the hospital setting and their interactions with staff (Abboud & Liamputtong, 2005; Adolfsson et al., 2004; Adolfsson, 2010; Corbet-Owen & Kruger, 2001; Leach et al., 2014; MacWilliams et al., 2016; Meaney et al., 2017; Murphy & Merrell, 2009; Simmons et al., 2006).

Properties of the physical space the women occupy while waiting for treatment can exacerbate distress (Meaney et al., 2017; Simmons et al., 2006). Women are often left in a ward full of other patients who may include pregnant women (Meaney et al., 2017), new mothers, and those seeking sterilization or voluntary abortions (Simmons et al., 2006). This was considered to be one of the hardest parts of the miscarriage for the women in Meaney et al.'s (2017) study, as they felt they could not openly express the emotions they were dealing with so as to not upset others around them. The women are acutely aware that they are experiencing loss, which separates them from everyone else in the room and leads to feeling as if they do not belong (MacWilliams et al., 2016). Further consternation arises from noticing they are low priority patients and must endure a prolonged waiting time (Adolfsson, 2010; Leach et al., 2014;

MacWilliams et al., 2016; Murphy & Merrell, 2009). Adolfsson et al. (2004) reported women waiting from one and a half to four hours before receiving treatment. Additional distress was described by Meaney et al. (2017) once the women were admitted for care. Only a curtain separated them from other staff, which enabled them to hear fetal monitors or conversations about their miscarriage. The women believed this atmosphere heightened their emotional stress and they felt that more sensitivity could be given to their situation by providing them a more private space (Meaney et al., 2017). Murphy and Merrell (2009) reported the testimony of one woman who was given a private room prior to surgical intervention, who claimed that it was positive to have a place to cry but it also meant that she was isolated away because no one came in to talk to her.

The interaction with medical staff takes a pivotal role in shaping the perceptions of the care a woman received (MacWilliams et al., 2016; Murphy & Merrell, 2009; Simmons et al., 2006). Many women sense they are unimportant to medical staff and their case is non-urgent, evidenced by body language and comments (e.g., “She has only had one miscarriage, and it’s not remarkable” [Adolfsson et al., 2004, p. 557]). Health care professionals have been characterized as indifferent and unsympathetic (Adolfsson, 2010; Corbet-Owen & Kruger, 2001; Leach et al., 2014; Simmons et al., 2006), with five of the eight women in MacWilliams et al.’s (2016) study viewing the delivery of the official diagnosis as abrupt, cold, and insensitive. Abboud and Liamputtong (2005) reported mixed responses regarding satisfaction with health care after miscarriage in their qualitative report with six ethnic women and their male partners. Women were generally more dissatisfied with their health care if it was in public services and complaints about hospital staff were often regarding errors or mistakes that were made. One woman described receiving conflicting information from different providers, which left her and her partner

confused about what to do. Another woman was told that everything was fine during her pregnancy with twins before learning that one of the twins had in fact passed away. Other complaints about hospital staff included doubt about what to expect and disputes over how the women wanted the remains to be handled. The women with privatized care had more adequate experiences. General practitioners seemed to be more accessible, personal, and understanding of the woman and her needs. The authors reported only one positive interaction with public health staff, which was the warmth, sympathy, and sincerity of a doctor performing an ultrasound who was able to reassure the woman in her moment of need (Abboud & Liamputtong, 2005). The few positive interactions with certain members of the medical community described by women in an Australian study were due to the sensitivity and emotional support provided by medical staff (Rowlands & Lee, 2010).

The above summarization of the trip to the hospital denotes the clash between medical involvement and the psychological repercussions after miscarriage (Klier et al., 2002; Simmons et al., 2006). On one hand, increased medicalization has reconceptualized pregnancy as a problematic disorder that requires surveillance of the maternal body and the at-risk fetus (Barker, 1998; Fordyce, 2013; Lupton, 2012). Women are expected to engage in prenatal care and could even be criminally prosecuted for purportedly harming the fetus by refusing obstetric interventions (Lupton, 2012). Advances in technology allow women to learn of their pregnancies earlier on and have thus increased both expectations of and reliance on medical care (Simmons et al., 2006).

On the other hand, there is a disregard for the experiential perspective from the women who feel frustrated that their needs or concerns are not met by the doctors and medical professionals they are working with (Barker, 1998; Rowlands & Lee, 2010; Simmons et al., 2006).

One woman experienced conversations with her doctor as very factual, with little acknowledgement that what she was going through was an emotional event (MacWilliams et al., 2016). Another participant from Leach et al.'s (2014) analysis stated that her obstetrician never offered condolences for her loss, to which she felt that even "dogs are a lot nicer, quite honestly, when they see someone grieve" (p. 14). Qualitative accounts from nurses' perspectives reveal that they recognize the emotional weight that women bear after a miscarriage but are limited by standards of care that create obstacles for meeting women's emotional needs (e.g., not having the time to sit and talk with them) (Murphy & Merrell, 2009). Some women suspect that staff do not realize they are experiencing loss instead of an illness and simply do not know how to offer support (MacWilliams et al., 2016; Simmons et al., 2006). Corbet-Owen and Kruger (2001) asked why medical professionals are not able to hear the experiences of their patients after miscarriage. They surmised that the medical hierarchy, under which the doctor is seen as the authority, is fueled by three factors: training (which emphasizes brief, intellectual rather than emotive communication); assumptions shaped by medical knowledge, personal beliefs, and cultural expectations; and women placing trust in the doctor rather than her own intuition because of power dynamics. The authors concluded that doctors can increase their understanding of patient experiences by setting aside their own suppositions and listening to the patient as the storyteller of their own concerns (Corbet-Owen & Kruger, 2001). Ultimately, the recognition of miscarriage as a valid loss is an acknowledgment that many women desperately seek from their physicians (Meaney et al., 2017; Rowlands & Lee, 2010; Simmons et al., 2006) and may even lead to healthier adjustment (Corbet-Owen & Kruger, 2001; MacWilliams et al., 2016).

In the aftermath of a miscarriage, women must cope with the transition of settling into life post-loss, and many struggle to manage the plethora of emotions that remain (Abboud &

Liamputtong, 2002; Gerber-Epstein et al., 2008; Leach et al., 2014; MacWilliams et al., 2016; Murphy & Merrell, 2009). Abboud and Liamputtong (2005) found that women used both physical strategies (e.g., resting, staying busy, looking after other children) and psychological strategies (e.g., convincing themselves the miscarriage was not their fault) as coping tactics. Meaney et al. (2017) also showed that keeping busy and caring for other children in the family was helpful for their participants. For some women, bringing a sense of normalcy back into their routine assists them in moving forward, but other women find this nearly impossible (Gerber-Epstein et al., 2008; Murphy & Merrell, 2009).

Most qualitative studies on the lived experience of miscarriage have included discussion about how women gain support during this time (Abboud & Liamputtong, 2005; Corbet-Owen & Kruger, 2001; Gerber-Epstein et al., 2008; Leach et al., 2014; MacWilliams et al., 2016; Meaney et al., 2017; Simmons et al., 2006) but the information has yielded mixed findings. Similar to what infertility research has demonstrated (Boivin et al., 1999; Gibson & Myers, 2002; Greil & McQuillan, 2004; Kahlor & Mackert, 2009), Meaney et al. (2017) found that women preferred support from family and friends over formal support such as counseling. Abboud and Liamputtong (2005) reported that mothers and sisters specifically were recognized as very supportive, as were other informal supports. Friends did small acts such as cooking or bringing flowers which the women appreciated and assisted them in positive coping (Abboud & Liamputtong, 2005). The women in Gerber-Epstein et al.'s (2008) study identified their mothers as the most important support person following their miscarriage, but also that informal supports such as partners, family, and friends expected the woman to quickly "bounce back, forget, move on" (p. 17). Leach et al. (2014), MacWilliams et al. (2016), and Rowlands and Lee (2010) all reported that women felt isolated due to a lack of support by family and friends, with Leach et al. (2014)

further commenting that the women's mothers and grandmothers were included in the people who left them feeling abandoned and misunderstood. All nine Latina women believed that culture was an influential part of her miscarriage experience, with one woman describing how the expectation in Hispanic families to have a large number of children impacted her emotionally (Leach et al., 2014).

Regarding partners and spouses, Abboud and Liamputtong (2005) and Leach et al. (2014) both reported the significant other as the women's primary support person. Gerber-Epstein et al. (2008) and Rowlands and Lee (2010) found that their participants recounted a range of how well they felt understood by their partners. Some women described them as understanding, supportive, and able to share the burden of the emotional pain. Other partners were not able to empathize or conveyed the message that the woman was the only one experiencing a sense of loss (Gerber-Epstein et al., 2008; Rowlands & Lee, 2010). There is evidence to support the notion that men grieve miscarriages differently from women (Broquet, 1999; Carolan & Wright, 2017; Meaney et al., 2017) and that in general their grief dissipates faster than for the woman (Abboud & Liamputtong, 2002; Adolfsson et al., 2004). Men are likely to view their role as one that is supportive and encouraging of his partner through the loss (Abboud & Liamputtong, 2002, 2005) and while planning subsequent pregnancies (Meaney et al., 2017).

Miscarriage often leaves a shadow over future pregnancies, with some women fearing the idea of ever becoming pregnant again (Abboud & Liamputtong, 2002; Adolfsson, 2010; Leach et al., 2014; Murphy & Merrell, 2009). A sense of insecurity or distrust toward their bodies may persist, such as worry that a physical problem will prevent them from carrying another pregnancy to term or that they are simply too old (Adolfsson, 2010). Women who have other children may find relief in knowing that they can get pregnant, but those who do not may entertain concerns

toward their health, behaviors, and fertility (Meaney et al., 2017). When women do fall pregnant, they may target certain gestational weeks as personal goals, including going past the gestation at which they had the previous miscarriage (Meaney et al., 2017). Some women find that they are so preoccupied with worry that they cannot enjoy their pregnancy (Meaney et al., 2017).

Andersson et al. (2011) conducted a qualitative investigation with 16 women to learn how they manage their feelings when they become pregnant after miscarriage. Five themes emerged, the first of which was *distancing herself from her pregnancy*. Women tended to have ambiguous feelings about being pregnant again and protected themselves by doing things such as waiting to buy items for the baby. The second theme was *focusing on her pregnancy symptoms*, in which women often looked to the usual pregnancy symptoms as confirmation that the pregnancy was proceeding. Third was *asking for an ultrasound examination*. This produced a variety of feelings typically beginning with apprehension and fear, as an ultrasound procedure was the confirmation of fetal death in the previous pregnancy. It also resulted in relief and inner peace that the pregnancy is healthy. The fourth theme was *searching for confirming information* in which women gather information via avenues such as the Internet or a magazine that reassures them the pregnancy is viable and that they have not done anything to corrupt or damage the fetus. When women did not find evidence that they have harmed the fetus (through behaviors such as eating certain foods or performing jarring physical activity), they felt comforted and calmer. Lastly, *asking for professional and social support* was identified. It was found that women expressed desire and need to talk to a professional about their anxieties but did not know where to turn. Women looked to medical professionals and personal supports for consoling and found that talking with another woman with the same experience was beneficial. The authors concluded that women were left to manage their emotions on their own, and typically used

defense mechanisms to minimize the level of intimacy she felt with this pregnancy after previous miscarriage (Andersson et al., 2011). Côté-Arsenault and Morrison-Beedy (2001) conducted an earlier study with 21 women in three focus groups on their expectations for pregnancy after loss and found similar findings in their six themes: (1) dealing with uncertainty; (2) wondering if the baby is healthy; (3) waiting to lose the baby; (4) holding back their emotions; (5) acknowledging that loss happened and that it can happen again; and (6) changing self. Flat affect and low attachment to the fetus was viewed as a protective coping skill for stress, as many of the women realized that a live baby is not a guarantee. The women described simultaneously waiting for disaster to happen and hoping that the pregnancy will be successful (Côté-Arsenault & Morrison-Beedy, 2001; DeBackere, Hill, & Kavanaugh, 2008).

Two situations of pregnancy loss warrant further comment below: first pregnancy and pregnancy after infertility. A first pregnancy is a very different experience than subsequent pregnancies because it officiates the transition from childlessness to motherhood and legitimizes femininity (Gerber-Epstein et al., 2008). When a first pregnancy is lost, questions and fears arise concerning women's fertility and their ability to fulfill what is perceived to be their essential role as a woman (Gerber-Epstein et al., 2008) and self-identity as a mother (Lindemann, 2015). Miscarriages after infertility generate similar worries. A woman who miscarries after assisted reproduction procedures has a higher likelihood for stress and anxiety than when the conception occurred naturally (Cheung, Chan, & Ng, 2013). Many of the aspects of deep grief are shared with those who are fertile, but this grief is complicated by the fear that one might never conceive again or give birth to a child (Freda, Devine, & Semelsberger, 2003). Freda et al. (2003) conducted a phenomenological investigation on miscarriage after infertility and identified nine themes which included *going back to 'square one', a struggle between hope and hopelessness*

for future fertility, running out of time, lack of understanding by others, and guilty feelings about whether they caused the miscarriage. There had been very little said to the women by other people that the women appreciated or found helpful. The authors suggested that understanding, acknowledging, and listening were the best ways to attend to their needs (Freda et al., 2003). Ultimately, the miscarriage experience for any woman is situated within the wider context of prior reproductive experiences (Simmons et al., 2012), with women who do not have living children facing additional concerns surrounding the uncertainty of whether they will ever become mothers (Freda et al., 2003; Gerber-Epstein et al., 2008).

Attachment, grief, and meaning making. During pregnancy, an attachment bond to the fetus begins to develop. Peppers and Knapp (1980) wrote about psychological aspects of perinatal death and bereavement within the mother-child relationship and presented nine milestones that likely add to the attachment bond. These events included planning and confirming the pregnancy; feeling the fetus move; regarding the fetus as an individual; giving birth; and seeing, touching, and caring for the new baby (Peppers & Knapp, 1980). Bennett, Litz, Lee, and Maguen (2005) purported that certain pre-birth factors can intensify the attachment felt toward the fetus, but comprehensive studies on these items have been limited. Such factors include how much time and effort it took to conceive, fertility history, amount of assistance it took to conceive, effort put into preparing for the birth, age of the mother, previous miscarriages, number of living children, current relationship state with the significant other, and family pressure (Bennett et al., 2005). There is some evidence that the attachment bond is greater in pregnancies of a longer gestation (Goldbach, Dunn, Toedter, & Lasker, 1991; Keefe-Cooperman, 2005; Lasker & Toedter, 1991), with the assumption being that gestational age, degree of attachment, and the resultant intensity of grief have a direct relationship (Klier et al., 2002). However, other authors

claim that attachment is not connected to length of gestation because the bond develops at varying points for individual women (Bennett et al., 2005; Côté-Arsenault & Mahlangu, 1999).

As pointed out by Shreffler et al. (2011), the discussion of attachment brings Bowlby's (1969) attachment theory to mind but this theory does a poor job at explaining reactions to miscarriage (Murphy & Merrell, 2009; Shreffler et al., 2011). The primary problem is that Bowlby originally conceptualized attachment between infants and mothers, where the mother is the attachment figure and provides safety and security (Shaver & Tancredy, 2001). Women may certainly feel attachment and a sense to protect the fetus but the fetus is not a source of safety and security for the woman, making it difficult to directly translate Bowlby's theory into perinatal attachment (Murphy & Merrell, 2009).

Various scales have been developed in order to learn more about perinatal grief, a few of which are briefly presented below. The Perinatal Bereavement Scale (PBS; Theut, Pedersen, Zaslow, Cain, & Rabinovich, 1989) measures bereavement resulting from miscarriage, stillbirth, or neonatal death in 26 items on a 4-point Likert scale. The scale discerns losses between early and late gestations and can identify gender differences in grief reactions (Theut et al., 1989). The Perinatal Grief Scale (PGS; Toedter, Lasker, & Alhadeff, 1988) examines factors that influence resolution of grief resulting from miscarriage, stillbirth, neonatal death, or ectopic pregnancy. Three areas of Active Grief, Difficulty Coping, and Despair represent normal grief reactions (Active Grief) and more severe grief reactions (Difficulty Coping and Despair) on a total of 84 items, or 33 items in the short version (Toedter et al., 1988). Hutti and dePacheco (1998) developed the Perinatal Grief Intensity Scale, measuring intensity of grief after pregnancy loss on 14 items across three dimensions of reality (how real the pregnancy and baby felt to the woman), congruence (congruence between the woman's miscarriage experience and desired

care), and confront others (ability to act in ways that increase congruence) (Hutti & dePacheco, 1998). Lastly, the Perinatal Bereavement Grief Scale (PBGS) was the first scale developed to measure the yearning for the lost pregnancy and baby (Ritsher & Neugebauer, 2002). Fifteen items that include thoughts and feelings such as, “You felt as if your baby were still inside of you” and, “You imagined what the baby would have looked like” provide information about a woman’s level of preoccupation with the deceased fetus (Ritsher & Neugebauer, 2002).

Research has used the aforementioned grief scales in order to learn more about the grieving process after loss. Neugebauer and Ritsher (2005) used the PBGS to measure yearning and depressive symptoms in the six months following miscarriage. Results indicated that depression and grief, while related, occurred separately in a significant number of participants and that approximately 20% still felt strong yearning for the baby up to six months after loss (Neugebauer & Ritsher, 2005). A Swedish study by Adolfsson and Larsson (2010) used the PGS to compare women’s grief reactions to Bonanno and Kaltman’s (2001) normal grief reactions to determine if women experience normal grief after a miscarriage loss. It was found that women experience grief after miscarriage in a similar way to general grief after the death of a loved one and that emotional healing occurs once the woman has expressed and worked through her grief (Adolfsson & Larsson, 2010). However, adopting grief models for miscarriage care implies that all women experience grief, which is not a universal reaction true to the experience of all women (Corbet-Owen & Kruger, 2001; Murphy & Merrell, 2009). Murphy and Merrell (2009) discuss the dangers of framing all miscarriage care from a grief or bereavement perspective and they argue that models of grief for adults are questionable on whether or not they can even be adequately applied to miscarriage. Thus, they propose that transition models that accommodate the

complexities of the miscarriage experience are more appropriate than grief models (Murphy & Merrell, 2009).

Finding meaning in the miscarriage is often a large part of women's recovery after loss (Carolan & Wright, 2017; Corbet-Owen & Kruger, 2001; Gerber-Epstein et al., 2008; Leach et al., 2014; Nikcevic & Nicolaides, 2014; Simmons et al., 2006). Some women have to revisit the meaning ascribed to their pregnancies in order to make sense of what once was (Carolan & Wright, 2017). For others, the search for meaning comes from seeking answers about why their miscarriage occurred (Leach et al., 2014; Nikcevic & Nicolaides, 2014; Simmons et al., 2006). Nikcevic and Nicolaides (2014) conducted a longitudinal study of 127 women where distress and meaning-making variables were examined at 4, 7, and 16 weeks post-miscarriage. More than half of the women reported that they had found meaning by 7 weeks and these results predicted levels of emotional distress at 16 weeks (Nikcevic & Nicolaides, 2014). Some women may find meaning through the creation of their own rituals. One couple found meaningful ways to create memories of the babies they lost through crafting photo albums, planting rose bushes, and using a particular set of plates that honored the deceased child (Abboud & Liamputtong, 2002). The need to create memories and remember the child was also noted by Corbet-Owen and Kruger (2001), but these women were filled with more regret that they did not choose a name, ever see the baby, or ask what gender the child was.

Supportive care and counseling. Lee and Rowlands (2014) provide a compelling argument for the use of mixed methods design to infuse findings from quantitative and qualitative literature on miscarriage in order to gain a fuller perspective of how to better understand women's wellbeing after loss. Quantitative research suggests that most women do not suffer from psychological distress beyond 6 to 12 months (Broen et al., 2005, 2006; Cumming et al.,

2007; Lok et al., 2010; Sham et al., 2010) while qualitative research indicates that miscarriage can have a lasting emotional impact, possibly even years after the event (Abboud & Liamputtong, 2002; Côté-Arsenault & Morrison-Beedy, 2001; Gerber-Epstein et al., 2008; MacWilliams et al., 2016). Lee and Rowlands (2014) assert that quantitative surveys can measure rates of anxiety and depression but do not accurately capture the affective elements (e.g., guilt, self-blame, grief, anger, etc.) described during qualitative interviews. Women likely experience a long and challenging adjustment after miscarriage but retain functional mental health levels, suggesting that a focus on resiliency rather than only the negative impact of miscarriage can further future research (Lee & Rowlands, 2014) and possibly lead to a better understanding of how to meet the emotional needs of women after early loss.

Musters et al. (2013) designed a questionnaire study in order to learn more about women's preferences for supportive care after recurrent miscarriage. The questionnaire consisted of demographics, a self-reported need for supportive care based on a 1-10 scale, and quantified supportive care options previously identified in a qualitative study by the first author (Musters et al., 2011). One hundred and seventy-one surveys of women from three hospitals in the Netherlands were analyzed and presented under three domains: (1) medical supportive care, (2) soft-skills, and (3) other types of supportive care.

For medical supportive care, the women indicated they wanted a first trimester plan with one doctor familiar with their obstetric history, regular ultrasounds, and information provided from their doctor on various facets of recurrent miscarriage, including diagnosis, treatment, and prognosis (Musters et al., 2013). In some qualitative studies, women have expressed dissatisfaction with the information they receive because it did not prepare them for the emotional or physical impact after loss (Abboud & Liamputtong, 2005; MacWilliams et al., 2016; Rowlands

& Lee, 2010) or provide options for available follow up support (Leach et al., 2014; Meaney et al., 2017). Men have indicated more information on what to expect after miscarriage would have allowed them to take better care of their partners (Abboud & Liamputtong, 2005).

Regarding soft-skills, women wanted doctors who listened to them, expressed understanding and empathy, took their concerns seriously, kept them informed on progress, and asked about their emotional needs (Musters et al., 2013). Many studies have discussed women's need for medical personnel who are validating and able to acknowledge her loss (Corbet-Owen & Kruger, 2001; MacWilliams et al., 2016; Meaney et al., 2017; Rowlands & Lee, 2010; Simmons et al., 2006), with Corbet-Owen & Kruger (2001) pointing out that medical training does not include lessons on how to shift from healer to that of counselor.

Other types of supportive care that women from Musters et al. (2013) valued was support from their friends and a medical or psychological professional if a miscarriage were to happen again in the future. The majority of women believed that bereavement counseling was not necessary (Muster et al., 2013). Unfortunately, van den Boogaard et al. (2013) found that adherence to evidence-based quality indicators for recurrent miscarriage was low among medical professionals and that general hospital adherence varied widely. New guidelines are not automatically espoused into clinical practice (van den Boogaard et al., 2013) and this may also be true for supportive care preferences.

Several authors have concluded that counseling is a necessary and helpful tool for women after miscarriage (Abboud & Liamputtong, 2002; Andersson et al., 2011) and evidence suggests that interpersonal counseling can decrease distress and depression after the event (Neugebauer et al., 2007; Séjourné et al., 2010; Swanson, Chen, Graham, Wojnar, & Petras, 2009). Moreover, women themselves have expressed desire to receive counseling and other formal support

(Musters et al., 2011; Simmons et al., 2006). Women from Musters et al. (2011) desired counseling during their next pregnancy or after a future miscarriage as a method of non-medical supportive care. A social worker was deemed as more approachable than a psychologist and they stressed the importance of the social worker having experience with patients who have a history of miscarriage. Furthermore, being offered counseling even if it was not needed at the time was perceived as important (Musters et al., 2011). Similar to what is seen in the infertility literature, it is likely that not every woman who suffers from a miscarriage needs psychological help (Kong, Chung, & Lok, 2014; Radford & Hughes, 2015; Séjourné et al., 2010), but that knowing services are available provides reassurance and peace of mind.

Much of the literature on counseling women after miscarriage is based in the nursing field and depicts specific ways that nurses can increase their supportive care. Swanson et al. (2009) randomly assigned 341 couples to one of the following groups: nurse caring (3 counseling sessions), self-caring (3 video and workbook modules), combined caring (1 counseling session and 3 self-care modules), and control (no treatment). The women who were assigned to the nurse caring group resolved their depression more quickly than women in the other groups. Nurse caring consisted of 3 one-hour counseling sessions by nurse counselors who were trained via methods such as role playing and studying interventions in Swanson's Caring Theory (Swanson, 1991, 1993) and Meaning of Miscarriage Model (Swanson, 1999a, 1999b). A social worker also provided support and feedback. In addition to accelerating the resolve of women's depression, nurse caring also hastened resolution of grief for both genders (Swanson et al., 2009).

Counseling may be most effective immediately after the loss, as studies have shown that brief interventions are useful shortly after miscarriage (Séjourné et al., 2010), particularly for women who experience high levels of psychological distress (Kong et al., 2014). Telephone

counseling has been identified as a potential brief therapy, with up to 82% having receptivity to this form of mental health counseling (Neugebauer et al., 2007). The use of online message boards has been noted as a useful outlet that helps women to feel less isolated and increases convenient, anonymous, and private support (Gold, Boggs, Mugisha, & Palladino, 2012; Hardy & Kukla, 2015). Carolan and Wright (2017) also reported participants using online message boards for support of their grief and loss, along with joining various sorts of other in-person miscarriage support groups. Some initiated individual counseling from a grief specialist (Carolan & Wright, 2017). Additionally, women have expressed a desire to connect with other women who have shared the same experience (Carolan & Wright, 2017; Corbet-Owen & Kruger, 2001; Gerber-Epstein et al., 2008; Radford & Hughes, 2015), much like the idea presented for peer mentorship in infertility support offered by Read et al. (2014). The Australian Stillbirth and Newborn Death Support (SANDS) organization has a parent peer support program, a 24-hour telephone helpline. Trained volunteers provide a safe and caring place for callers to share their story and gain support. Callers are provided an opportunity to gain information and support from a parent who has previously experienced the loss of a baby (Boyle, Mutch, Barber, Carroll, & Dean, 2015).

Finally, several recommendations for professionals have been expressed. It is important for professionals to remember that this is a time when women are likely to feel anxious and distressed, and some may feel forgotten or abandoned by their doctors and family members (Cumming et al., 2007; Murphy & Merrell, 2009). It is often not helpful to assist the woman in moving on or assuring her that she can have another child; rather sensitivity and encouragement to verbalize her loss are more appropriate (Abboud & Liamputtong, 2002). Ultimately, grief care should incorporate a long-term perspective (Fukushima et al., 2014), with an understanding that

women's emotional needs vary depending on the meaning and context of their lost pregnancy (Corbet-Owen & Kruger, 2001).

Grief Within the Field of Counseling

Clinical Definitions and Guidelines

Diagnostic and Statistical Manual. Counselors use the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychological Association [APA], 2013) as a tool to evaluate client distress. Bereavement was first included in the third edition of the DSM as a complication of major depression (APA, 1980). In the fourth edition of the DSM (APA, 1994), the guidelines required symptoms to be present for 2 months after the loss and non-characteristic of normal grief reactions. These earlier versions of the DSM treated bereavement as an exception to the clinical presentation of depressive disorder (Fox & Jones, 2013), but new criteria for bereavement was provided with the 2013 release of the current edition of the DSM-5 (APA, 2013). The 2-month period of time was changed so that a bereaved person could be diagnosed with major depression after only 2 weeks of symptoms, assuming they met all other criteria (APA, 2013). Support for the removal of what has come to be known as the bereavement exclusion comes from empirical research that suggests there is little difference between bereavement and depression (Zisook & Kendler, 2007; Zisook, Shear, & Kendler, 2007). Opponents of the decision expressed concern that the decision would medicalize grief reactions (Bandini, 2015; Fox & Jones, 2013; Friedman, 2012; Parker, 2013).

International Classification of Diseases. The International Classification of Diseases, 10th Revision (ICD-10) is a coding list of various diagnoses and procedures often used for medical billing purposes (Wing, 2016). The entire list is made up of 21 alphabetical code classifications (e.g., certain infectious and parasitic diseases; diseases of the nervous system; diseases of the

digestive system; pregnancy, childbirth and the puerperium; injury, poisoning and certain other consequences of external causes) (International Classification of Diseases [ICD], 2018). Grief or bereavement can be located in two areas within this classification system. The first is under the F01-F99 codes for mental, behavioral and neurodevelopmental disorders (ICD, 2018). Here, grief is associated with F43.21 adjustment disorder with depressed mood (ICD, 2018). The second location is under the Z00-Z99 codes for factors influencing health status and contact with health services. Bereavement is found under Z63.4 disappearance or death of family member (ICD, 2018). Both F codes and Z codes are commonly used by mental health professionals.

Council for Accreditation of Counseling and Related Educational Programs. The Council for Accreditation of Counseling and Related Educational Programs (CACREP) sets the standard for quality in counselor training at the master's and doctoral levels (Lee, 2013). The current set of CACREP standards (CACREP, 2016) regulates the following areas: the learning environment; professional counseling identity; professional practice; evaluation in the program, entry-level specialty areas; and doctoral standards.

Under section 2: professional counseling identity, standards for the eight core areas to be covered within the counseling curriculum are listed (CACREP, 2016). Part F.3. describes the requirements for learning 'human growth and development', an area that typically corresponds with a class that covers events across the lifespan. A few items (see, e.g., F.3.f., F.3.g., F.3.i) provide a potential foundation for grief, death, and bereavement to be considered. For example, item F.3.g. requires that "effects of crisis, disasters, and trauma on diverse individuals across the lifespan" be covered in counselor training (CACREP, 2016, p. 11). To date, CACREP (2016) has no specific criteria outlining how grief and bereavement shall be taught to counselor trainees.

Counselor Training and Ability to Work with Grieving Clients

Counselor educators are charged with ensuring that counseling trainees are prepared to work with clients in clinical settings and most program coordinators feel that teaching grief counseling to trainees is important (Humphrey, 1993). However, variation exists in how grief training is offered to students (Low, 2004), which contributes to existing gaps between grief research outcomes, education, and methods of counseling grieving clients. In her dissertation study, Low (2004) examined grief and loss preparation in 79 CACREP-accredited school counseling programs. Most of the programs (60%) offered a form of grief and loss preparation, but 40% of the programs offered none at all. Half of the programs offered an elective course but a required course was offered in only 11% of programs. The rationale provided by the programs that did not offer courses on grief and loss was a lack of room to add additional credits (78%), because it was not a CACREP requirement (35%), and financial constrictions or a lack of trained staff (25%) (Low, 2004). Eckerd (2009) also found that faculty issues, which included insufficient expertise and number of staff, along with another course or department covering the topic, curriculum issues, and lack of demand or interest as main reasons why death and dying courses were not offered in psychology programs. Many counseling students end up acquiring grief training through infusion with other program curricula (Hannon & Hunt, 2015; Horn, Crews, & Harrawood, 2013; Humphrey, 1993; Ober, Granello, & Wheaton, 2012), rather than through a specific course on death, bereavement, or grief counseling. Additionally, Ober et al. (2012) surveyed 369 counselors on their training, personal and professional experiences, and counseling competence related to grief and found that counselors were most familiar with grief theories that have little or no empirical support.

The most recognized grief theory in Ober et al.'s (2012) study was Stage Theory (Kübler-Ross, 1969), with 42.8% of participants stating they had *a lot* or *some* familiarity with this model. Originally conceptualized as five stages of dying in the seminal book *On Death and Dying* (Kübler-Ross, 1969), denial, anger, bargaining, depression, and acceptance eventually became obscured and known as the stages of grief (Friedman & James, 2008). The change occurred throughout the 1970's, when the theory was often taught in sociology and psychology college courses, with students carrying their knowledge of Stage Theory into their careers as therapists, social workers, and doctors (Friedman & James, 2008). Misrepresentation in the media further advanced the idea for specific stages of grief, and the fact that the stages had originally been exclusive to the experience of dying became confounded (Friedman & James, 2008). Kübler-Ross (1969) herself discussed in her book that the stages were not based on empirical research and instead were drawn from her and her students' reactions and feelings to interviews conducted with terminally ill patients. Only about a quarter of Ober et al.'s (2012) participants were familiar with meaning making theories (Neimeyer, 2001) and they were the least familiar with the dual-process model (Stroebe & Schut, 1999), two theories that have some empirical validity (Richardson, 2007; Richardson & Balaswamy, 2001; Schut, Stroebe, van den Bout, & Terheggen, 2001). A lack of standardization on grief competencies may allow training when it does occur to focus on theories that are more commonly known, but not necessarily best standards of practice (Breen, 2010; Ober et al., 2012).

Regarding counselor preparedness to provide grief counseling in the study by Ober et al. (2012), counselors rated themselves highest on Personal Competencies and lowest on Conceptual Skills and Knowledge, which the authors interpreted as counselors perceiving themselves as having adequate self-awareness and self-care to work with grieving clients but that they felt

much less prepared when it came to specific skills and knowledge about grief (Ober et al., 2012). These results were replicated by Imhoff (2015), who used the same Grief Counseling Experience and Training Survey (GCETS) to gather information about grief training and competency of counseling students in his dissertation study. The need to enhance professional skill development is further bolstered by Horn et al. (2013), who discovered in an unpublished study that those who attend workshops on grief counseling reported lower levels of anxiety about working with death-related topics. However, grief counselors have identified problems such as the cost of purchasing material or attending workshops and conferences, seclusion from geographical areas that provide more chances for professional development, and a lack of time to gather, read, and learn written material (Breen, 2010). It is also important to recognize that not every U.S. state requires counselors to gather continuing education credit hours, meaning that some counselors may receive little to no training on grief counseling at all and still meet the criteria for providing these services.

Infertility Grief

Ambiguous losses associated with infertility. The losses associated with infertility are often hidden to others, a situation that differs from other forms of loss (Lindsey & Driskill, 2013), such as the death of an adult relative. Examples of losses experienced from infertility include loss of the pregnancy and birth experience, loss of a genetic legacy, loss of the parenthood experience, loss of expectation and vision of the ideal family, and loss of general milestones across the lifespan. There is a sense of a lost dream and loss of a hoped-for child rather than an actual child (McCarthy, 2008). These are invisible and intangible losses (Lindsey & Driskill, 2013; McCarthy, 2008) and not known to others unless specifically disclosed by the affected woman.

Infertility and disenfranchised grief. Infertility has been interpreted as an experience of disenfranchised grief due to the silence surrounding the loss and the lack of social validation and support (Daniluk, 2001; Doka, 2002; Lee, Neimeyer, & Chan, 2012; Walter & McCoyd, 2009). Some women find it difficult to discuss their infertility with others, and may keep their IVF treatment to themselves (Hammarberg et al., 2001). Other people may not know how to respond to women dealing with infertility, and women have reported hurtful and insensitive comments made by others (Bell, 2013; Benasutti, 2003; Kirkman, 2001). Women have reported dealing with their grief in isolation because of a lack of public acknowledgement that their losses are real; the women in McCarthy's (2008) study believed that this contributed to the deep sense of isolation that they endured.

Miscarriage Grief

Ambiguous losses associated with miscarriage. Bennett et al. (2005) outlined reasons for why perinatal losses are unique compared to other forms of loss. First, the loss of a potential child entails future-oriented losses such as anticipated joy, parenthood and maternal identity, and status in community and culture. Women are not mourning an actualized baby, but mourning the *loss of the opportunity* to birth a baby (italics added for emphasis, van den Akker, 2011). This is fundamentally different from losses that are sustained from the death of an adult, with whom the relationship and memories are centered in the past. Numerous studies (Bray, 2015; Carolan & Wright, 2017; Keefe-Cooperman, 2005; Leach et al., 2014; Lindemann, 2015; van den Akker, 2011) have further described the specific future-oriented losses experienced after miscarriage surrounding identity, hopes and dreams, and shattered expectations. The second aspect of perinatal loss discussed by Bennett et al. (2005) explains the underpinnings for the disenfranchisement of miscarriage grief, which is expanded upon below.

Miscarriage and disenfranchised grief. A perinatal loss is an invisible and silent event (Leach et al., 2014; MacWilliams et al., 2016; Meaney et al., 2017), with little societal recognition of the significance (Bennett et al., 2005; Corbet-Owen & Kruger, 2001). Similar to that of infertility, it may be difficult for others to empathize with the loss and know how to offer condolences, even if they were supportive during the pregnancy (Bennett et al., 2005). Stoyles (2015) points out a paradox in the assumptions that are revealed when people respond to the news that a woman miscarried. Some responses assume feelings of grief and distress, reflecting a belief that the woman must have wanted the baby. Other responses assume that there was little or no significance to the loss, and encourage the woman to “try again” or “have another” (Stoyles, 2015, p. 96). A discussion of the invalidations by and need for acknowledgement from medical professionals was included in a previous section, but these dynamics also expand to family members, significant others, and society as a whole (Leach et al., 2014; MacWilliams et al., 2016; Meaney et al., 2017; Rowlands & Lee, 2010). No formal rituals exist in Western culture that provide norms on how to recognize and acknowledge perinatal loss (Carolan & Wright, 2017; Corbet-Owen & Kruger, 2001; Rowlands & Lee, 2010), which may mean that long term closure is unlikely (van den Akker, 2011).

Disenfranchised Grief

There are certain grieving rules that exist within society that “specify who, when, where, how, how long, and for whom people should grieve” (Doka, 1999, p. 37). For example, after the death of a grandparent a person may engage in a ritual that mitigates the grieving process, such as attending a visitation or funeral, reading an obituary, or taking time off work. These cultural practices are identifiable and clear, and provide social support and help to facilitate grieving for the bereaved (Betz & Thorngren, 2006; Meyers, 2016; Mortell, 2015). However, grieving rules

do not always align with the attachment that one feels to whom or what was lost, leaving survivors vulnerable for their grief to be disenfranchised (Doka, 1999). Disenfranchised grief was first described by Kenneth Doka in 1989 to conceptualize loss that “is not, or cannot be, openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p. 4). The bereaved may not feel free to discuss their experience and may not receive social validation or sympathy (Mortell, 2015).

Doka’s (1989) original conception of disenfranchised grief consisted of three situations in which disenfranchised grief may occur: when the relationship is not recognized, when the loss itself is not recognized, or when the griever is not recognized. Two more situations were later added: when the death is disenfranchising, or when the way an individual grieves is not validated (Doka, 1999, 2002).

Typology of Disenfranchised Grief

The relationship is not recognized. Western culture places a more important emphasis on kin-based relationships than on relationships with less recognizable ties (Doka, 1999, 2002). Despite longevity and quality of the relationship, the level of closeness of non-kin relationships may not be known or appreciated (Doka, 2002). Grief may be disenfranchised when the relationship between the bereaved and the deceased is not clear or when the level of closeness is not understood. Even if the relationship is recognized, mourners may still be denied the opportunity to grieve publicly, instead being expected to support and assist family members (Doka, 1999, 2002). Friends, neighbors, foster parents/siblings, in-laws, step-parent/siblings, colleagues, caregivers, counselors, roommates (Doka, 1989, 1999, 2002), and online companions (Doka, 2002) are all examples of relationships that are potentially not recognized. Furthermore, some relationships are not socially sanctioned, such as in the case of extra-marital affairs, cohabitation, and

some gay and lesbian relationships (Doka, 1999, 2002). It is also possible for there to have been no actual relationship for a loss to be felt, as with the death of a beloved celebrity (Doka, 1999).

The loss is not acknowledged. When the loss itself has not been socially identified as significant, grief is not expected or validated (Doka, 1999, 2002). Doka (1999, 2002) and Mortell (2015) recognized abortion, perinatal death, infertility, and miscarriage as reproductive losses that fit within this typology. Significant losses can occur even if a person is still alive, such as in the event of mental illness or personal transformation (e.g., gender transition) (Boss, 1999, 2016), but these losses may become disenfranchised because the loss is not clear (Doka, 2002). In other situations, the loss results from life transitions, such as job loss, home loss, or divorce. Sometimes the loss is intangible, and therefore unrecognized or invalidated (Doka, 2002). Subtle or secondary losses can even occur from joyous celebrations, such as a sense of loss of autonomy following a wedding or the birth of a child (Doka, 2002). Loss can also develop after an athlete with hope for a sports career endures an injury or for the parents of a child born with developmental disabilities (Doka, 2002).

The griever is excluded. Certain characteristics of the bereaved may contribute to the disenfranchisement of their grief. In this circumstance, the person is not socially defined to be capable of experiencing grief, leading to little or no recognition of their sense of loss or need to mourn (Doka, 1999, 2002). For example, both the very young and the very old are generally perceived by others to have little understanding of, or reaction to, the death of a significant person (Doka, 2002) and may be excluded from conversations or grieving rituals (Doka, 1999, 2002). Disenfranchised grief may also occur for persons with mental illness or developmental disabilities (Doka, 2002) due to fallacious perceptions that they do not experience grief or understand the concept of death.

Circumstances of death. In some situations, the nature of the death carries social stigma and evokes shame or embarrassment for the bereaved. There may be reluctance to seek out social support as well as limits to the support that is offered by others (Doka, 1989, 1999, 2002). The survivors of a loved one's suicide or an AIDS-related death may be careful in sharing the loss with others due to the associated stigma (Doka, 1989, 1997, 2002). Another instance that may inhibit the expression of grief or social support is when the deceased is devalued, such as in case of the death of an alcoholic or when a person is executed (Doka, 2002). Even some cases of homicide lead to potential disenfranchisement of the survivors' grief (Doka, 1999).

Ways individuals grieve. While there is no "correct" way to grieve, there are times when a person's way of dealing with grief is not deemed socially acceptable (Doka, 1999, 2002; Mortell, 2015). For example, abusing substances to cope (Mortell, 2015) or expressions of emotion that are contradictory to what is expected (e.g., inappropriate anger; lack of emotional expression) may be viewed with disapproval (Martin & Doka, 2000). It is also possible for one to self-disenfranchise, where the self fails to acknowledge the grief (Kauffman, 1989, 2002) due to perceived social expectations (Kauffman, 2002).

Counseling Interventions

Those whose grief is unsanctioned by society may be left to mourn in private (Doka, 1999). Grief counseling can include validation, sensitivity to the losses experienced, and creative interventions that facilitate the grieving process (Doka, 1999). Choosing or creating a ritual is encouraged, especially for those who felt excluded in a ritual from a previous loss (Doka, 2002). Mortell (2015) and Pesek (2002) encourage support groups where members can process how the loss has impacted their lives and form helping relationships with other group members.

Regardless of the intervention, empathic support should remain a major element, as Neimeyer and Jordan (2002) noted that empathic failure was a central issue with disenfranchised grief.

Robson and Walter (2012) provided a critique of disenfranchised grief and concluded that social expectations about grief are hierarchical rather than existing in a binary of being either allowed or disallowed (e.g., a kin parent is expected to experience more grief than a non-relative neighbor). They propose that these hierarchies precede disenfranchisement, the experience of which may be binary—you either feel your grief is acknowledged or it's not (Robson & Walter, 2012). Further research is needed to learn more about grief hierarchies.

Applications of Disenfranchised Grief

Researchers have applied disenfranchised grief to areas such as pet loss (Cordaro, 2012), bereavement among lesbian and gay persons (McNutt & Yakushko, 2013), physician burnout (Lathrop, 2017), renal transplant failure (Gill & Lowes, 2014), later-life homelessness (Burns, Sussman, & Bourgeois-Guerin, 2018), and the loss of family and friends to gun-related violence (Lawson, 2014). Other studies have written about the disenfranchised grief following a traumatic birth (DeGroot & Vik, 2017) and relinquishing a child for adoption (Aloi, 2009). Lang et al. (2011), Hazen (2003), and Mulvihill and Walsh (2014) all studied the disenfranchisement after perinatal losses at varying gestational age. In addition to the experiential and relational aspects of disenfranchised grief, Lang et al. (2011) also identified ambiguity surrounding the viability of the pregnancy, what to expect in physically passing the fetus, how to handle the remains, and sharing news of the event.

Ambiguous Loss

First coined in the 1970s by researcher and family therapist Pauline Boss, *ambiguous loss* defines “a situation of unclear loss that remains unverified and thus without resolution” (Boss,

2016, p. 270). The obscurity of the loss confuses the grieving process because there is no clearly defined path to adjustment and rituals or social support may not be available (Boss, 1999, 2010; Walter & McCoyd, 2009).

There are two types of ambiguous loss (Boss, 1999, 2004, 2010, 2016). The first is a physical absence with a psychological presence. Without the proof of death or permanence of the loss, a person remains psychologically present, called “gone, but not for sure” (Boss, 2016, p. 270). Families may not know the location of a loved one or whether they are alive or dead. There are several situations in which this type of ambiguous loss may occur. For example, a missing person from an event such as war (e.g., MIA status), a natural disaster, disappearance, or kidnapping. A missing body specifically is another example, perhaps from a murder, plane crash, or being lost at sea. Other examples do not contain an assumption or question of death, but are still considered to be losses with a physical absence of a person but a psychological presence. Incarceration, immigration, military deployment, divorce, and foster care or adoption of a loved one are examples. Other incidences may occur through the life stages, such as with work relocation, when young adults leave home, and a spouse moving to a care facility (Boss, 2016). Infertility and miscarriage would also fall under this first type of ambiguous loss; there is a physical absence of a pregnancy, but a psychological presence of the envisioned pregnancy or child.

The second type of ambiguous loss is a psychological absence with physical presence (Boss, 1999, 2004, 2010, 2016). A loved one may be alive but missing on a cognitive or emotional level. This may be referred to as “here, but not here” (Boss, 2016, p. 270). Again, there are several circumstances in which this form of ambiguous loss may occur. Issues of the brain such as dementia, traumatic brain injury (TBI), coma, or autism are examples. Chronic mental illness, depression, addiction, obsessions, and complicated grief are other instances (Boss, 2010, 2016).

Gender transition of a loved one can be an ambiguous loss (Boss, 2016) and may be experienced by parents as both types (Wahlig, 2015). For example, there is a physical absence of the child's birth sex with a psychological presence of their personality and a psychological absence of a certain gender with a physical presence of the child (Wahlig, 2015).

Ambiguous loss generates significant stress because it impedes resolution and creates confusion regarding who is in or out of a family (Boss, 2004, 2016). Rather than a clear ending as there is with death, an ambiguous loss induces "a gradual slipping away that is full of confusion" (Boss, 2010, p. 141). Relationships within the family system may be significantly affected from blurred family boundaries, unstructured hierarchies, and frozen grief (Boss, 1999, 2004). Families may be left on their own to cope with their grief and find themselves stuck between despair and hope (Boss, 1999, 2006, 2007, 2016).

Assumptions of the Theory

Ten underlying assumptions ground the theory of ambiguous loss. As outlined by Boss (2016) they are presented briefly below:

1. A phenomenon can exist even if it cannot be measured.
2. It is assumed that truth is relative and not attainable.
3. Ambiguous loss is a relational phenomenon and assumes there was an attachment to the missing person.
4. Cultural beliefs and values influence how individuals, families, and communities tolerate and perceive ambiguous loss.
5. The source of pathology lies with the type of loss and not with the type of grief.
6. Closure is a myth and without finality, loss and grief may continue for years, or a lifetime, or across generations.

7. Naming the stressor as ambiguous loss allows the coping process to begin.

8. It is possible to find meaning of a loss that remains unclear by adopting a dialectic, rather than binary, way of thinking.

9. Resilience specifically means increasing one's tolerance for ambiguity. It is also assumed that families have a natural resilience, and tolerance for ambiguity is influenced by cultural beliefs and values.

10. It is assumed that families can be both physical and psychological and both are sources of resilience. A psychological family is made up of loved ones near or far, related or not related, alive or dead.

Counseling Interventions

Dialectical thinking. Boss (2016) claims that a common response to an ambiguous loss is absolute thinking, but binary perspectives are not helpful in this instance. Dialectical thinking is recommended instead, a process of holding two contrasting thoughts at the same time in an effort to adopt both/and thinking. For example, "She's both here and also gone" (Boss, 2016, p. 273), or, "I am both a daughter and the parent to my parent" (Boss, 2010, p. 142).

Six guidelines for resiliency. Boss (2010) proposed six guidelines for adapting to the ambiguous loss. These guidelines are not prescriptive or linear, but instead occur in a pattern that allows for movement back and forth between them. Cultural differences and unique individual traits are embraced, and thus expectations for a normative grief sequence are renounced. The guidelines are intended to promote health and resiliency when faced with this complicated form of loss. As described by Boss (2010, 2016), the six guidelines are discussed below.

1. *Finding meaning.* In order to make sense out of the situation, a process of recursive both/and thinking is adopted.

2. *Adjusting mastery.* The goal here is to become comfortable with the ambiguity (Boss, 1999) by holding two opposing ideas at once, similar to adopting dialectical thinking as described above. People can regain mastery over their lives by balancing their need to control their own life with acceptance of the irresolvable loss.

3. *Reconstructing identity.* People may be forced to become flexible with gender roles and routines in order to accommodate the situation. Assumptions in our own identity, as well as our community identity are often uncovered at this time. Identity changes may even become blocked by stigma or discrimination.

4. *Normalizing ambivalence.* Ambivalent or conflicted feelings can be better managed and minimized when they are brought out into the open. Finding a trusted person to confide with can increase resiliency toward negative emotions.

5. *Revising attachment.* Here, Boss specifically describes learning to accept rather than resist the ambiguity within a relationship where dementia is present. The idea is to celebrate the person while also grieving lost connections. Imagining the situation as both/and, not either/or can be helpful.

6. *Discovering hope.* Through avenues such as religion, meditation, nature, exercise, the arts, or the company of others, hope can be created. Life can grow in a new way, even if recovery or change to the situation is not possible.

Other authors have made recommendations for counseling techniques that include and expand upon Boss' suggested interventions. Jackson (2018) incorporated the six guidelines for resiliency and encouraged dialectical thinking in his treatment recommendations, and added avoidance of approaches that are contraindicated and adopting a not-knowing perspective as a clinician. Betz and Thorngren (2006) combined family stress theory with narrative therapy

techniques to propose a model for counseling families who are dealing with ambiguous loss.

This model permits counselors to assist clients in articulating their losses, identifying available resources, and creating or redefining meaning assigned to the losses.

Applications of Ambiguous Loss

Ambiguous loss has been applied to numerous areas of study, including singlehood among never-married adults (Jackson, 2018), parents of transgender youth (Coolhart, Ritenour, & Grodzinski, 2018; Norwood, 2013; Wahlig, 2015), caregivers of those with disorders of consciousness (Giovannetti, Cerniauskaitė, Leonardi, Sattin, & Covelli, 2015), resiliency with same-sex couples (Dziengel, 2012), families with missing loved ones after 9/11 (Boss, 2004), and immigration (Perez & Arnold-Berkovits, 2018; Solheim, Zaid, & Ballard, 2016). Regarding reproductive loss, Golish and Powell (2003) examined the ambiguous losses associated with premature birth and accompanying grief. Two other articles by Golan and Leichtentritt (2016) and Sawicka (2017) investigated the narratives of women who had endured a stillbirth, with both studies mentioning how the grief following the event was disenfranchised. There are few publications that examine infertility or miscarriage from the ambiguous loss theory.

Summary

This literature review presented research on five content areas related to the topic of this dissertation: (1) infertility, (2) miscarriage, (3) grief within the field of counseling, (4) disenfranchised grief, and (5) ambiguous loss. Definitions and statistics were provided for both infertility and miscarriage, as well as details of the research conducted in both areas of reproductive loss. Then, a discussion of grief within counselor education was provided. Finally, the origins of the disenfranchised grief and ambiguous loss theories were examined.

In Chapter III, the proposed methodology for the current study is presented. The researcher begins with information on the selected phenomenological approach. A breakdown of the study design follows, including a description of the researcher, research questions, sampling and recruitment methods, data collection, and the data analysis procedure. The chapter concludes with a detailed section depicting how the researcher will ensure trustworthiness.

CHAPTER III

METHODOLOGY

Research Design

The purpose of this chapter is to describe the research design and procedures selected for this study. The rationale for employing a phenomenological approach is provided below. Then, research questions are discussed, followed by a description of the researcher. Finally, the process that will be utilized for data collection and analysis is presented.

Few qualitative studies on women affected by infertility and miscarriage have focused on the grief experience. The aim of this phenomenological study is to explore the lived experience of infertility and miscarriage grief and provide a discussion of the associated ambiguous losses and how grief has been disenfranchised. The use of an exploratory qualitative approach allowed the study participants to tell their grief stories during an in-depth interview. The narratives were then analyzed from a phenomenological perspective to identify and describe common themes.

Phenomenological Approach

Phenomenology, the study of the lifeworld (van Manen, 1997), was determined to be the best approach suited for this study. A phenomenological study will describe common meanings of the lived experience of a phenomenon for several individuals (Creswell, 2012, 2013). There is an assumption that an underlying structure to the lived experiences of the participants in the study exists, and that experiences can be reduced to a description of the universal essence of the phenomenon (Creswell, 2012, 2013; van Manen, 1997). This description of the phenomenon consists of “what” the participants experienced and “how” they experienced it (Moustakas, 1994;

Spiegelberg, 1975). From a phenomenological perspective, to do research is to want to know the world as we live in it as human beings (van Manen, 1997). Researching, questioning, and theorizing is then considered to be an “intentional act of attaching ourselves to the world, to become more fully part of it, or better, to *become* the world” (van Manen, 1997, p. 5, italics included in original text).

Creswell (2013) further asserts that beyond description, phenomenology is an interpretive process in which the researcher interprets the meaning of the participants’ lived experience. Martin Heidegger founded interpretive phenomenology, also termed hermeneutics, in 1916 as a way to interpret the ontological meanings of the human existence (Spiegelberg, 1975). Heidegger pursued the meaning of ‘being’ for humans and he viewed hermeneutics as a research philosophy that uncovers ‘being in the world’ through the interpretation of the world (Heidegger, 1962; Spiegelberg, 1975). Heidegger believed that since all humans influence and are influenced by the world around them, they cannot make sense of the world by detaching (bracketing) from it (Annells, 1996; Koch, 1995). Bracketing is a process in which the researcher intentionally reflects upon and attempts to eliminate past experience, knowledge, and assumptions so as not to influence the research (Koch, 1995; Moustakas, 1994). Heidegger (1962) believed that prior understandings of the researcher created a fore-structure, consisting of fore-having, fore-sight, and fore-conception, all of which were necessary to make true interpretation possible. According to Heidegger, fore-structures can never be eliminated (and therefore, never fully bracketed), but only corrected and modified (Koch, 1995). This circular or spiraling process is known as the hermeneutic circle of interpretation (Gadamer, 1989; Koch, 1995), and describes the analysis of the interaction between the participant and the researcher. Each individual’s background is considered, and the analysis encompasses reflection and interpretation of the interview and the

data, or text, that is developed from both the researcher and the participant (Conroy, 2003). This researcher will use the hermeneutic circle in this way for the duration of the study, and will let this process lead to an evolving sense of understanding of how her background influences her view of the data.

For this study, hermeneutic phenomenology (van Manen, 1997) was selected for exploration of the topic. Hermeneutics is the study of persons (van Manen, 1997) and is a theory for interpreting text and meaning within typical life practices (Lopez & Willis, 2004), while focusing on what humans experience rather than what they consciously know (Solomon, 1987). Hermeneutics involves an attempt to understand something from another person's perspective (van Manen, 1997) while considering the social forces that potentially impact their point of view (Ricoeur, 1976). This perspective was selected because societal expectations for women regarding pregnancy and motherhood may influence their experience of infertility and miscarriage grief. Max van Manen (1997) developed an approach which encompasses six methodological themes for hermeneutic phenomenological research: (1) turning to a phenomenon of interest; (2) investigating experiences as it is lived; (3) reflecting on essential themes; (4) describing the phenomenon through writing and rewriting; (5) maintaining a nursing relation to the phenomenon; and (6) considering the parts and the whole. van Manen's (1997) approach will be used as a methodological guide throughout all aspects of this study.

Research Questions

The overarching research question guiding this study is: What is the meaning of infertility and miscarriage grief experience for women? Additional sub-questions were formulated based on the theoretical grief frameworks used in this study and the identified problems. The sub-questions for this study are: (1) What are the ambiguous losses associated with infertility and

miscarriage; (2) How is infertility and miscarriage grief disenfranchised; (3) How can counseling services be improved for women who are experiencing or who have experienced infertility and miscarriage grief?

Role of the Researcher

Phenomenological research requires that I as the researcher and the primary instrument of data collection remain aware of my own preconceptions and biases (Marshall & Rossman, 2016; Moustakas, 1994). In hermeneutic phenomenology, this is achieved through explanation of personal experience (Lopez & Willis, 2004). I describe myself as a childfree woman, meaning that I have made a conscious decision to never become pregnant and birth a child of my own. I have never been pregnant, nor am I aware of any reason that I could not achieve a pregnancy and healthy birth. Since I have chosen a life path that is different from the societal norm, I am often questioned by other people about my decision. While most people do not ask questions with ill intentions, oftentimes their comments or questions come across as invalidating (“You just haven’t met the right man yet,”; “Who will take care of you when you’re old?”; “That is a woman’s purpose,”; “You’ll change your mind when you’re older.”). I have become an advocate for women having the ability to choose the lifestyle and family plan that they believe is best suited for them. Throughout my graduate studies I have maintained an interest in the field of human sexuality, sexual health, and sex therapy. Topics of reproductive loss have appeared throughout my studies and research in these various areas. I began to realize that women who have experienced reproductive loss encounter a similar process of invalidation as I did as a childfree person (“You can try for another,”; “Just relax and stop trying, then it will happen,”; “Have you considered adoption?”). This sparked a curiosity about what it feels like to experience a desire to have a child but encounter grief along the way that is potentially exacerbated by comments and

advice put forth by others. My hope is that this research will allow women who have encountered infertility and miscarriage grief to reflect on their interactions with other individuals and on how support can be improved.

Based on both my personal experience with invalidations described above and on my knowledge gained from the literature review, I approach this study with several assumptions. First, I assume that most of the women in this study will have difficulty articulating aspects of their grief at certain points throughout the study. The future-orientation of miscarriage (Bennett et al., 2005) and infertility loss is vastly different from the past-oriented losses that occur with death, job loss, and the like. However, I believe it is unlikely that most women in this study will have the vocabulary to describe the losses in that sense, and that this lack of vocabulary on how to articulate the grief at least in part comes from the lack of discussion and visibility that exists in our culture on these reproductive losses. I assume that this will be part of the ambiguity that the women describe, even if it is not in that language. I also assume that awareness or knowledge of social grieving rules and rituals will not be explicit for most women because we do not often talk in such language in day-to-day life regarding grief and loss.

Second, I assume that most of the women who elect to participate in this study will have had a significant experience with their infertility or miscarriage, and that this will likely be an emotional experience for them. This assumption is based on a pilot study on infertility that I conducted with eight cis-gender women (McBain & Reeves, 2019). While I realize that some women are not as emotionally affected by reproductive loss and am hopeful that I can gather a variety of perspectives, I do expect that the sample from the current study will be consistent with the literature in that women tend to be recruited and participate in research when the experience was significant. In order to prevent my prior assumptions from interfering with data collection

and analysis, I kept a journal throughout the duration of this study to document my personal attitudes, biases, values, and knowledge.

Participants

For this dissertation study, the researcher interviewed women affected by infertility and miscarriage. Inclusionary criteria for study participants were as follows: Must identify as a cis-gender female; must be at least 18 years of age; must have access to a computer and an active email address; must have access to a phone and an active telephone number; and must meet the clinical definition of infertility for their age group at present or in the past *or* must have had at least one miscarriage at or before the 19th week of pregnancy. The exclusionary criterion was a previous diagnosis of an intellectual disability. This was chosen based on the possibility that an individual with an intellectual disability may not be able to fully comprehend the risks and total impact of sharing her experience. Broadly, each participant was described by one of the three following categories.

Women affected by infertility without miscarriage. The women in this group met criteria for infertility as defined by the CDC (2018), the inability to conceive after at least one year of unprotected sex. These women had either never been pregnant, or had at least one successful pregnancy which resulted in a live birth. The grief experience resulted from infertility only. Four participants fell into this category.

Women who have experienced miscarriage without infertility. The women in this group experienced the loss of a pregnancy at or before the 19th week of pregnancy (CDC, 2017b, 2017c). The women could have had any number of miscarriages and the grief experience could focus on any one or all of their miscarriages, as determined by the woman who gave the interview. They may or may not have had living children and they did not meet criteria for the

clinical definition of infertility (CDC, 2018; WHO, 2018a, 2018b). Four participants fell into this category.

Women affected by infertility and miscarriage. The women in this group have experienced both infertility and miscarriage. They could have had any number of miscarriages, which must have occurred at or before the 19th week of pregnancy (CDC, 2017b, 2017c). The women may or may not have living children. The miscarriage(s) could have occurred at any time throughout the woman's life, including before knowing that she was dealing with infertility. The grief experience focused on the experience of both infertility and miscarriage, although the extent to which these two reproductive losses intertwine was determined by the woman who gave the interview. Eight participants fell into this category.

Appropriate sample sizes in phenomenological research varies, with some recommendations including 3-10 participants (Dukes, 1984) and 5-25 participants (Polkinghorne, 1989). The target number of participants for this study was 15-20 women and a total of sixteen cis-gender women completed the informed consent process and interview. Four of the women had endured infertility without miscarriage and four of the women had endured miscarriage without infertility. The remaining half of the sample had experienced both. Nine of the participants identified themselves as White or Caucasian, six identified as Black or African American, and one participant identified herself as Latina. All of the participants were partnered and fifteen of the sixteen women were married. The average age of the participants was 37, with a range from 26 to 44 years old. See Table 1 for a demographic representation of each participant by ethnicity, age, and reproductive loss.

Table 1. Demographic Information

	Infertility	Miscarriage	Both
Caucasian	Marie (37)	Gloria (37) Rosa (33)	Hilary (38) Carrie (40) Maya (37) Scarlett (33) Anne (30) Victoria (26)
African American	Audrey (43) Meryl (38) Margaret (40)	Diana (35)	Elizabeth (44) Marilyn (44)
Latina		Joan (44)	

Sampling Strategy and Recruitment

Three types of purposive sampling strategies were used in this study (Creswell, 2013). Criterion sampling includes all cases of interest that meet a certain criterion (Miles & Huberman, 1994), and is the experience of infertility or miscarriage in this study. Convenience sampling was employed so that the researcher may directly contact individuals she knows who are or have been affected by infertility or miscarriage (Creswell, 2013). The final sampling strategy was snowball sampling, which allowed potential participants to contact others who may meet study criteria and want to participate (Miles & Huberman, 1994). It was possible that some women who were aware of this study may know others who may have wanted to participate, and snowball sampling allowed for recruitment of these women.

Recruitment occurred from a combination of approaches. The researcher had been in contact with three gatekeepers who had expressed an interest in distributing the information about this research study once it was approved. The first gatekeeper is the owner of a counseling office which provides counseling services and support groups for infertility. The second gatekeeper is a nurse practitioner who works with many women who have experienced reproductive

loss. The researcher contacted these two gatekeepers through online messages to inform them that the study was approved and asked that they please distribute an attached flyer (Appendix A). The flyer was created by the researcher, and included information about the study as well as the researcher's contact phone number and email address (redacted in Appendix A). The third gatekeeper is the CEO of a non-profit counseling agency. The researcher had been given permission to make an announcement at the next monthly staff meeting after study approval to make staff at the agency aware of this study. Staff were eligible to participate and they may have also passed along the study information to anyone they knew who may have wanted to participate, including their family, friends, or clients. Hard copies of the flyer were made available for anyone who was interested. Additionally, a staff email was sent out by the researcher with general information about the study and an electronic copy of the flyer was attached. The purpose of providing both the verbal announcement and email announcement is to reach a wider number of staff. Not all staff are present for the monthly staff meetings, meaning the email reached those who were not able to attend. The verbal announcement allowed for the researcher to reach the majority of staff in-person and provided a face of who is conducting the research. This may have provided the start of a rapport with potential participants. All communication about this study took place between the researcher and the interested party; their inquiries remained anonymous and their choice to participate or distribute information to others was not disclosed to the CEO or other staff. Men also heard about the study from this announcement and while they were not eligible to participate, they may have passed along the information if they believed they knew someone who would have liked to participate.

There were several individuals that the researcher knew or had met directly who had expressed interest in participating in this study or passing along the information to others. These

individuals were contacted via email (Appendix B) or text, depending on the type of contact had in prior interactions. An attempt to recruit participants from the Internet was also made. The researcher reached out to sixty-one administrators of various support groups on infertility or miscarriage via email. The group facilitator was asked to pass along the information about this study to anyone who may have been interested. The researcher provided an introduction, the purpose and rationale for the study, and contact information in the email (Appendix C) and a copy of the flyer was included as an attachment. Approximately ten group admins responded that they would distribute the flyer to their group.

Informed Consent

Every potential participant had the ability to contact the researcher by phone, text, or email, regardless of the recruitment method that was used to provide them with the information. The researcher responded to any individual expressing interest in the study through the method in which they contacted her (phone, text, or email) and explained that the next step would be to set up a time to go over informed consent. Informed consent allowed the potential participant to make a more informed decision about whether they would have liked to participate in this study and allowed the researcher a chance to appropriately screen the individual to ensure that they met criteria for participation. See Appendix D for Western Michigan University Human Subjects Institutional Review Board (HSIRB) approval documents, including the informed consent document.

As individuals contacted the researcher expressing interest in the study, an email address was collected from them and a time was established to go over informed consent. Approximately 10-30 minutes before the scheduled time to go over informed consent, the researcher emailed the participant a link to the informed consent and demographic survey on SurveyMonkey. At the

scheduled time for informed consent the researcher called the potential participant on the phone. Once on the phone with them the researcher directed them to their email and the link to SurveyMonkey. The potential participant was walked through informed consent verbally over the phone (Appendix D). This gave them an opportunity to ask questions in real time and gave the researcher the opportunity to screen for their eligibility based on the inclusionary and exclusionary criteria. At the end of the informed consent form, they were asked if they understood and agreed to participate in this study. If they answered, “Yes,” there was verbal confirmation, and then they were instructed to check a box on the form that said, “I agree.” There was also a signature box on the informed consent form. The researcher explained to the potential participant that by typing their name on the signature line, they were electronically signing the consent form. She went on to inform them that their signature is not a binding agreement that they must go through with their interview and that they reserve the right to end their participation at any time; rather their signature is an acknowledgement that they read and understood the informed consent form and that they had the opportunity to ask any questions.

Once the informed consent form was finished, electronically signed, and verbal confirmation of their willingness to participate had been attained, the researcher set up a time to conduct the interview with the participant. Once the interview was scheduled, the participant was instructed to continue to the next page on SurveyMonkey, which was the demographic questionnaire (Appendix E). The demographic questionnaire was comprised of items such as number of pregnancies, number of miscarriages and gestation at which the miscarriage(s) occurred, number of living children, specific infertility diagnosis, and any fertility treatments, as applicable to each participant. The student researcher and participant briefly went over the questions to give the participant a chance to ask clarifying questions about the form, and then the student researcher

hung up the phone while the participant spent an additional few minutes filling out the demographic questionnaire. Once the demographic questionnaire was complete, the process of informed consent was finished and the participant was ready for their interview. To ensure that participants did not have second thoughts, the researcher discussed informed consent again at the beginning of the interview. If the participant did a face-to-face interview, a hard copy was brought to the interview. The researcher went over it with the participant again and had her sign it. If the participant was doing an interview over the phone, the researcher verbally reviewed informed consent before starting the interview and had the participant verbally state that she agreed to participate in this study. This ensured that participants provided consent at the beginning of their interview.

Data Collection Methods

The most common form of data collection for qualitative research is an interview (Paisley & Reeves, 2001). This phenomenological study gathered data through in-depth interviews (Creswell, 2013; Marshall & Rossman, 2016; Moustakas, 1994), a strategy that is used to gain the deep meaning of the participants' experience in their own words (Marshall & Rossman, 2016). In phenomenological interviewing, structure refers to how the researcher manages the process of questioning rather than dictating what is said, and a phenomenological researcher has the freedom to structure their interview in a way that supports a comprehensive investigation (Bevan, 2014). For this study, the researcher used a semi-structured interview approach. She developed a set of open-ended questions to provide structure to the interview, while maintaining flexibility in how the questions were worded and the order in which they were asked (Paisley & Reeves, 2001). This approach permitted freedom to elaborate on interest points, probe where appropriate, and ask relevant follow-up questions. See Appendix F for the interview protocol.

Data collection began in November 2018 and concluded in January 2019. Pseudonyms were selected by the researcher and organized randomly from 1 to 20, to accommodate the maximum number of potential participants. Participants were assigned pseudonyms based on the incidental order of their interviews. The length of the interviews ranged from 45 to 124 minutes, with the average interview lasting 72 minutes. Five of the interviews were conducted in-person and eleven were conducted over the phone. Two of the phone interviews had originally been scheduled for in-person but were rescheduled or changed to phone interviews due to circumstances such as inclement weather. The length of time and average was the same for the phone interviews as it was for all sixteen interviews, but the in-person interviews ranged from 64 to 102 minutes, with an average of 74 minutes.

Data Procedures

The researcher had five points of contact with every participant. The first was when the potential participant initiated contact with the researcher about their interest in the study. The second point of contact was going over informed consent and completing the demographic questionnaire if the person met the inclusion criteria and indicated consent to participate in the study. The third point of contact was the interview, which consisted of in-depth questions about their grief experiences related to their infertility or miscarriage. Interviews took place either in-person or over the phone, depending on the geographic location of the participant to the researcher. Every effort was made to conduct interviews in-person. It was estimated that each interview would last approximately 60 minutes. Each interview was audio recorded and then transcribed into a Microsoft Word document by the researcher. The audio files were stored on an encrypted device that was password protected and was deleted after transcription was complete and verified. The transcripts only identified the participant by a pseudonym and all other identifying

information was redacted. This included items such as names of friends or family members, places of work, schools, doctors' names and offices, social media, and other institutions or organizations with which the participant was affiliated. The fourth point of contact was the first member check, the purpose of which was to verify information. The participant read the transcribed copy of their interview and was invited to add or clarify anything they felt would add to a more comprehensive understanding of their story. They were not allowed to change or delete anything that was written already from the interview. The participant was also asked to ensure that all identifying information had been redacted. The participant had two weeks to complete and return the verified transcript to the researcher via email once the document had been sent. Twelve women returned their feedback within the allocated time frame, with an additional participant sending in her feedback late. The remaining three participants did not respond for the first member check. Nine of the participants sent back their transcripts with additional comments, and four of the participants stated outright that they had no further feedback or additions. The women varied on the amount of feedback they provided, with one participant adding two words to her transcript, and other participants providing up to several paragraphs throughout the document. Two participants added comments line by line throughout the document to add detail and clarity. Several participants in some way expanded on the stories they had told during their interview to encompass more of the emotion. If the researcher did not receive the first member check back from the participant within the two-week time frame, she moved forward with data analysis with the original transcription. The fifth and final point of contact was the second member check. This took place after the researcher had completed phase four of data analysis. At that point, the researcher had a sufficient idea of what the themes were and how they fit together, and a good grasp of the overall story that the themes told about the data (Braun & Clarke, 2006).

Phase 5 consisted of further refinement and definition of themes. This was a point in data analysis when the feedback from participants was suitable, because it was a time when themes had been explored and written in such a way that was appropriate for participant review and the information was helpful to the researcher in the final stages of data analysis. The participant again had two weeks to complete their feedback and send it back via email. Eleven women returned their feedback within the allocated time frame and two participants returned their feedback late. Nine of the participants stated that they had no further additions to the second member check. Three participants provided additional comments and paragraphs throughout the document. The nature of these comments were generally the women elaborating on how the preliminary theme resonated with their experience. One participant did not provide feedback within the document; rather, she stated in her response email that she wondered if there was a better way to reference a relative who had passed away than as “loved one”, as it implies that a lost fetus was not a loved one. Once the participant returned their second member check their participation in the study was complete. If the researcher did not receive the second member check back from the participant within the two-week time frame, she continued with data analysis. Participants were informed that even if they did not have additions or feedback for either member check, they were still encouraged to email the researcher with this information so that their participation in the member checks could be marked as complete. Once the participant had provided feedback after the second member check she was provided with a \$20 gift card as a gesture of gratitude for her contribution.

Overall participation in this study consisted of initiating contact for participation, completing informed consent, one interview, and two member checks. The total time of participant involvement in the five points of contact listed above was estimated to be 2.75 – 3 total hours. As

soon as the participant had successfully completed informed consent, her interview was scheduled. The researcher transcribed the interviews and gave the transcripts back for the first round of member checking as she completed them. The participant's ability to move from point of contact 3 to 4 and from point of contact 4 to 5 was dependent upon the student researcher's ability to provide the participant with the necessary transcript and information for member checking. Every effort was made to provide these materials to the participant within a timely fashion. The researcher was able to provide most of the participants with their transcription for the first member check between 2 to 4 weeks after their interview. The researcher proceeded with data analysis and the second round of member checking as the aforementioned timeframes allowed (two weeks for each member check). It was expected that all participants would complete their involvement within six months, which was estimated by the researcher based on her expectation of how long it would take to move through the phases of data analysis. The time frame from the first point of contact to the completion of participation for the thirteen women who returned the second member check ranged from 13 to 22 weeks, with an average of about 18 weeks spent as an active participant. Consistent with a phenomenological approach, data analysis occurred continuously and simultaneously with data collection (Creswell, 2013; Crist & Tanner, 2003).

Data Analysis

In accordance with van Manen (1997), hermeneutic phenomenological reflection was used in order to grasp the essential meaning of the topic. This reflection involved a process of consideration, clarification, and making the structure of the lived experience explicit throughout data analysis. When a phenomenon is analyzed, themes that make up the structure of the experience are identified (van Manen, 1997). For this study, thematic analysis was employed as a procedural process to make the structure of the lived experience of infertility and miscarriage

grief explicit. This method was chosen because of its ability to identify, analyze, and present themes within a data set in rich detail (Braun & Clarke, 2006). By using this approach, this researcher attempted to explain and understand the meaning of infertility and miscarriage grief experience by interpreting the interview data through the ambiguous loss and disenfranchised grief frameworks. Other hermeneutic phenomenological studies have utilized Interpretive Phenomenological Analysis (IPA), which emphasizes an interpretive process in search of the meaning of the phenomenon (Crist & Tanner, 2003). One of the disadvantages to using Braun and Clarke's (2006) thematic analysis is that, while recursive, the process was more prescriptive than IPA. However, this approach allowed the researcher to uncover specific thematic elements related to the research questions and theories of ambiguous loss and disenfranchised grief and was thus selected as an appropriate method of data analysis for this dissertation.

Braun and Clarke (2006) developed a six-phase method that provides a clear protocol for conducting thematic analysis. Thematic analysis can vary across different perspectives and epistemologies, but consistently involves searching for themes across a data set to find recurrent patterns of meaning (Braun & Clarke, 2006; Ho, Chiang, & Leung, 2017; van Manen, 1997). The six-phase method of thematic analysis as described by Braun and Clarke (2006) was used for analysis of the data set. Thematic analysis is a recursive process, with continuous back and forward movement between the six phases. A description of each phase as discussed by Braun and Clarke (2006) is presented below.

1. *Familiarizing yourself with the data.* This initial phase consists of transcription, reading and re-reading the data, and noting initial ideas. This is also the phase where writing begins, which continues throughout the coding and analysis process.

2. *Generating initial codes.* This phase involves producing initial codes from the data set in a systematic way.

3. *Searching for themes.* In this phase, codes are sorted and organized into potential themes. Visual representation, such as tables or a thematic map, may also be generated at this point to prompt the researcher to begin thinking about the relationship between the codes, themes, and different levels of themes (e.g., overarching themes and sub-themes).

4. *Reviewing themes.* This phase consists of two levels of refining themes. The first is reviewing the theme at the level of the coded extracts to determine if there is a coherent pattern. Once this has been achieved, the researcher moves on to level two, which is reviewing the theme in relation to the entire data set. The thematic map is evaluated and refined until it satisfactorily represents the themes.

5. *Defining and naming themes.* In this phase, ongoing refinement of each meta-theme and sub-theme takes place. Clear definitions and names for each theme are generated, as well as identifying the “story” of the analysis.

6. *Producing the report.* This is the final phase of analysis, where the story of the data is told, excerpts from the data are selected that provide evidence of the identified themes, and the research questions are answered. A scholarly report of the analysis is ultimately produced.

First the researcher began by transcribing all of the sixteen interviews to begin immersion into the data. Each transcript was read through once after it was completed. Then the transcriptions were read through a second time, and the researcher made notes in the margins and on the back of each transcript of initial ideas for coding. The researcher was reflective when reading each transcript and reread all interview field notes. The notes were documented on note cards and

incorporated into a hand-written paragraph on the back of each transcript that also detailed her own reactions, assumptions, and reflected on potential blind spots (Richards, 2015).

Secondly, the researcher read over the transcripts a third time and continued to search for latent themes in the data that described the phenomenon of infertility and miscarriage grief in the most basic way related to each research question (Braun & Clarke, 2006; Foss & Waters, 2007). This consisted of words and phrases that were comparable in meaning or connected somehow to the research questions, along with new findings that the researcher found significant (Creswell, 2012). Since the researcher was manually coding the data, potential patterns were highlighted (Braun & Clarke, 2006; van Manen, 1997) and lines were drawn to indicate segments of data. To keep the context of the segment intact, relevant surrounding data were included, and the data were coded for as many potential patterns as possible (Braun & Clarke, 2006).

Third, the researcher cut out each piece of code and began organizing the pieces of code into approximately 30 categories of broad, initial groupings (Braun & Clarke, 2006). Reflexivity was continued using journaling (Lincoln & Guba, 1985) so that the researcher could ensure that these preliminary groupings reflected the participants' experience of infertility and miscarriage grief. In this phase the researcher created a visual thematic map (Appendix G) of how she was visualizing and organizing the theme-piles (Braun & Clarke, 2006). The researcher reread each grouping category and placed pieces of code together that shared similar features into piles of candidate themes and subthemes. A miscellaneous pile was also created at this phase to temporarily set aside any pieces of code that did not fit within the candidate themes.

After the emerging themes were identified, the researcher organized all candidate themes by research question in the fourth phase. The researcher reread each pile and made decisions on

whether the candidate themes should be collapsed or made into separate themes for further refinement of the data. There were also new themes that were generated as well as some of the themes being dispersed into other piles. This process was repeated until the researcher determined that all candidate themes made a coherent pattern (Braun & Clarke, 2006) in relation to the research questions. The thematic map was updated to reflect the new understanding of thematic patterns. At this phase of analysis, the researcher had strong candidate themes and created a document of all meta- and subthemes with a descriptive paragraph detailing salient points about the meaning of each theme. This document was sent to the participants for the second member check and to the peer reviewer for feedback.

In the fifth phase, the researcher continued refinement to determine the essence of each theme. She used feedback from participants and the peer reviewer to help define the story of each theme, as well as how the themes fit together to answer the research questions (Braun & Clarke, 2006). The themes were considered on their own, as well as how they related to each other. The researcher continued to practice reflective journaling (Lincoln & Guba, 1985) to ensure that the resulting meta- and subthemes were truly the result of the analysis process and the participants' accounts of infertility and miscarriage grief. Themes were determined by prevalence and salience amongst the research participants as they related to the research questions, and the theories of ambiguous loss and disenfranchised grief.

In the last phase, the researcher identified vivid excerpts that captured the essence of each meta- and sub-theme. The final report was written, and told the story of the participants' infertility and miscarriage grief experiences.

Trustworthiness

Phenomenological knowledge is empirical based on experience; however, phenomenological research is not an empirical analytic science (van Manen, 1997). The validation and evaluation principles established for quantitative research do not accommodate the flexible process of qualitative investigation (Creswell, 2013). Trustworthiness of a study ensures that measures of rigor are in place that recognize the subjectivity within qualitative research (Marshall & Rossman, 2016; Merriam, 1988). In this study the researcher followed Lincoln and Guba's (1985) criteria for trustworthiness, which includes credibility, transferability, dependability, and confirmability.

Credibility. Credibility involves activities that increase the likelihood that credible findings and interpretations are produced (Creswell, 2013; Holloway & Wheeler, 2002; Lincoln & Guba, 1985). Such activities include prolonged engagement with the data and triangulation, which is the act of employing different sources, methods, investigators, and theories to corroborate the evidence (Creswell, 2013; Lincoln & Guba, 1985; Miles & Huberman, 1994; Patton, 1980, 1990). This study uses two activities to enhance credibility: peer reviewing and member checking. In peer review, an external check of the research process is conducted (Lincoln & Guba, 1985; Marshall & Rossman, 2016). The researcher asked a peer from her doctoral program to act as the "devil's advocate" by asking questions pertaining to the methods, meanings, and interpretations presented, and to provide a space for sympathetic listening for her own cathartic experience (Lincoln & Guba, 1985). After phase four of data analysis was complete, the researcher sent the peer reviewer the same document that had been sent to the participants for the second member check, and a copy of Braun and Clarke (2006). During the meeting, the peer reviewer asked questions and processed two main areas with the researcher: data analysis and the

candidate themes. The feedback from the peer reviewer and the participants contributed to final decisions made about the meta- and subthemes. Member checking is a process that asks for the participants' reactions, corrections, and elaborations and solicits their view of the credibility of the results and interpretations (Marshall & Rossman, 2016; Merriam, 1988; Miles & Huberman, 1994). This study exercised member checking by sending the participants a copy of their transcript immediately after transcription had been completed. The participants had the opportunity to clarify or add anything they believe would contribute to a more thorough depiction of their experience. The researcher also sent the participants the preliminary themes that were generated after phase four of Braun and Clarke's (2006) thematic analysis protocol. The participants had the opportunity to share their thoughts about whether their lived experience had been captured.

Transferability. Transferability refers to the likelihood that the study findings can be transferred to other settings or similar situations (Creswell, 2013; Holloway & Wheeler, 2002; Marshall & Rossman, 2016). This concept is akin to external validity in quantitative research. Since phenomenology does not allow for generalizations (van Manen, 1997), rich description is necessary to assist readers in determining whether the findings from the study can be transferred (Creswell, 2013; Lincoln & Guba, 1985). Thick, rich description allows readers to follow details about aspects such as the participants or themes that will help them determine whether the findings from this study can be transferred (Creswell, 2013).

Dependability. Dependability is the transparency of the researcher in detailing the process of decision-making applied throughout the data analysis and generation of themes and conclusions (Marshall & Rossman, 2016). An audit trail consists of clear documentation of these decisions (Creswell, 2013; Holloway & Wheeler, 2002; Marshall & Rossman, 2016). Dependability of the study can be attested to if the process described in the audit trail is deemed

acceptable (Lincoln & Guba, 1985). In this study, dependability was ensured through the use of an audit trail, which included notes on any design changes or revisions that take place as ideas and themes begin to emerge. Additionally, personal thoughts and assumptions of the researcher were documented along with reflections and reactions throughout the process.

Confirmability. Confirmability is the extent to which the data analysis and final conclusions are supported by the data and reflect the goals of the study, rather than representing the researcher's prior assumptions (Creswell, 2013; Marshall & Rossman, 2016). Again the audit trail was used to provide an account of decisions made throughout the process so that anyone can trace the logic that led to the codes, themes, and final interpretations. Furthermore, the audit trail also contained the process of reflexivity, a practice where the researcher reflects critically on her own assumptions and monitors her relationship with the participants and their reactions to the participants' reports (Holloway & Wheeler, 2002). As the measurement tool, phenomenological researchers must recognize how their unconscious preconceived attitudes, beliefs, and assumptions impact data collection and analysis (Creswell, 2013; Holloway & Wheeler, 2002). According to van Manen (1997), rather than bracketing prior knowledge, the researcher must appreciate that prior knowledge builds the study and has an influence over the study design and formulation of research questions. This researcher engaged in journaling (Lincoln & Guba, 1985) throughout the duration of this study in order to document personal attitudes, biases, values, and knowledge, and provide a record of decisions made in the refinement of this study.

Summary

This chapter presented the methodology used for the execution of this study. A brief report of the phenomenological approach to qualitative research and the application to the current study was offered. The research questions were identified and the role of this researcher

was described. Methodological procedures such as participant selection, sampling, recruitment, data collection, data procedures, and data analysis were included. In the next chapter, the results of the study are presented.

CHAPTER IV

FINDINGS

Introduction

The first section of this chapter will present a depiction of the study participants. This includes information composed from the demographic questionnaire and details collected about the nature of their reproductive loss. The next section comprises an in-depth analysis of the data and a discussion of the research findings that emerged from the sixteen interviews. Selected quotations are included, which strive to provide the reader with a greater understanding of the lived experience of infertility and miscarriage grief and also reflect the personal voice of each participant (Creswell, 2013). Lastly, a collective narrative is presented to describe the meaning of the grief experience.

Description of Participants

This section presents a summary of all participants included in this study. To maintain anonymity, certain details such as state of residence, occupation, and gender and current age of living children are not disclosed. Each participant summary was compiled with information that she provided on the demographic questionnaire and during her interview.

Women Affected by Infertility Without Miscarriage

Four of the participants met criteria for infertility as defined by the CDC (2018), the inability to conceive after at least one year of unprotected sex:

Audrey – Audrey is a 43-year-old African American female. She has a history of uterine fibroids and attempted to conceive for five years. She underwent two D&C procedures to clear

blockages in her reproductive organs. She declined IVF treatment and eventually had a hysterectomy. Audrey went through the process to become a foster parent and adopted her two children when they were ages two and five.

Meryl – Meryl is a 38-year-old African American female. She has a history of PCOS, endometriosis, cysts, and fibroids. She had undergone a slew of surgeries over several years that included one myomectomy (removal of fibroids) and several draining or excising of cysts. She had done numerous rounds of Clomid, Femara, Letrozole, and “other pills” while under the treatment of her reproductive endocrinologist. She had three unsuccessful rounds of IVF with two different doctors. Her fourth round of IVF resulted in the birth of healthy twins. She ultimately required surgery to remove both fallopian tubes and later had a full hysterectomy. Meryl disclosed that the fertility procedures cost her between \$30,000 and \$40,000.

Margaret – Margaret is a 40-year-old African American female. She had a history of ovarian cysts and scar tissue that required surgery in her early twenties and had blockages in her fallopian tubes. With the financial assistance of family, friends, and credit cards, she was able to afford one round of IVF, which was unsuccessful. She experienced two failed adoptions: During the first attempt Margaret and her husband had met with and been chosen by the birth mother, who at the time was still pregnant, but then ultimately chose another couple to adopt the baby. In the second attempt, Margaret had the baby in her home for five days, with the birth mother then changing her mind and taking the child back. Margaret and her husband attempted to adopt a third time and were successful. She is now in early menopause.

Marie – Marie is a 37-year-old Caucasian woman. A reproductive endocrinologist diagnosed her with ovulatory dysfunction and endometriosis, resulting in “at least” two surgeries to remove scar tissue. She did several rounds of Clomid and Letrozole, and “at least” three IUIs, all

of which were unsuccessful. After five years of trying to conceive, she chose to pursue IVF, which resulted in the birth of her child. At the time of her interview she was seventeen weeks pregnant with her second child, which was the product of a transfer of a frozen embryo that remained after the initial round of IVF.

Women Who Have Experienced Miscarriage Without Infertility

Four of the participants experienced the loss of a pregnancy before the 19th week of pregnancy (CDC, 2017b, 2017c):

Diana – Diana is a 35-year-old African American woman. She described herself as a healthy person, and stated that she had a history of regular menstrual cycles and normal papanicolaou smears. Her first two pregnancies were non-complicated and produced the healthy births of her older children. Her third pregnancy resulted in a miscarriage at approximately 8 to 9 weeks of gestation. Her fourth pregnancy produced a healthy child.

Gloria – Gloria is a 37-year-old Caucasian woman. Her first pregnancy resulted in a miscarriage at 9 weeks gestation and was classified as a blighted ovum, in other words, an empty sac with no fetal tissue. The sac was removed by her obstetrician. Her second and third pregnancies resulted in healthy births of her living children. Her fourth pregnancy resulted in a miscarriage that was confirmed at 14 weeks of gestation, with the fetus having stopped growing at approximately 12 weeks. She was given her choice of three options: wait to see if she will miscarry naturally, schedule a D&C procedure, or take a vaginally-inserted medication to induce the miscarriage at her discretion. She chose to take the medication at home, and endured the delivery of the fetus over the toilet, cutting the umbilical cord with a pair of scissors, and placing the fetus in a strainer in the bathroom sink. She ultimately was rushed to the emergency room due to uncontrollable hemorrhaging.

Rosa – Rosa is a 33-year-old Caucasian woman. Her first pregnancy resulted in the healthy birth of her first child. The fetus in her second pregnancy stopped growing at approximately 6 weeks, which she did not discover until her 9-week appointment. She took Misoprostol, the vaginally inserted medication, to induce the miscarriage at home. The next day at her OB's office she was prescribed a second dose due to residual tissue in her uterus, which resulted in significant hemorrhaging. She did not go to the emergency room. Approximately three to four months later she began hemorrhaging again and underwent a partial D&C at her OB's office to remove necrotic tissue in her uterus that was a by-product of the initial miscarriage event. Rosa was a victim of sexual assault during her childhood, the effects of which complicated her grieving process.

Joan – Joan is a 44-year-old Latina female. She was the only participant who spoke English as a second language and who was not born in the United States. Joan had a diagnosis of PCOS but did not experience difficulty getting pregnant; rather, she produced blood clots when pregnant that impaired her ability to sustain pregnancies. She had been pregnant a total of six times, with five of those pregnancies resulting in miscarriages between 5 ½ and 8 weeks gestation and one ectopic pregnancy. She underwent one IUI procedure after her third miscarriage. Her fifth pregnancy resulted in the birth of a healthy child, and was later followed by her last miscarriage from her sixth pregnancy. She and her husband adopted a child within a year of the last miscarriage.

Women Affected by Infertility and Miscarriage

Eight of the participants experienced both infertility and miscarriage:

Hilary – Hilary is a 38-year-old Caucasian woman. She had two successful, non-complicated pregnancies and delivered healthy children before she and her husband decided to add to

their family. After trying to conceive for about fourteen months and visiting her doctor, who advised her to just be patient, she fell pregnant naturally. At nine weeks gestation she went to the doctor after experiencing some spotting and the doctor verified that she was miscarrying. She miscarried the pregnancy naturally at home without significant pain. After two more years of trying to conceive, she fell pregnant again. At approximately 10 weeks gestation she went in for her first ultrasound and the doctor could not find a heartbeat. She was sent home to “wait and see”, and came back for an appointment the following week, during which it was confirmed there was no heartbeat and that the fetus had stopped growing at about six weeks. She underwent a D&C procedure to remove the fetal tissue, an event that she described as “traumatizing”. Hilary has since had a fifth pregnancy that resulted in the live birth of a healthy child.

Anne – Anne is a 30-year-old Caucasian woman and had been attempting to conceive for about five years. She received a diagnosis of PCOS approximately six months after she and her husband started trying to conceive and since then had tried a slew of medications and timed cycles. She underwent two unsuccessful IUIs. Her first round of IVF resulted in a pregnancy, which was miscarried at three weeks gestation. Her second and last round of IVF was unsuccessful. About two months before her interview for this study, Anne and her husband had their six remaining embryos terminated and decided to live their lives without further pursuit of having children.

Carrie – Carrie is a 40-year-old Caucasian female. She had a diagnosis of PCOS and her husband had a low sperm count. She is the only participant to disclose male-factor contributions to why she was not conceiving. One menstrual cycle after starting a medication to treat problems with her thyroid, Carrie became pregnant with her first child. She attributed the pregnancy to the thyroid medication and a change in her husband’s diet. Her second pregnancy showed that she

had low progesterone and she miscarried that pregnancy at seven weeks gestation. Her third pregnancy produced a healthy live birth of her last child.

Elizabeth – Elizabeth is a 44-year-old African American woman. She became pregnant with her first child unexpectedly without intervention. This pregnancy produced a blighted ovum, which Elizabeth found out at her nine-week appointment, and she required a D&C to clear the remains. She later had a second pregnancy that ended in miscarriage at ten weeks and it was recommended by her doctor to take medication to induce expulsion. Elizabeth disclosed that she had chosen to have an abortion earlier in her life and described how her miscarriage grief was complicated by this event. Elizabeth also tried fertility medications and at least one IUI during her attempts to get pregnant but the timeline of these procedures was unclear.

Maya – Maya is a 37-year-old Caucasian woman. Her first conception occurred naturally but resulted in an ectopic pregnancy and ultimately caused Maya to lose her left fallopian tube. She underwent three IUIs and medications, all of which were unsuccessful. She tried acupuncture and attributes this to her resulting healthy pregnancy and birth of her only child. Two years later she attempted to achieve pregnancy again with the use of fertility medications and fell pregnant on the first round. She went in for an ultrasound at eleven weeks gestation and was told there was no heartbeat and that she would miscarry. She and her husband continued trying to conceive for some time after the miscarriage, but within the last year have decided that they are now done pursuing another pregnancy.

Scarlett – Scarlett is a 33-year-old Caucasian woman. She and her husband have been attempting to conceive since 2013. She had a diagnosis of stage two endometriosis and a history of uterine polyps, for which she underwent two surgeries. Scarlett had done six IUI treatments, all of which were unsuccessful. Her first IVF attempt resulted in a fraternal twin pregnancy. At

her first prenatal appointment it was discovered that one of the twins was a blighted ovum and the second twin had a low heartbeat. At seven weeks Scarlett was told there was no longer a heartbeat on the surviving twin. She had a D&C procedure several weeks later. She since has done two more embryo transfers, both with two embryos each and neither transfer resulting with implantation.

Marilyn – Marilyn is a 44-year-old African American female. She is divorced, which she attributed directly to her infertility struggles, and has been in a long-term relationship with her current partner for the last ten years. She had irregular ovulation since adolescence and had two D&C procedures to clear blockages in her reproductive organs. She became pregnant for the first time after she began dating her current partner. This pregnancy miscarried in the 18th week of gestation after Marilyn discovered the head was crowning while sitting down to use the restroom. She went to the hospital and required another D&C procedure. Several years later she became pregnant for the second time. She was told at about 10 weeks along there was no longer a heartbeat and she underwent a fourth D&C a week later to clear the remains. Marilyn got pregnant for the third and last time several years ago, which resulted in the healthy birth of her only child. Marilyn disclosed a history of sexual rape and molestation from when she was a minor child, and stated that her reproductive loss grief would randomly trigger negative memories about these past events.

Victoria – Victoria is a 26-year-old Caucasian female. After one year of trying to conceive she was put on fertility medication and then underwent three unsuccessful IUI procedures. In her first IVF attempt, two embryos were transferred but neither resulted in implantation. Her second IVF attempt also transferred two embryos, which led to a chemical pregnancy. Two days after

finding out she was pregnant, Victoria had a miscarriage. She has not pursued medical intervention since.

Findings

Thematic patterns began to emerge as the data were gathered, coded, and refined. Many of the themes are interconnected and share overlapping qualities, which was expected given the intricacy of the grief experience. The themes are presented with their corresponding research question (see Table 2), beginning with the three sub-questions. A table of supporting quotes follow each theme. The overarching research question is answered as a narrative based on the findings from the sub-questions and is presented in the last part of this section.

Table 2. Themes

Research Questions	Themes and Sub-themes
RQ1: What are the ambiguous losses associated with infertility and miscarriage?	<ol style="list-style-type: none"> 1. Loss of Normative Life Experiences 2. A More Personal Loss
RQ2: How is infertility and miscarriage grief disenfranchised?	<ol style="list-style-type: none"> 1. Stigma Leads to Silence 2. A Lack of Clear Grieving Rituals 3. Elements of Insensitive Encounters <ol style="list-style-type: none"> a. assumptions and expectations b. assuaging the situation c. lack of effort and absence
RQ3: How can counseling services be improved for women who are experiencing or who have experienced infertility and miscarriage grief?	<ol style="list-style-type: none"> 1. Further Training 2. Increasing Access to Appropriate Resources <ol style="list-style-type: none"> a. connection to professional support b. removal of barriers to existing support 3. Characteristics of Validating Support <ol style="list-style-type: none"> a. presence and availability b. empathy and understanding c. acceptance and permissiveness

The overarching research question was: *What is the meaning of infertility and miscarriage grief experience for women?*

The three sub-questions are:

1. What are the ambiguous losses associated with infertility and miscarriage?
2. How is infertility and miscarriage grief disenfranchised?
3. How can counseling services be improved for women who are experiencing or who have experienced infertility and miscarriage grief?

Findings for Research Question 1

What are the ambiguous losses associated with infertility and miscarriage?

Theme 1: Loss of Normative Life Experiences

The participants all identified expectations and beliefs they had about what path their lives would take to achieve pregnancy and motherhood. Many of the women could describe their original family vision in great detail, including when they would begin having children, how many children they would have, and the imagined or hoped-for gender and birth order. The overall sense was that having children was a natural order of life that followed other life stages, as Marilyn described: “We finished college, we got married, we bought a house, a new car. It was just like [having children] was next.” The build-up of the envisioned future family, which was often constructed at an early age, was consequently extremely difficult to adjust to and produced enormous amounts of grief when it was not realized.

Fifteen of the sixteen women commented on how their infertility or miscarriage had robbed them of anticipated life stages and events. A blissful future pregnancy was a life experience that several women believed they would never have again after enduring infertility or miscarriage. Gloria described how losing her first pregnancy to miscarriage tainted her later pregnancies:

Every pregnancy after that, it wasn't until I got to the nine-week mark, which is when I lost my first one, before I even started to feel more comfortable, and not until we got to the twelve-week mark that I even breathed a sigh of relief. Now that we've had this [second] loss past that twelve-week mark, any future pregnancies are going to be certainly very different than my very first one, which was so full of hope and excitement. Not that another pregnancy won't be, but it will also be littered with fear and anxiety.

Some of the women waited until very late in their pregnancies to tell others or begin buying items in preparation for the baby. Marilyn said, "I can't celebrate this pregnancy basically until I see this baby alive and well...Not until the very end did I start buying stuff, because I didn't trust it. I didn't trust that I'm going to have this baby." After four miscarriages, Joan stated that she quit her job and put herself on bed rest early in her fifth pregnancy because she was so afraid of miscarrying her child, even though no doctor had insisted she needed to go on bed rest. She had been seeing a therapist to grieve the previous miscarriages, but during this pregnancy she stated the focus of her therapy shifted to, "How can I survive being pregnant?" There was also a strong sense of being cheated out of what should have been an exciting time in their lives. For those without living children, a major loss was that of the entire life stage of parenthood, raising children alongside their peers, and eventual grandparenthood. Anne captured this in her statement, "I'm in a stage of life where friends are constantly getting pregnant. I'll probably get a break from that for a little while and then they'll be becoming grandparents and then that'll be another thing I miss out on."

The participants also described mourning a future child or idea of a child as that child fit within the family unit; essentially, they were mourning the *vision* of how their family would have looked had a would-be child actually been conceived or born. The women who experienced miscarriage had a particularly strong assertion that the loss of that specific child could not be replaced by another pregnancy, because the timing of that child's birth in the calendar year or

birth order was unique. Hilary explained, “I was, and still am, missing the babies being part of our lives and knowing that their absence was changing our family as much as their presence would have.” These losses of otherwise normative life experiences are ambiguous because they follow a future-orientation. This is different from the past-oriented loss of a loved one, in which there are often memories to look back on and someone to remember. A future-orientation made the loss difficult to articulate and mourn because there was not a clear picture in mind of who was being grieved; essentially, it was the imagined picture of who the child would have been that the women were mourning. The participants talked about grieving the loss of a child that they did not know—there oftentimes was no known gender, name, no personality, or no memories of that child within the family to look back on. Joan described this as, “A loss of what could have been. It’s a loss of, I don’t know how you look like, I don’t know how you sound like, I don’t know all these and that makes it harder—not knowing.”

Additional supporting quotes from participants regarding the theme Loss of Normative Life Experiences are given in Table 3.

Table 3. Supporting Quotes: Normative Life Experiences

RQ1: Normative Life Experiences	<p>“I was expecting [to get pregnant] once I got married, because of course that was the whole dream, you get married, you have a family. That’s what I saw for my life, that’s what I expected, even growing up.” – Audrey</p> <p>“I always wanted to have a little girl. You have these fantasies about—and I say fantasy because now I know they are very naïve ideas—oh, we’re going to get married, and then we’re going to get pregnant.” – Joan</p> <p>“I feel like I just lost the ability to enjoy the first couple months [of pregnancy] and to enjoy the fact that I was able to get pregnant again...I felt like it just robbed me of happiness for a couple months.” – Diana</p>
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Theme 2: A More Personal Loss

Thirteen women discussed deeply personal and internalized elements that contributed to the intensity of the loss. Throughout the interviews, it became apparent that a major aspect of what made reproductive loss so difficult to grieve was a sense that it was a much more private and intimate loss than what is felt with the death of a loved one. Carrie said,

I lost my father two years ago. [Grief from infertility and miscarriage] is different because it gets you in the core of yourself. It's not outside of you...it feels the closest to your inner self that it could possibly feel. It's way stronger than any other grief I've experienced.

One of the key factors for why the loss felt so personal was because the loss was connected to her own body. Even when the reproductive loss was not the fault of the woman, a sense of personal responsibility lingered, as Rosa described:

It's still your body so you somehow feel like you should have been able to make this happen. My grandmother passed, that was awful and sad but...it wasn't immediately connected to me. But this [miscarriage], it was guilt and alone and sad and just shameful, even though it's not. I think that makes it different, having it be something that is so very, very, very personal to you. It was in my body, I somehow felt responsible for it.

A few of the women admitted to feeling deficient because their bodies would not do what they are "supposed" to do, as Meryl explained,

I felt like this is what we're supposed to do, be able to make babies and that's what distinguished you from men. This is our superpower so to speak, and so I felt like part of my womanhood was lost because I did connect motherhood and womanhood. So I felt like that was a loss.

The connection to the body also produced a sense of unfairness that applied to not ever feeling, or having felt and lost, life within. Elizabeth's father died suddenly several years ago and then she later grieved her cousin's suicide. She went on to say,

[Infertility and miscarriage grief] was so personal because it was in my body and I can't explain that feeling. I can explain the grief from losing my father...Those things were outside of me and even though I could still rationalize it a little bit, I couldn't really

rationalize having a miscarriage...I can't unfeel that feeling or unlearn that feeling of having life inside of me and then it's just gone.

As Elizabeth stated in the above quote, articulating the personal sense of reproductive loss proved to be difficult because there are few known or accepted responses for how the loss is justified. Many of the participants commented that they could rationalize the death of an older relative because they had lived a good life or they had been ill and are no longer in pain, but few could make sense of the experience due to the ambiguity of how the loss is articulated and conceptualized.

Additional supporting quotes from participants regarding the theme A More Personal Loss are given in Table 4.

Table 4. Supporting Quotes: A More Personal Loss

RQ1: A More Personal Loss	<p>"I felt like the biggest component of the grief from the miscarriages and infertility was the fact that it was an internal process for me and not something that was visible to the outside world. It was a part of my body." – Hilary</p> <p>"It's so a part of me. It's like a deep desire in my heart and in our family and in our marriage. It's so close to home. Not that a loss of a family member or whatever isn't close to home, but I think...because it's part of my body, it's just supposed to work." – Victoria</p> <p>"It really started to take a toll on me because I felt like I was less than a woman. You feel like as a woman you want to give your husband a child, that's what my body is meant for." – Marilyn</p>
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Findings for Research Question 2

How is infertility and miscarriage grief disenfranchised?

Theme 1: Stigma Leads to Silence

Fifteen participants discussed how social stigma related to infertility and miscarriage impaired their ability to freely discuss and disclose their pregnancies. Miscarriage stigma starts before any woman ever experiences a miscarriage herself, and is linked to a cultural message that discourages women from disclosing pregnancy before the end of the first trimester in order to circumvent having to go back and tell others that they are no longer pregnant in the event that a miscarriage occurs. The women in this study discussed the secrecy that enveloped pregnancy, which often had negative consequences on miscarriage loss and failed fertility treatment procedures. Maya said,

At first we didn't tell anybody the first time that we were pregnant. We wanted to wait until the twelve weeks when you're safe and all of that. So we didn't tell anybody and that I think definitely made it harder then when we lost [the pregnancy] because nobody knew. There was nobody to catch you when you fall type of feeling.

Stigma prevented many of the participants from talking about their miscarriage or infertility because they were embarrassed, felt shameful, or otherwise did not want to confront the “failure” of not being able to conceive or carry their pregnancy to term. In reference to her infertility, Marie stated, “I don't know why, but there's a stigma around it. I think it makes you feel like less of a woman. It makes you feel like you're failing somehow, so you just don't tell anybody.”

The majority of women in this study expressed a desire to talk about their experience, but felt they must be cautious about when or to whom they told their story, or otherwise felt that they couldn't converse about it at all because it is presumed to be a rude topic that should be kept quiet. In the following quote, Marilyn captures the sentiment that stigma prevents the details from being shared and allows other people to stay at a surface-level reality of the experience:

At no time did anyone share their experience. It was none of that. I guess because of guilt and shame [infertility and miscarriage are] taboo and we're not actually going to talk about

the experience of a miscarriage. I'm going to make sure that you're okay, as far as you're breathing, eating, you're not suicidal, that kind of thing. If you think about it, there's this stigma around it, so if the stigma was removed [there would be] open dialogue.

Maya emphasized that the historical message about infertility and miscarriage is that they are a “big, deep, dark secret. We don't talk about stuff like that; that's not a polite subject. It was very taboo and very brushed under the rug.”

The overall sense was that not discussing reproductive loss is an archaic maxim that constrained support for previous generations and that it is time to change the future of how infertility and miscarriage are discussed and represented to women. Anne provided her thoughts about how this could happen:

I think that the best thing at this point is for women to talk about what they're going through...Just getting stuff out there and normalizing it, because there's so much shame associated with this. 'Don't talk about it.' We should be able to talk about it and we should be encouraged to talk about it.

Infertility and miscarriage stigma keeps the losses silent and hidden; Anne is suggesting that talking more openly about experiences of reproductive loss would make the invisible visible, a sentiment that was shared by several other participants.

Additional supporting quotes from participants regarding the theme Stigma Leads to Silence are given in Table 5.

Table 5. Supporting Quotes: Stigma Leads to Silence

RQ2: Stigma Leads to Silence	<p>“We didn't share with people. I think as you go through infertility it's such a difficult thing that you need people and support in your life.” – Victoria</p> <p>“You don't tell anybody [that you're pregnant] in case something happens and then you don't have to retell everyone. Well, that is a terrible approach...I think we have to move away from that to remove the stigma of it being hush-hush, you just deal with it quietly.” – Rosa</p>
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Theme 2: A Lack of Clear Grieving Rituals

When a loved one passes away, a ritual such as a funeral may help with the bereavement process, but a lack of grieving rituals currently exist to support women during or after a reproductive loss. Elizabeth illustrated why a lack of rituals minimized her grief:

Grief from miscarriage is a silent grief. There aren't death announcements to send out. In most cases there's no wake, funeral, or burial. There's an unspoken message that you don't have permission to grieve because the pregnancy wasn't full term.

A lack of rituals de-legitimized the women's grief, leaving several of them to wonder if they had any right to be mourning at all. In some circumstances, a lack of socially accepted rituals complicated the grieving process, as Diana described:

Normally with most companies or corporations, you get bereavement days if someone in your family dies... You have ten days usually you can take. But I didn't get bereavement days, right, because the (company) wouldn't see [the miscarriage] as a loss... So I literally went back to work, not the next day but the day after and it was terrible. It was awful, because I remember all the cramping and I remember it was just so awful. It wasn't my direct boss, she was absolutely supportive, it's the system around her. She really couldn't do much about it.

It is difficult to count exactly how many women in this study had participated in grieving rituals because they appeared to have different definitions and classifications for what constituted a "ritual." Ten women in this study stated that they had not participated in any kind of ritual to help facilitate their grief, but two of the women, Maya and Hilary, both disclosed that they got tattoos to memorialize the children they lost to miscarriage. When asked if she had engaged in any grieving rituals, Audrey initially responded, "No," but then followed up with, "The one thing, well, of course I believe in prayer." However, it was not directly stated that prayer was used as a grieving ritual. On the other hand, Marilyn was very clear that prayer had become part of a grieving ritual for herself: "I created rituals where I would take the ultrasound pictures and put them on my altar and pray and do things like that." The lack of identifiable and socially

acceptable grieving rituals meant that it was up to the woman to create her own meaningful practices that fit her best. While this allowed for flexibility and individuality, it also meant that more intentionality had to be taken to craft the ritual, which seemed inhibiting for some of the women. Anne said: “There was a lot of things that I thought about and I wanted to do, but I didn’t want to plan it...It felt too overwhelming to deal with.” A few women stated that the idea of creating rituals never came to them. Margaret said, “At the time I didn’t think about doing that,” and Rosa made a similar statement: “I don’t know why, I guess it just didn’t occur to me.”

Despite the incongruence of identified grieving rituals, all sixteen women were able to come up with examples of appropriate rituals that may be helpful to women experiencing reproductive loss. The most predominant idea was planting a tree or plant in memory of a lost pregnancy, with five of the women giving this example. Hosting a memorial ceremony or funeral for miscarried babies was also a prevalent idea, regardless of the gestation and even if there were no remains to bury. Other ideas were journaling, naming the child, creating art, and buying or creating an object (such as a Christmas ornament or stone plaque) with a significant date and/or the lost child’s name.

Additional supporting quotes from participants regarding the theme A Lack of Clear Grieving Rituals are given in Table 6.

Theme 3: Elements of Insensitive Encounters

All of the women were asked to describe interactions with others that they perceived to be unsupportive. The people involved ranged from close friends and family, to acquaintances or co-workers and strangers, to even the doctors and other medical care providers, including counselors. Three subthemes emerged from the characteristics of these interactions and are presented below in descending order of prevalence.

Table 6. Supporting Quotes: A Lack of Clear Grieving Rituals

RQ2: A Lack of Clear Grieving Rituals	<p>“I had a sister who carried a child until 22 weeks and had to have an emergency surgery and the baby was delivered but the baby didn’t survive. They had a funeral because there was something tangible to bury and memorialize. I felt like because mine were so early on... even if I had miscarried at home and if I had seen something tangible I could bury in my own cemetery, I think would have been easier.” – Hilary</p> <p>“It would’ve been different if it were a miscarriage or even with our disrupted adoption, like after that I thought about what can we do to commemorate or what can we do to go through that experience or ritual. So no, at the time with the infertility I did not do anything after the IVF didn’t work.” – Margaret</p>
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Assumptions and expectations. There were instances in which people would make assumptions about the woman or her experience of infertility and miscarriage. Assumptions were particularly hurtful because they possessed an air of “knowing” that other people did not have the right to claim. Audrey, who is the mother of two adopted children, described a particularly hurtful interaction:

When they finally had to do a partial hysterectomy, I’ll never forget the day I had to sign the form stating that I’m aware that I can never have kids...I was filling out the form and the lady said, oh well, you have two kids, I’m sure you don’t need anymore. You don’t want anymore anyway. And I’ll never forget sitting there, I just began to bawl... You saw that I have two kids so you assume that I birthed two kids and now I’m having a hysterectomy and that’s okay. But I never got to experience that piece.

For Audrey, an assumption was made about her path to motherhood that resulted in an insensitive comment that left her feeling exposed. Scarlett discussed that her parents assumed she would get pregnant eventually, which invalidated the grief she felt throughout the infertility journey:

I think earlier in our trying [to conceive], maybe a year or two before we were thirty, I think especially my parents were like, you’ve got all the time in the world, don’t worry about it, when we would have these losses of not being pregnant.

She went on to describe how she found it difficult to truly confide and rely on them as comforting supports.

In other circumstances, people would comment on the woman's experience that reflected their expectation for how she should be handling the situation. Elizabeth explained,

One of my brother-in-laws said that to me, you've got to move on. I'm like, no, I don't. I don't have to. It's July and I had a miscarriage in May. No, I don't have to move on. I don't ever have to move on if I don't choose to. I'm never going to move on, that experience is always going to be a part of me.

In describing an interaction with a childhood friend, Anne stated:

She had asked me one time, 'well when are you going to be happy again?' It's like, that's a great question and I can't wait until the day comes where I feel that the clouds lift and I can breathe and don't have this heaviness in my chest. But it wasn't like, oh I can't wait for you to be happy again, it was like, well when are you going to be over this so that way you're less depressing?

Expressing assumptions and expectations conveyed a knowledge about the woman and her experience that they simply did not possess, and at worst, suggested that the other person knows better than she does about how she should be handling the situation.

Assuaging the situation. There were times when other people would make comments or act in ways that the women perceived as attempts to make them feel better or offer hope. While most of the women acknowledged that people are well-intended, trying to make them feel better was ultimately just not helpful. Not only was it false hope, but it also completely minimized the loss itself. Rosa emphasized this point by describing that assuaging her grief suggested she was overreacting:

I think people are just trying to help you feel better but I wasn't ready to feel better... What I know is that you have to let yourself have those feelings, and when everyone around you is trying to mitigate those feelings, it's not helpful. Definitely made me feel like I was irrational or being dramatic, which I was not being. I was a mother who just lost a child that we wanted. I wasn't being irrational; I wasn't being ridiculous. I was sad and I

needed to just be sad for a little bit. They weren't trying to, but definitely those are not things to say to someone who just experienced a loss like that.

Hilary emphasized that acknowledging the loss was more helpful than downplaying the pain:

A lot of the times the things you try to say to comfort people are not comforting to them in that situation. Saying things like, 'I'm sorry for your losses' is fine because you're not trying to make it okay for them. But I think if you're trying to say things to make it feel better for them, you're doing them a disservice because I remember people saying things like, 'God's got those babies in his arms' and I felt like, I didn't want them in God's arms, I wanted them in mine. Those were the things where people intended them to be comforting, but they were not. I think that kind of attitude of trying to make it more comfortable in that situation was not helpful.

Other comments that the women found to be insensitive included advice-giving (which implied that she was not doing everything she could be doing to achieve or keep a pregnancy) and those that suggested it will get better. The women generally asserted that they were well aware of the reality of their situation and that there were at times very real possibilities that they may not be able to create or complete their desired family vision. As devastating as that may have been, trying to make them feel better, trying to find a solution or fix the problem, or making light of the situation invalidated their loss and inhibited the grieving process.

Lack of effort and absence. There were times when other people did not physically or emotionally "show up" to support the participants. This included people who seemed disinterested in her journey or struggle, or people who did not follow through on their promises to provide support. Anne described a situation with friends from her church who had asked how they could show love and support for her amidst fertility treatments. Anne told them she enjoyed receiving cards in the mail, and they agreed that sending Anne cards was something they would do. Anne continued,

I was super excited because I was like, hey, that seems like a super simple thing but also something that really means a lot to me, and the fact that they asked says a lot. They never ended up sending any cards and it was really confusing because I was at a point

where I'm like, okay, so either they just simply forgot, which was hurtful because how could you forget? You said you were going to do that. You know what I'm going through and you forgot about me. That was really, really hard. So it's like you either forgot or you chose not to, and either one of those outcomes does not feel good. To not feel like you mattered to them, that they couldn't take the time.

Sometimes even after the women reached out for support, others still did not put forth effort to be there. Meryl described the following situation with her mother:

I told her that we were struggling. She was not supportive in the way that I felt like I needed her to be supportive and that really did put a rift between us during that time and after that. The first time where our IVF did not work...my mom still never called, never texted, and didn't answer none of my calls and it was literally three days later I finally left her a message, we're not pregnant. So she finally called and was very dismissive and made the whole conversation about her. I didn't really share much more with her.

Absence took both emotional and physical forms, and resulted with the women feeling disconnected from or abandoned by other people whom they trusted to be some of their strongest guides and supporters. Rosa had experienced a drawn-out and complicated miscarriage, which left her wondering if it was normal to still be bleeding six weeks later, but reaching out to her doctor became problematic. She said,

My doctor was out of the country and my primary care physician was not in the loop of all this stuff that was going on...I'd have to start all over and [the PCP would] have to get my file from my OB, who's not even in the office. Then the nurse couldn't answer any of my questions, which I understand from a legal standpoint she's not allowed to do that, but still, I had this question and I had no one that knew my situation that could answer it and that was very frustrating to me. And again, she was doing missionary work, how mad can I be? But I was mad. I just felt like I was left alone.

Rosa acknowledged that her obstetrician had no way of knowing that she would require follow-up interventions, but added that had a clearer follow-up regimen been part of the entirety of the miscarriage experience, this situation would have been avoided.

Common elements of the insensitive interactions that women encountered were described above and included people who expressed assumptions and expectations, attempted to make the

situation better, and put forth little effort or were otherwise absent. These subthemes came from examples that the women described of times when they perceived that their infertility and miscarriage loss and grief were not supported.

Additional supporting quotes from participants regarding the theme Elements of Insensitive Encounters are given in Table 7.

Table 7. Supporting Quotes: Elements of Insensitive Encounters

<p>RQ2: Elements of Insensitive Encounters</p>	<p><i>Assumptions and Expectations</i></p> <p>“In my mind I was not giving up, even though I’d had multiple losses. I’d have comments of people saying, you just need to accept reality or whatever...so it was a very painful journey for me.” – Joan</p> <p>“The whole, just relax, it’ll happen when it’s supposed to happen. My mom was like, why you spending all that money?” – Meryl</p> <p><i>Assuaging the Situation</i></p> <p>“I was told, ‘At least it happened before you saw [your] baby!’ That was not helpful at all. That statement implies my grief is lessened because I didn’t carry to term or to a term where the fetus had features.” – Elizabeth</p> <p>“‘At least you have two children’. Like, what if I wanted five or what if I wanted ten? That’s great, but you’re not hearing me. You’re not hearing my pain.” – Diana</p> <p><i>Lack of Effort and Absence</i></p> <p>“My husband...told his parents and they never said anything to me or acknowledged the struggle in the slightest.” – Scarlett</p> <p>“[My oldest sister and mother] weren’t quite as inquisitive or they didn’t show as much—it was just me updating them on what was going on. It was never as much of them, hey, what’s going on this month, where are you at...That was one of the things that I found surprising was that for being so close to me they were not really, I don’t even know the right word to say it, but they didn’t—they weren’t as involved as I thought they would be.” – Marie</p>
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Findings for Research Question 3

How can counseling services be improved for women who are experiencing or who have experienced infertility and miscarriage grief?

Theme 1: Further Training

The participants all discussed their thoughts and opinions about the quality of existing professional services. The need for further training to improve how mental health and medical professionals meet the needs of women affected by infertility and miscarriage grief was described by fifteen women. An overall sentiment existed throughout the interviews that the women believed that most people reasonably recognize that infertility and miscarriage loss leads to grief; what they thought could be improved with additional training was further knowledge of the extent and permeability of their pain. The women hoped that this information would provide mental health and medical professionals with a greater understanding of the emotional implications of reproductive loss, and increase their ability to respond in ways that are compassionate and would legitimate the deeply raw and burning grief reactions.

The women provided examples of their own experiences with counselors and various other members of the medical community who were perceived as not fully grasping the magnitude of their loss and grief. Victoria described how the language that her counselor used damaged her ability to build trust:

I went and I had never been [to counseling] before, and I sat down and I was just crying my eyes out on this couch and feeling very uncomfortable...I think [the counselor] was trying to connect with me, but all she kept saying was, 'This really sucks, this really sucks'. She used that terminology and I don't know, but that just hit me the wrong way. I think she was trying to be with me and recognize it, but...I guess I would just say, imagine the deepest grief and pain daily that you've ever been in...I just wish she would have been more attentive, just like my friend was, like how you can really feel heard and feel seen. Even the tone she said it in, it all felt off.

Scarlett contacted three counselors over the years she had been trying to conceive and found that,

They were lost in the science of it and couldn't get past that to talk about whatever else. I had one suggest to me, 'Do you think'—she said, 'this is kind of off the wall, but do you think if you just held a baby, if that would get your hormones going?'

Six of the participants specifically spoke to feeling dehumanized in their interactions with medical professionals. Marie said,

Unless you have a really good team of doctors, you can feel like a number sometimes and not as much like a person. Where what you're going through is the most important thing to you, to a doctor sometimes it feels like you're just a patient, you're just a number in the system... When you're going through [infertility] it's such a feeling of loneliness to a degree. You just want to feel like you're important and that your case is important and they value what you're going through.

Marilyn felt it was important for medical professionals to recognize the whole person:

Being compassionate and all those other things is not a part of protocol. That needs to be put into the protocol. Some compassion. You're not dealing with a mannequin, you're not in medical school, you're not practicing on a mannequin. This is a person who, in addition to the physical, is also emotional and spiritual and all these other things. All of those things need to be looked at, all parts of the person need to be considered.

The women expressed an impression that if their mental health and medical professionals had a deeper understanding of the emotional magnitude of infertility and miscarriage loss, they would attend more to the personal side of the experience.

The women varied on whether or not it was necessary for infertility and miscarriage to be practiced as a specialization area, but what they agreed on was that any supplemental training specific to infertility and miscarriage could equip professionals with more tools to facilitate and be sensitive to the grief. Three specific areas of future training were identified by the women and are presented below in descending order of prevalence. First, it was suggested that further training encompass responsiveness from a trauma-focused lens, as six of the women described their infertility and miscarriage experiences as traumatic and an additional participant stated that the

grief from her losses triggered past trauma. Meryl described the trauma of ongoing infertility grief every month for three years:

It was literally every single month and that's the trauma piece behind it, too. I just want [counselors] to know it's different and get some specialty training in it and understand what infertility is so you're not re-traumatizing someone, or thinking you know about their experience or you inadvertently ask a question that triggers them.

Part of the additional training included screening for signs of trauma, PTSD, or depression and suicidality as a routine aspect of counseling services and follow-up medical appointments.

Next, five women discussed that improved training would include minority culture and history in order to provide more effective care and increase the quality of services that are provided to minority race women. Audrey stressed that counselors need to have an ability to see her experience of reproductive loss through a cultural lens as an African American woman because not all stories of infertility are created equal:

Counselors don't look at every situation as being different...The culture that I come from is different from someone else's culture, so to know that the culture is different, to know that the people are different, to know that the income status is different. Everybody doesn't have the opportunity to go and do [IVF], or everybody doesn't have that opportunity to do the surrogates, or different things like that.

Additional training on infertility and miscarriage would need to be inclusive of the racial disparities between prevalence and access to treatment in order to comprehensively represent all affected women.

The participants also talked about the necessity for doctors to recognize the distrust that exists for Black women toward the medical community based on the history of medical apartheid that includes experimentation and sterilization. Diana said,

Rightfully so, there's no trust there...to even things like prenatal visits. So many women don't go to their prenatal visits, either due to limited access or I mean, anything. Just not wanting anyone to potentially harm their baby. The knowing that you can trust your

medical professional, would be, I think that would start to help, but also medical professionals just understanding, starting with implicit bias training, to understand what it's like to treat diverse clientele.

This cultural history added additional layers to the trauma that some participants experienced in situations where they endured emergency surgeries or hysterectomies. During her interview, Meryl recalled in great detail the story of a ruptured uterine cyst that led to sepsis and required her to be rushed to the hospital by ambulance. One of her biggest fears was now needing a hysterectomy, which would close the door to having biological children forever. On top of this already life-threatening experience, she described being under the care of a White nurse who was ignoring her and her friends' questions about what was happening:

Part of this too is a lot of the mistrust and stigma that a lot of Black people have about medical professionals, and so that first nurse was a White lady and it just, I felt like it traumatized me how she was doing. I remember saying, 'Don't let them touch me'.

Meryl lost consciousness and awoke two days later to the news that she had been given a hysterectomy. What separated the training the participants were suggesting from other cultural sensitivity trainings was a precise targeting of how the history of sterilization and reproductive experimentation on African American women connected to a heightened sense of fear and distrust related to the care they received for their infertility and miscarriage.

Finally, two participants thought that their counselors having additional training allowed them to understand the overall experience more completely through incorporating a medical perspective. Anne's therapist specialized in infertility and one aspect that she found particularly helpful was that her therapist was well versed on related medical procedures:

I could ask her questions about, okay how does this work, then how I felt about it. That was very, very helpful to have her to talk about all of that with, and just go sit and cry when I needed to and really try to work out how I was feeling.

Meryl shared similar sentiments about her therapist, who she stated was also a nurse.

The specific additional training points included elements of trauma-focused interventions, racial and cultural disparities and history, and medical procedures and terminology. The participants suggested that additional training should be provided to any mental health or medical professional who may encounter women affected by infertility and miscarriage, but particularly those with whom they have a high likelihood for working together. These more obviously included obstetricians and reproductive endocrinologists, but less obviously expanded to nurses, administrative or supportive staff at fertility clinics, and mental health providers with concentrations in areas such as grief or women's issues.

Additional supporting quotes from participants regarding the theme Further Training are given in Table 8.

Theme 2: Increasing Access to Appropriate Resources

Twelve participants discussed the need for resources that provide emotional support, particularly mental health services and support groups which help women cope during their difficult time. Two subthemes emerged.

Connection to professional support. Overall, the women expressed that the information about available resources that was provided to them throughout their infertility journey or after the miscarriage experience was insufficient. Several women implied that having information and resources earlier in the process, whether that be at the start of their infertility journey or immediately after a miscarriage, was crucial for maintaining or bolstering their ability to cope. Victoria stated that if mental health support resources had been provided to her by her doctor, she “would’ve benefitted from that earlier in the process.” Their doctor office or medical facility was often cited as the desired place to receive the first bit of information about what kind of emotional support was available because many women first learn of their reproductive loss in a medical setting, as

Table 8. Supporting Quotes: Further Training

RQ3: Further Training	<p>“The counselor I spoke with wasn’t necessarily trained or didn’t have experience in speaking on the subject matter [miscarriage]. I felt like she helped me process it but a lot of that was me intentionally processing that all on my own rather than her working through that with intention, if that makes sense, to help me.” – Hilary</p> <p>“A lot of times doctors are so focused on statistical things and the more clinical side of things and they forget about the people side of things. Telling somebody that she may never be able to carry her own child, don’t just gloss over that.” – Margaret</p> <p>“We are already dealing with things like systemic racism and institutionalized discrimination and racism that [miscarriage stigma] is not something extra that they need to carry around. That they need a safe place to process their sadness and their anger and their devastation and their despair and their longing...to know that it’s safe to talk about.” – Diana</p> <p>“The pressure that African American women have on us from—that’s not ours to own—the implications of slavery...breeding and having all of these babies and the stereotypes are out there...and when you walk into a room with someone who doesn’t look like you, you’re carrying that. If someone doesn’t take the time to really get to know someone or even looking into the culture or even ask those questions, they might be coming in with those pre-conceived notions when they’re in a counseling session, or when they’re treating someone in the doctor’s office.” – Elizabeth</p>
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Gloria emphasized: “I think having them available through the OB, because that’s usually the first contact that a woman has when she’s going through this experience is with her obstetrician.”

The overall sentiment was that even if the woman did not want or need these services, having the choice to opt-out was more important than having nowhere to turn at all. Many participants discussed that they eventually found adequate support; however, they would have preferred that they had been made aware of available resources by a trusted professional, rather than leaving it up to them to find their own professional mental and emotional support. Elizabeth stated:

You're so devastated after a miscarriage that you don't know what you need...I just thought I was left out there to figure it out on my own. If I wasn't in the mental health field, I wouldn't have known how to navigate and look for stuff.

Carrie said, "I did not really make an active decision not to pursue assistance in dealing with the grief, I just didn't think to pursue help...I didn't think about emotional self-care during it."

Removal of barriers to existing support. Since many of the women were left to their own devices to find adequate professional support, they discussed the obstacles that they encountered along the way. One of the main problems was with availability of appropriate services that were conveniently located and accessible. Carrie said, "I did seek out a support group and the closest support group that I found was about an hour away." Victoria echoed this experience:

I've looked at support groups before and there are not very many. The closest one is an hour away and that's just really difficult after you get done with work. You don't really want to drive an hour somewhere, at least I didn't.

Others had difficulty finding support related specifically to reproductive loss. Hilary attended a group through her church:

It wasn't necessarily grief issues; I think it was for life issues. I think that they were dealing with life issues and emotional problems and it was focusing on feelings. I walked through [the grief] on my own with an expectation of what I needed to heal from and what I needed help with, even though the study and the group that we were doing wasn't focused on miscarriage and grief and loss.

It is interesting to note that Hilary had a background in the mental health field, without which may have altered her ability to adapt this group to her own needs.

Meryl and Elizabeth discussed how a lack of support groups and connection with other Black women created a barrier for support because majority-race women did not understand the complexity of their experience. Elizabeth elaborated on being the only Black female in a support group of White women:

It was all Caucasian women from a higher income bracket than mine. I connected with them on the basic level of miscarriage and having infertility, but the other socioeconomic issues that I may have been having, they weren't having them...If they had to pay out of pocket for their infertility treatment, they were able to do it. Now, we already have a barrier because you're not going to understand where I'm coming from. The pressure to get pregnant is I got three tries with the health insurance and that's it. Even in the support group, I still felt alone. I really didn't feel like everyone really, really understood the added pressure of what was contributing to my situation.

Lastly, two participants acknowledged a financial barrier. Victoria commented on how cost became an impediment for attending counseling: "I would've gone if it was covered or not as pricey every time, just because going through infertility you are paying a lot of money for your treatments and medications. That was just part of it." Gloria struggled with finding a counselor or psychologist who was covered through her insurance or employee health program: "Insurance was impossible...If I had been suicidal or something, it could easily have sent somebody over the edge. What I had to go through just to get mental help was impossible."

Additional supporting quotes from participants regarding the theme Increasing Access to Appropriate Resources are given in Table 9.

Theme 3: Characteristics of Validating Support

Every woman provided detailed examples throughout their interviews of times when they felt supported and descriptors that comprised the best support they received. Features of the most welcomed and helpful support were organized into the following subthemes.

Presence and availability. Much of the most caring support included people who would share time or space with the woman with an understanding that just being there was valuable. Some women had family members, partners, or friends who would come along for important appointments, provide meals during difficult times, tend and care for her after a miscarriage or

Table 9. Supporting Quotes: Increasing Access to Appropriate Resources

RQ3: Increasing Access to Appropriate Resources	<p><i>Connection to Professional Support</i> “Once I found out I wasn’t able to conceive I’m walking out with nothing, no information, no anything...To me, I was just left in the unknown.” – Audrey</p> <p>“Even leaving the ER [after the miscarriage], they give you your medical discharge and they have all the physical things you’re supposed to watch out for and take care of, but nothing on the mental health side.” – Gloria</p> <p><i>Removal of Barriers to Existing Support</i> “I did get some information from the facility we were going through. They gave me the information for a therapist and I think I reached out to her, but she didn’t have any openings or she never got back to me, something like that.” – Margaret</p> <p>“I just didn’t get what I needed in terms of having somebody else to connect with and talk with that I felt understood. Even when I joined a few online support groups, I was the only Black female in it. The experiences were a little different as it related to a lot of stuff.” – Meryl</p>
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fertility treatment, and use pronouns such as “we” and “us” rather than “you.” Margaret had an appointment for an embryo transfer, to which her husband was unavailable to go with her. She said,

One of my friends who was like a little sister to me was like, well I’ll take you. For her to do that and take that time out of her day and stay there with me the whole day and drop me off at home and stay with me at home; that whole thing, just being selfless and willing to help in any way was an amazing testament to who she was.

After Victoria’s miscarriage her husband was unable to come home from work right away.

I called my friend, who’s been a huge person in my life, and so I went over to her house and she is the most sweet human being ever and just listened to me and cried with me...That was what I needed, was just to have somebody there to cry with me, to hold me, to grieve with me so I wasn’t alone in it.

When people were present and available the women felt less lonely and less like they were going through the experience alone. This was important, as many of the accounts of grief included notions that grief from reproductive loss is an isolating and lonely experience.

Empathy and understanding. Others who expressed empathy for the participants' situation were viewed as particularly supportive. A person who was showing genuine empathy would try to imagine what it was like from the woman's point of view, which was a step beyond "yessing" her, or otherwise pacifying her through mere agreement that she was grieving. This included people who did their best to understand without passing judgment and people who were sensitive to the woman's reactions to news of their own pregnancies. Maya emphasized that how her sister-in-law told her that she was expecting was

the best way anybody can handle it...She told me before she told anyone else in private so that I had a chance to deal with my feelings surrounding that before she announced it to everyone else. Then, I will never forget, the next comment out of her mouth was, 'what can I do to make this easier for you?' That was the best thing anyone has ever said to me, hands down.

Many of the women also discussed how some of the best support they encountered was from other women who had endured infertility or miscarriage themselves because they inherently knew what she was going through without the woman having to explicitly explain it. Joan and her husband opened up to their pastor after learning that he and his wife had also experienced a miscarriage: "When we were able to share those experiences with people who understood what we were going through, it felt very safe."

Acceptance and permissiveness. This subtheme was characterized by support that allowed the woman to lead her own grieving process in the way that felt authentic for her. It was important to the women to feel that they had some control over making decisions in their lives and were supported in those decisions without being questioned. Some women talked about how their partners or doctors were accepting of their decisions about moving forward (or not) with fertility treatments. Maya exclaimed,

There were plenty of times that my husband and I looked at each other and I said, okay, I'm done. We need to break this for just a while. We can pick this back up but I need to be done right now. I cannot do this again. I cannot do it one more month. I need to be done. And he would be like, okay, we're done then. We'll stop, we'll wait, and we'll regroup and whenever you feel like you're okay we'll re-do this. Luckily I had a husband who was very supportive of that and very much let me lead the journey.

The women whose husbands were accepting and permissive of how they were feeling and what they needed tended to be the same women who had also reported that their relationships with their partners had grown stronger throughout their journey of infertility or miscarriage.

Some of the participants discussed how important it was for counselors and other professionals to be accepting of their strongest and deepest emotions. Anne felt that it was important for the counseling room to be,

a safe space that you can talk about whatever it is you're thinking, because through some of those really, really dark and suicidal times, not only did I want to hurt myself, but I wanted to hurt my friends' kids...It was really hard to not have a lot of anger and hatred toward these babies that did nothing but be born, and so being in a place where you can talk candidly with whomever it is that you're speaking with and being able to be honest and not judged and truly cared for and comfortable—I think that's really important.

Ultimately, the women wanted to know that they could grieve in ways that felt right for them without being judged or invalidated; for instance, needing to cry and grieve for up to several weeks or months after a miscarriage or needing to take some time to heal emotionally before attempting to conceive again. When those who surrounded them were supportive of their own determinations for how they needed to grieve, they felt validated and loved. Elements of presence, empathy, and acceptance are already established fundamentals of basic counseling skills; however, as this study has discovered, there is room for improvement in how these tenets are utilized as therapeutic tools for women affected by infertility and miscarriage.

Additional supporting quotes from participants regarding the theme Characteristics of Validating Support are given in Table 10.

Table 10. Supporting Quotes: Characteristics of Validating Support

RQ3: Characteristics of Validating Support	<p><i>Presence and Availability</i></p> <p>“My sister would follow every appointment, she would call or text, she offered to go with me [to appointments]. Every step of the way it was like, okay, what are we doing this week?” – Marie</p> <p>“The lady that hosts the group of women, the first day I went it was actually just her and I because nobody else showed up. She was the first person ever to sit there and talk to me.” – Audrey</p> <p><i>Empathy and Understanding</i></p> <p>“The one time I felt supported mainly was when I talked to the other lady who had gone through infertility, where all the feelings that she felt I knew I had felt, and everything she had gone through I had gone through. That was just the main time that I felt completely supported. I felt heard and connected.” – Carrie</p> <p>“[My friend] brought a meal the next night [after the miscarriage] but she also wrote us a letter and gave us an ornament of a little bird...She’s never had it happen to her but her words were just so empathetic and kind, it was like she just really got it.” – Gloria</p> <p><i>Acceptance and Permissiveness</i></p> <p>“Being able to help physicians and counselors to understand that first there should be a lot of trust... [The woman] may not even say it, but just acknowledge it and say, it’s okay. I don’t know if you’re feeling this way, but it’s okay if you are feeling this way. I think that will open opportunity for the person to say, yeah this is how I feel.” – Joan</p> <p>“After the second miscarriage I was so angry. [My friend and I] were having a phone conversation one evening where I was venting about the miscarriage. She stopped and asked me, ‘What do you feel like you need to do?’ I hadn’t thought about it before, nor had anyone asked me. I replied, ‘I’m tired and I feel like I don’t want to try anymore’. Having said those words out my mouth freed me in that moment. I needed to be honest with myself and begin to figure out my healing journey without the pressure of getting pregnant again.” – Elizabeth</p>
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Findings for the Overarching Research Question

What is the meaning of infertility and miscarriage grief experience for women?

To answer the overarching research question, a narrative is provided below that further comments on the experience of infertility and miscarriage grief. This narrative includes a description of the spiral process from expectation to reconstruction and includes an account of particular aspects of both forms of reproductive loss that together provide a deeper understanding of the meaning of infertility and miscarriage grief.

The women in this study were able to identify clearly expectations that they had for achieving pregnancy and motherhood, which oftentimes had originated when they were young. Some participants described sociocultural influences, such as playing with “pregnant” dolls or watching media that portrayed happy depictions of motherhood, that inspired their own visions of what motherhood would look like for them. Alongside the visions of their future families, the women received mirror messages, often during adolescence and young adulthood, that pregnancy was something to be prevented, rather than something that would be difficult to achieve. Fifteen of the sixteen women had strong convictions that they would be able to conceive or have non-complicated pregnancies when they made the decision to do so.

This expectation about pregnancy and motherhood was the root of where the grief stemmed from when the women were unable to conceive or carry the pregnancy to term. The loss itself was the loss of the desired and normative life stages of pregnancy, motherhood or parenthood, and eventual grandparenthood, and encompassed the loss of meeting the would-be child. The future-orientation of these losses made articulating the losses and facilitating the grief difficult because there were no clear social grieving norms to provide a structure for that process in the way that social norms are instilled for past-oriented losses, such as from the death of a family member. The women also experienced ambiguity in identifying clearly who or what was lost.

The future-orientation of loss meant that the women were grieving something or someone that never realized, rather than dealing with a past-oriented loss of someone who ceased to be.

In this study, the ambiguous losses precede the grief that was disenfranchised. Ambiguity is prevalent in four ways. First, ambiguity is present in the loss itself, which entails the loss of life stages and would-be children. The resulting disenfranchised grief appeared to then be related to grief that could not be publicly mourned because of a lack of social recognition that future-oriented losses are valid losses. Second, how the women articulate their loss is ambiguous because the losses were often hard to identify explicitly. This appeared to result in disenfranchised grief from a lack of open acknowledgment because the women were not able to talk freely about their loss. Third, other people experience ambiguity when trying to determine how to support the woman. This is likely due, at least in part, to the stigma that prevents open dialogue about reproductive loss which would help prepare individuals for how best to respond. This leads to grief that is not socially supported because there is a lack of clear guidelines on how to respond to the infertility or miscarriage. Fourth, at some point throughout their journey of reproductive loss, several women stated they had been living with unanswered questions such as, “Will I ever be a mom?”, “Will we ever complete our family?”, “Why is this happening to me?”, and for women who have suffered miscarriage with no living children, “Am I mom or am I not a mom?” This was an ambiguity of what the future would hold and many of the women internalized these thoughts and did not outwardly express them.

The twelve women in this study affected by infertility described the experience as a chronic, ongoing, and cyclical process that repeated month after month. The emotional roller coaster (Daniluk, 2001; Gray, 1996; Imeson & McMurray, 1996; Parry, 2004; Shapiro, 2009; van den Broeck, Emery, Wischmann, & Thorn, 2010; Watkins & Baldo, 2004) was described during this

time by the participants. One difference between the infertility and miscarriage experience is that infertility instilled a sense of hope in the women, even if the hope was small. The hope that the women described appeared to be related to their ability to reconstruct their expectation each month about their chances of conceiving. Some of the women who had attempted IVF treatments stated that, when they began the process, they experienced a renewed sense of hope which allowed them to reconstruct their expectations for how they would achieve pregnancy. This ability to reconstruct expectations with each attempt at conception illustrates the spiral nature of the beginning expectations of how pregnancy will be achieved and how those expectations are adjusted as they progress through the infertility experience.

Twelve of the women in this study had experienced a miscarriage. The gestation at the time of the loss ranged from approximately 2-3 weeks to 18 weeks and the most miscarriages that any one woman had endured was five. Miscarriage was generally described as an event, which differed from the ongoing nature of the infertility process. The subsequent grief was more acute, with nine women stating that their grief was the most intense either right when they found out the pregnancy was terminated or immediately following the miscarriage expulsion. Some aspects of the grief process varied, depending on the story of the woman. Gloria talked about experiencing grief in a two-step process; first on the day she was told the fetus had stopped growing, and the second on the day the fetus expelled. Rosa was still experiencing complications from the miscarriage several weeks later, with the final procedure being done approximately six weeks after originally being told the pregnancy had terminated. She stated that the prolonged nature of her miscarriage experience complicated her grieving process.

In a sense, the gestation at which the miscarriage occurred created additional layers to the subsequent grief. Anne miscarried at three weeks gestation, so her loss was described mostly as

that of the expected family and timing of the child's birth. Marilyn miscarried at eighteen weeks and lost the family vision, and expelled the fetus, but because her pregnancy was so progressed she went through labor, pushing and delivering the fetus, and afterward had the opportunity to see and hold the remains. To some extent, the gestation of the fetus at the time of the miscarriage had certain implications for the grieving process because the context was different.

The women who experienced miscarriage had often expanded their specific expectations for their family vision upon learning that they were pregnant. Pregnancy offered some certainty to the future through such items like a due date or birth order. After the miscarriage, the women ended up reconstructing their expectations for what their future families would look like. This appeared to be a spiral process with each new pregnancy. Rosa stated that after one miscarriage her view had changed to no longer feeling the urge to have a second child. Joan said her hope diminished with each miscarriage that she would ever become a mother and questioned what a life without children would be like.

For the eight women who had experienced both forms of reproductive loss, it appeared that one was more salient than the other. Carrie and Anne both answered questions more often as it pertained to their infertility, whereas Marilyn and Hilary talked more about their miscarriage grief. The women in this study were all at different stages of their journeys of reproductive loss. All of them spoke to how their infertility or miscarriage had impacted and changed them along the way. For many of the participants, reconstructing their expectations for what they envisioned for their families assisted them in coping and adjusting to the situation. Even women who went on to have children had in some way adjusted their expectations, such as accepting that the timing of their children did not align with what they had originally planned. Accepting a new life vision was a large part of this adjustment and coping process. Several women were able to find

new purpose in their experience by helping other women affected by reproductive loss and educating others about the grief.

Summary

Chapter IV revealed the findings from this phenomenological study. Sixteen women affected by infertility and miscarriage provided an in-depth interview of their grief experience. Eight meta-themes and eight subthemes were discussed. The losses associated with infertility and miscarriage were ambiguous because they differed from a past-orientation of loss, of which there are more clear social grieving norms, rituals, and customs. The first theme described a loss of normative life experiences that women reasonably expect to have if they so choose. The second theme described differences in how the loss was felt. The resulting grief was disenfranchised through the social stigma that prevents open dialogue and a lack of clear grieving rituals. Insensitive responses from others included when people expressed assumptions and expectations, tried to make the situation better, or did not show up as a support. Counseling services can better meet the needs of women affected by reproductive loss through further training of mental health and medical professionals and increasing access to available resources by connecting to support sooner and removing existing barriers. Helpful and welcomed support involved those who were present and available to the woman, expressed empathy and understanding, and were accepting of the woman and her grieving process.

CHAPTER V

DISCUSSION

This chapter will present the overall conclusions derived from the results of this qualitative research investigation. First, a summary of the study is presented, followed by a discussion of related literature, implications for counselor education and graduate student training, and recommended areas for future research.

Purpose Statement and Research Questions

Given the identified problems of low help-seeking behavior for counseling, the lack of available literature on infertility and miscarriage grief experiences, and the inconsistencies in grief training in counselor education graduate programs, the purpose of this study is to examine the infertility and miscarriage grief experiences of women to better understand both the ambiguity of their loss and how their grief may be disenfranchised.

The overarching research question guiding this study is: What is the meaning of infertility and miscarriage grief experience for women? Additional sub-questions were formulated based on the theoretical grief frameworks used in this study and the identified problems. The sub-questions for this study are: (1) What are the ambiguous losses associated with infertility and miscarriage; (2) How is infertility and miscarriage grief disenfranchised; (3) How can counseling services be improved for women who are experiencing or who have experienced infertility and miscarriage grief?

Findings Related to the Literature

There were several findings in this study that were consistent with the results of other research studies. All of the participants began their interview by telling the story of their reproductive loss journey. The women affected by infertility in this study described similar stages of the process that has been previously reported in prior studies. Generally, these stages included finding out or suspecting that there was a problem (Ferland & Caron, 2013; Parry, 2004); actively trying to achieve pregnancy, with ten women stating that they had participated in some type of medical intervention (Parry, 2004); and somehow reworking their expectations to move forward (Daniluk, 2001; Ferland & Caron, 2013; Parry, 2004). Several of the women described feeling left behind by their friends and family who were having children and moving into the next phases of the life cycle, which was similar to findings by McCarthy (2008) and Wirtberg et al. (2007).

The women affected by miscarriage had all either stated or implied that these were wanted pregnancies, although some of the women expressed a cautious excitement upon learning of their pregnancy, especially if they had difficulty conceiving or had experienced miscarriage in the past. In congruence with numerous accounts of miscarriage, several participants in this study discussed the physical indicators of cramping, pain, or vaginal blood loss (Adolfsson, 2010; Adolfsson et al., 2004; Murphy & Merrell, 2009), and details from the medical appointment that confirmed the fetal death (Adolfsson, 2010; MacWilliams et al., 2016; Murphy & Merrell, 2009). Many of the women in this study had interactions with medical staff that were congruent with previous studies on perceptions of care, and included insensitivity (MacWilliams et al., 2016) and feeling unimportant (Adolfsson et al., 2004). Future pregnancies for the women in this research study were or are expected to be associated with fear (Abboud & Liamsputtong, 2002; Adolfsson, 2010; Adolfsson et al., 2004; Leach et al., 2014; Meaney et al., 2017; Murphy and

Merrell, 2009), but this was also true for the women who had experienced infertility in this study as well.

One of the meta themes in this study was the loss of normative life experiences, which included milestones in the life span such as exciting future pregnancies or grandparenthood. These losses are invisible and intangible and are typically not known to other people unless disclosed by the woman herself, which contributes to the ambiguous nature of infertility and miscarriage loss. Other studies that have identified invisible and intangible losses are McCarthy (2008), and McBain and Reeves (2019). These losses possess a future-orientation (Bennett et al., 2005) of the hope and expectations for the potential would-be child (Bray, 2015; Carolan & Wright, 2017; Keefe-Cooperman, 2005; Leach et al., 2014; Lindemann, 2015; McCarthy, 2008; van den Akker, 2011). The women in this study also discussed ways that their grief had been invalidated or not recognized by both personal and professional supports (Daniluk, 2001; Doka, 2002; Leach et al., 2014; MacWilliams et al., 2016; Rowlands & Lee, 2010). This often included accounts of hurtful comments said by others (Bell, 2013; Benasutti, 2003; Kirkman, 2001; Stoyles, 2015) that were thoughtless or judgmental.

Another area that was similar to previous findings was that of access to resources and attaining supportive care. The women in this study expressed a lack of medical information provided by their doctors (Abboud & Liamputtong, 2005; MacWilliams et al., 2016; Musters et al., 2013; Rowlands & Lee, 2010), insensitive interactions with medical and mental health professionals (Corbet-Owen & Kruger, 2001; MacWilliams et al., 2016; Meaney et al., 2017; Musters et al., 2013; Simmons et al., 2006), and a desire for more information about counseling and formal support options (Musters et al., 2011; Simmons et al., 2006). An overall assertion from the women in this study was that resources should be offered early to every woman who experiences

a loss, because having the option to opt-out of services is more important than having nowhere to turn at all.

Discussion

The strength of this dissertation study is the examination of the results through the lens of the ambiguous loss and disenfranchised grief frameworks. Despite numerous studies identifying grief and loss as major components of infertility and miscarriage, very few have used the aforementioned grief theories to explain and contextualize the experience. Several of the research findings are discussed further below.

In the ambiguous loss framework, there are few examples of how infertility, miscarriage, and reproductive loss in general are categorized within the two types of loss: physical absence with psychological presence, or psychological absence with physical presence. Infertility and miscarriage both include a void of the desired child (physical absence) and an ongoing sense of loss of the would-be child (psychological presence), which classifies it as a Type 1 physical loss (Boss, 2016). This type of ambiguous loss is otherwise known as “gone, but not for sure,” because there is no proof of permanence to the loss (Boss, 2016). With infertility, part of the emotional roller coaster may be the sense that for that month or round of fertility treatment, the opportunity to have that child is gone, but the opportunity to have a child in the future is not gone for sure. With miscarriage, there is a permanence to the loss because the fetus has passed away. In this circumstance, it may also be true that the opportunity to birth that child is gone, but that the opportunity to have a child in the future is not gone for sure. Therefore, what appears to categorize infertility and miscarriage as a Type 1 physical ambiguous loss within the framework is the loss of the *opportunity* for that child, rather than the loss of the child itself, and the uncertainty for many affected women of whether they will be able to get pregnant or birth a future

child at all. In other words, infertility and miscarriage are ambiguous losses in which the opportunity to have a child is “gone, but not for sure.” Furthermore, the examples that Boss (2010, 2016) provides of Type 1 ambiguous loss are past-oriented losses (i.e., a person who disappeared, was incarcerated, immigrated, or a home or job that was lost). There are virtually no examples of future-oriented losses in the ambiguous loss framework as it is currently described.

One of the substantial findings in this study was the ambiguous nature of losing normative life experiences. Other studies have discussed the disruption of anticipated life stages (Lindsey & Driskill, 2013; McCarthy, 2008; Wirtberg et al., 2007), the invisibility of losses associated with infertility and miscarriage (Lindsey & Driskill, 2013; McBain & Reeves, 2019; McCarthy, 2008), and the fear that envelops future pregnancies (Abboud & Liamsputtong, 2002; Adolfsson, 2010; Leach et al., 2014; Murphy & Merrell, 2009). Almost all of the women in this study described a similar invisible loss of future life stages and milestones; however, these losses are conceptualized differently. First, orienting these losses in the future highlights the distinctness of reproductive loss from other types of loss that are situated in the past. Second, conceptualizing a future pregnancy as a normative life experience that is lost along with other major events provides space for helping women articulate the meaning of what is lost about the pregnancy experience. Given that making meaning of their reproductive loss is a major aspect of moving forward from infertility and miscarriage (Carolan & Wright, 2017; Corbet-Owen & Kruger, 2001; Daniluk, 2001; Gerber-Epstein et al., 2008; Leach et al., 2014; McCarthy, 2008; Nikcevic & Nicolaides, 2014; Simmons et al., 2006), this conceptualization may assist women in working through their fear about future pregnancies from a grief-based perspective.

Doka (1999, 2002) identifies five typologies of disenfranchised grief: (1) the relationship is not recognized; (2) the loss is not recognized; (3) the griever is not recognized; (4) the death is

disenfranchising; and (5) the way an individual grieves is not validated. Doka (2002) recognizes perinatal death, abortion, and infertility as losses that are not recognized, and miscarriage is also considered to be an unacknowledged loss. It is interesting to note that all eight meta themes from this research seem to loosely correspond with the three areas that define disenfranchised grief; grief that “is not, or cannot be, openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p. 4). Grief that cannot be openly acknowledged corresponds with the meta themes ‘loss of normative life experiences’ and ‘a more personal loss.’ Grief that cannot be openly acknowledged corresponds with ‘stigma leads to silence’ and ‘a lack of clear grieving rituals.’ And grief that cannot be socially supported corresponds with ‘elements of insensitive encounters’, ‘further training’, ‘increasing access to appropriate resources’, and ‘characteristics of validating support.’

Two of the most noteworthy findings of this study are the specific descriptions of what makes interactions with other people insensitive versus validating. Some of the qualitative studies on infertility and miscarriage included examples of unhelpful comments other people had made regarding a woman’s reproductive loss, and were not dissimilar from examples the women provided in this study. These include examples of all three subthemes from the ‘elements of insensitive encounters’ meta theme: assuaging the situation (i.e., “At least you know you can have a child,” and, “You’re still young. You can still have a baby”; Abboud & Liamputtong, 2005, p. 9), assumptions and expectations (i.e., “Someone would say she understood how I felt...It’s so annoying! Patronizing! Frustrating!”; Gerber-Epstein et al., 2008, p. 17), and lack of effort and absence (i.e., “My mom wasn’t calling to support me. And I was like, how can you not call me?”; Leach et al., 2014, p. 14). Ferland and Caron (2013) provide a table of recommendations for how informal and formal supports can respond to women with infertility by providing

examples of what to or what not to say and do. Several of the helpful responses aligned with the subthemes from ‘characteristics of validating support’: presence and availability (i.e., “I am here for you if you want to talk about it”), empathy and understanding (i.e., “I am sorry you are going through this”), and acceptance and permissiveness (i.e., “Support her decision to stop medical interventions”; Ferland & Caron, 2013). The knowledge provided by this dissertation study about insensitive versus validating support is important because it provides a structure for how to provide effective support to women affected by infertility and miscarriage. Other people, including counselors and counselor educators, can incorporate this structure into their work with affected women or students. This information goes beyond reporting examples of comments and interactions to explaining *why* they are either helpful or non-helpful.

Conclusions

This study explored the grief experience of infertility and miscarriage in depth. The women in this study generally purported that other people in their lives acknowledged that their reproductive loss produced grief, but what they were missing was a more accurate understanding of how abstrusely the loss had impacted the women’s lives. The results of this study add to the literature on reproductive loss to better illustrate the profundity of the loss. The grief that results from infertility and miscarriage is deeply intense and personal, and is separate from the grief that is produced when a loved one passes away. Many of the women had devoted a great amount of energy, time, money, and effort into conceiving or ensuring they would have a healthy pregnancy, which produced a sense of guilt and feelings of failure when the pregnancy was not actualized. This internalized and personal sense of grief also made it more difficult for the women to find support and acknowledgement of their loss because grieving norms recognize a more outward type of loss, such as with the loss of a family member.

Delimitations

Delimitations allow the researcher to report parameters of what the research did and did not examine (Creswell, 1994). This research study was narrowed to the following parameters: (a) participation included cis-gender females and did not include their partners; (b) participants were affected by one or both of the reproductive losses, infertility and miscarriage; (c) participants shared their experiences of grief related to their reproductive loss(es); (d) the researcher examined the data through the lens of the ambiguous loss and disenfranchised grief theories; and (e) the researcher specifically focused on describing the meaning of the grief experience of infertility and miscarriage.

Limitations

One limitation of this study was created from data collection. The researcher recruited participants from around the United States, and it was not geographically possible to conduct all interviews face to face. Eleven of the interviews were conducted over the phone, which limited the researcher's ability to observe non-verbal behavior. During her interview, Maya at one point made a gesture to her head that described what was going on "up here" in her mind during the monthly roller coaster of attempting conception. It is possible that conducting some interviews over the phone took away from anecdotal information that the researcher could gather about their grief narratives. Interviews were conducted over the phone to circumvent potential technological and confidentiality issues through online video methods.

Another limitation of this study comes from the demographic questionnaire, which gathered information on the participants' age, race, marital status, and reproductive loss, as applicable to each participant. However, the demographic questionnaire did not ask the participants for information related to their careers, education level, or socioeconomic status

(SES). This information would have been useful because the participants' SES has implications for the support that the participant could or could not receive due to barriers and availability of resources.

Implications for Counseling and Counselor Training

One of the identified problems introduced in this study emphasized the importance of increasing visibility and accessibility to counseling services for women affected by infertility and miscarriage in order to improve help-seeking patterns. Previous studies (Abboud & Liamputtong, 2005; Boivin et al., 1999; MacWilliams et al., 2016; Read et al., 2014; Rowlands & Lee, 2010; Souter et al., 1998) have revealed that information provided on support services is often desired, but deficient. Given this and the literature which recommends integration from medical and mental health professional resources (Boivin et al., 2012; Boivin & Gameiro, 2015; Cunningham & Cunningham, 2013; Dancet et al., 2013; Peterson et al., 2012), more intentional collaboration and advocacy for emotional support and counseling services should be offered to affected women. This may be done through infertility counseling at a fertility clinic (Peterson et al., 2012), or integrated (Boivin et al., 2012) or relational (Cunningham & Cunningham, 2013) models of care.

At the very least, counselors should become knowledgeable of the support resources available locally in their community, as well as online, and be prepared to make appropriate referrals. Some women may need a referral for couples counseling, as reproductive loss can weigh heavily upon the couple relationship (Bell, 2013; Benasutti, 2003; Ferland & Caron, 2013; Wirtberg et al., 2007). Relational models in couples counseling may assist couples with communication and connection while dealing with the impact of reproductive loss. Counselors who can offer clients a variety of options—including the nearest face-to-face support groups, online support groups, and other forms of networking with other women—may provide women with a

sense of choice and control in a situation that they may feel otherwise powerless. Some of the women in this study suggested that a peer program that matches women with other women affected by reproductive loss would be beneficial. Read et al. (2014) presented the idea for peer mentorship in infertility support, which may be particularly beneficial given that several studies report that women desire to connect with other women who have shared the experience (Carolan & Wright, 2017; Corbet-Owen & Kruger, 2001; Gerber-Epstein et al., 2008; Radford & Hughes, 2015). A peer program could even be implemented over the phone or through online services such as Skype, reaching a much larger population of affected women than face-to-face support groups. One of the participants in this study stated that such a peer program would be particularly useful for African American women because it would help them find other women who shared the additional concerns of medical distrust, apartheid, and systemic racism and discrimination. An African American woman's experience of reproductive loss will not only encompass grief but will also be complicated by systemic forces that perpetuate stratified reproduction (Ceballo et al., 2015; Ginsburg & Rapp, 1995) and distrust for medical professionals. The risk for death by ethnicity varies widely, with African American women having the highest rates of pregnancy-related mortality at 42.8 deaths per 100,000 live births, compared to only 13 deaths for White women (CDC, 2019). Specific resources and support in place for minority race women will better meet their unique needs during or after reproductive loss because it will acknowledge the racial disparities that African American women encounter. Therefore, counselors should not only be educated on the history of medical apartheid, but also advocate for bolstering appropriate resources for minority race women.

The information provided from this dissertation could also improve how counselors and counselors-in-training are prepared for working with women affected by reproductive loss. For

instance, one of the meta themes in this research addressed further training for medical and mental health professionals on how to better meet the needs of women grieving reproductive losses. This further training has numerous implications. First, grief training in graduate level programs is inconsistent due to a lack of standardization in accreditation standards (CACREP, 2016), which may lead to inconsistencies in effectiveness of grief counseling outcomes across the counselor education field. Next, counselors will have a more comprehensive understanding of how historical and systemic racism contribute to complications of the grieving process for minority race women. Third, as the women in this study reported in congruence with several others (Adolfsson, 2010; Adolfsson et al., 2004; Corbet-Owen & Kruger, 2001; Ferland & Caron, 2013; Leach et al., 2014; MacWilliams et al., 2016; Simmons et al., 2006), women affected by infertility and miscarriage have had poor encounters with medical and mental health professionals. For the participants in this study, poor encounters included abandonment, dehumanization, and invalidations from medical professionals, and insensitivities in language and technique by mental health professionals. Further training that focuses on how to use basic counseling skills to have sensitive interactions may increase satisfaction and help-seeking behavior. Further training may include exposure to real stories that counselors and graduate students may not have had otherwise. One of the participants in this study suggested that infertility and miscarriage training could include reading autobiographies or biographies of people who have experienced infertility and miscarriage, following relevant posts or groups on social media, or attending a local support group meeting on reproductive loss.

This study also has implications that elaborate on counseling skills and interventions with women affected by infertility and miscarriage. Interventions suggested throughout the reproductive loss literature include addressing cognitive distortions (Fekkes et al., 2003; Slade et al., 2007;

Verhaak et al., 2005), action-oriented coping strategies (Daniluk & Tench, 2007), and therapeutic techniques such as the empty chair approach, expressive arts, and externalizing the problem (Bray, 2015). This study suggests further recommendations. First, counselors may be able to help women process and put language to their grief. Some women may not believe their grief is valid or may not have the ability to articulate the loss because of the ambiguity and distinct nature from more familiar, past-oriented loss. Counselors may also be able to help women make assertions and requests of what they need from others. The women in this study who had been able to instruct others on what they found helpful had more ownership and control over how they handled the situation.

Second, given the previous quantitative literature on traumatic reactions (Engelhard et al., 2001; Farren et al., 2016) and the qualitative accounts from the women in this study, trauma-focused approaches and interventions may be relevant for clients affected by infertility and miscarriage. Inventories that screen for psychiatric symptomology and perinatal grief scales (Neugebauer & Ritsher, 2002; Theut et al., 1989; Toedter et al., 1988) may be useful in practice when assessing new clients with a history or current experience of reproductive loss. Furthermore, a history of trauma or PTSD is associated with lower birth weight and gestational age (Seng, Low, Sperlich, Ronis, & Liberzon, 2011). Women who experience traumatic reactions to their reproductive loss may be at an elevated risk for developmental complications in future pregnancies.

Third, counselors could help clients create their own rituals for facilitating their grief. The women in this study who had experienced miscarriage appeared to have an easier time identifying rituals they might find helpful and when to implement them than the women who had endured infertility. This may be due to the fact that infertility is a more cyclical process, while

miscarriage is more linear and similar to the process of grieving a loved one that has passed away. Counselors can assist clients with infertility in identifying healthy rituals that may take place monthly while trying to conceive or before or after fertility treatments. Women affected by either reproductive loss may benefit from exploring personal and unique ways they can facilitate their grief and memorialize significant steps of their journey.

Recommendations for Future Research

Future research should continue to expand on the differences and similarities between past- and future-oriented losses in order to develop sufficient grieving rituals and emotional support services for those affected by this type of loss. Information from quantitative and qualitative research may contribute to the development of a model for counseling women affected by reproductive loss and may encompass elements such as authenticating the loss, developing grieving rituals, and screening for psychological issues and symptomology.

Studies on reproductive loss should also expand to include the experiences of other populations. Racial minority women experience infertility at higher rates than White women (Chandra et al., 2013), yet research tends to be done primarily on majority race women. Women of lower SES are also frequently excluded from treatment (Bell, 2014). Further research should be inclusive of varying racial and socioeconomic demographics in order to gain a more comprehensive picture of all women's experience of reproductive loss. Continued examination of how racial and socioeconomic barriers impede access to appropriate support is also necessary. To date, there is also a dearth of literature on the grief experiences of men during or after infertility and miscarriage, although there is evidence that men grieve differently from women (Broquet, 1999; Carolan & Wright, 2017; Gibson & Myers, 2002; Meaney et al., 2017; Peterson et al., 2006). Doka (2002) recognized that fathers and siblings in the family unit are still disenfranchised more

than mothers who experience perinatal loss, although future research should also include lesbian, gay, and transgender relationship dynamics. These relationships may rely on IVF or the use of a surrogate to have a baby, meaning they may struggle to conceive or experience miscarriage. Studies on reproductive loss may include further investigation of infertility and miscarriage, but may also expand to abortion, stillbirth, and infant death.

Another area of future research is that of grief competencies of counselors and counseling students. More information is needed in order to understand the advantages and disadvantages to formal training (Horn et al., 2013) and attitudes toward grief training (Hannon & Hunt, 2015). This information may be useful in order to better understand how standardization of grief competencies may improve effectiveness and confidence of those working with grieving clients.

Summary

This qualitative phenomenological investigation examined the grief experiences of women affected by infertility and miscarriage through the lens of ambiguous loss and disenfranchised grief. The results of this study provide a new perspective on how to conceptualize reproductive loss and the resulting grief. This information may be relevant to counselors and counselor educators by increasing accessibility of services, improving training, and adapting current counseling skills for working with this population. Further research should investigate future-oriented losses and expand to various other populations.

Appendix A
Recruitment Flyer

Western Michigan University

A Phenomenological Investigation of Women's Infertility and Miscarriage Grief Experiences

Volunteers wanted for a research study

- Are you currently or have you in the past experienced the inability to conceive after one year of unprotected sexual intercourse?
OR
- Have you ever had a miscarriage at or before the 19th week of pregnancy?

If you answered YES to one or both of the above, you may be eligible to participate in a study about women's experiences of infertility and miscarriage grief. To participate you must be a woman age 18 or older with access to a computer and phone.

The purpose of this study is to gain a greater understanding of how women experience grief related to their infertility or miscarriage and what meaning they make from these events. A potential benefit to you is providing you a space to talk about your experience and express your grief. You will also be contributing to a greater understanding of the silent grief that surrounds infertility and miscarriage, which may better inform mental health and medical policies. I'm interested in this research to provide a voice to women to tell their stories and increase visibility of these painful experiences.

Participants of this study will sit with me for an interview, during which I will ask questions related to your experience of infertility or miscarriage grief. The interview will be audio recorded and ***all participant information will be confidential and protected***. Additionally, you will have the opportunity to check your interview to add or clarify content, and later you will be asked to provide feedback on how I captured your experience. Further details will be provided in our first conversation. It is estimated that you will spend 2.75 – 3 hours total over no more than 6 months as a study participant. Once you have responded on how well your experience was captured, your participation will be complete and you will receive a **\$20 gift card**.

If you are not interested in participating in this study but you know someone who might be, please forward this information on to that person.

This research is being conducted by Tristan McBain, a Counselor Education and Supervision Ph.D. doctoral candidate in the Counselor Education/Counseling Psychology Department at Western Michigan University located in Kalamazoo, Michigan.

For more information, please contact Tristan McBain

Appendix B

Email to Seek Participants

The following was sent via email to individuals whom the researcher knew personally that had expressed interest in participating or passing along information about this study:

“Hello [name],

My name is Tristan McBain and we met at [varies depending on the person]. I hope you are doing well. I am writing you because I am at a point where my dissertation study has been approved and I am currently taking participants.

The study is titled, *A Phenomenological Investigation of Women's Infertility and Miscarriage Grief Experiences*. As a brief refresher, my program is Counselor Education and Supervision, Ph.D. program at Western Michigan University and I am currently a fourth year doctoral candidate.

The purpose of this study is to gain a greater understanding of how women experience grief related to their infertility or miscarriage and what meaning they make from these events. I'm interested in this research to provide a voice to women to tell their stories and increase visibility of these painful experiences. ***All participants will be confidential and protected.***

Attached to this message is a flyer that explains the purpose of the research, what being a participant entails, and how to contact me to set up an interview or ask for more information. I am requesting that you please distribute this flyer to anyone you believe would like to participate. It is my hope that I can be a part of ending stigma and bringing awareness to the grief behind infertility and miscarriage.

Thank you for your time and consideration.

Sincerely,

Tristan McBain

Appendix C

Email to Gatekeepers of Online Support Groups

The following was sent to the identified gatekeepers of the online support groups:

“Hello,

My name is Tristan McBain and I am a fourth year doctoral student in the Counselor Education and Supervision Ph.D. program from the Counselor Education/Counseling Psychology Department at Western Michigan University. I am currently conducting research for my dissertation study, *A Phenomenological Investigation of Women’s Infertility and Miscarriage Grief Experiences*.

The purpose of this study is to gain a greater understanding of how women experience grief related to their infertility or miscarriage and what meaning they make from these events. I’m interested in this research to provide a voice to women to tell their stories and increase visibility of these painful experiences. *All participants will be confidential and protected.*

Attached to this message is a flyer that explains the purpose of the research, what being a participant entails, and how to contact me to set up an interview or ask for more information. I am requesting that you please provide a copy of this message or flyer to your group. It is my hope that I can be a part of ending stigma and bringing awareness to the grief behind infertility and miscarriage.

Thank you for your time.

Sincerely,

Tristan McBain

Appendix D

Western Michigan University HSIRB Approval Documents

WESTERN MICHIGAN UNIVERSITY



Institutional Review Board
FWA00007042
IRB00000254

Date: November 5, 2018

To: Glinda Rawls, Principal Investigator
Tristan McBain, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair

Re: IRB Project Number 18-10-39

This letter will serve as confirmation that your research project titled "A Phenomenological Investigation of Women's Infertility and Miscarriage Grief Experiences" has been **approved** under the **expedited** category of review by the Western Michigan University Institutional Review Board (IRB). The conditions and duration of this approval are specified in the policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may **only** be conducted exactly in the form it was approved. You must seek specific board approval for any changes to this project (e.g., ***you must request a post-approval change to enroll subjects beyond the number stated in your application under "Number of subjects you want to complete the study"***). Failure to obtain approval for changes will result in a protocol deviation. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the IRB for consultation.

Reapproval of the project is required if it extends beyond the termination date stated below.

The Board wishes you success in the pursuit of your research goals.

Approval Termination:

November 4, 2019

Office of the Vice President for Research
Research Compliance Office
1903 W. Michigan Ave., Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276
WEBSITE: wmich.edu/research/compliance/hsirb

CAMPUS SITE: Room 251 W. Walwood Hall

Western Michigan University
H.S.I.R.B.

Approved for use for one year from this date:

NOV 05 2018


HSIRB Office

**Western Michigan University
Department of Counselor Education/Counseling Psychology**

Principal Investigator: Glinda Rawls
Student Investigator: Tristan McBain
Title of Study: A Phenomenological Investigation of Women's Infertility and Miscarriage Grief Experiences

You have been invited to participate in a research project titled "*A Phenomenological Investigation of Women's Infertility and Miscarriage Grief Experiences*." This study is being conducted for the student researcher's dissertation research. This consent document will explain the purpose of this research project and will go over all of the details of being a participant, including the time commitment, procedures, and the risks and benefits of being a part of this study. Your participation in this study will be confidential. Please read this consent form carefully and completely. Please ask questions at any time if you need more clarification.

What are we trying to find out in this study?

The purpose of this study is to examine the infertility and miscarriage grief experiences of women in order to better understand both the ambiguity of their loss and how their grief may be disenfranchised. This study will provide a clearer understanding of the grief that women endure related to these reproductive losses and how they can most effectively be supported.

Who can participate in this study?

You may participate in this study if you are a cis-gender female of age 18 years or older. You must have access to a computer and an active email account. You must have access to a phone and an active telephone number. You must have had at least one miscarriage at or before the 19th week of pregnancy OR met the clinical definition of infertility for your age group at present or in the past. This definition is the inability to conceive after one year of unprotected sexual intercourse if you are or were age 34 or younger and six months if you are or were age 35 or older. Some women may meet criteria for both infertility and miscarriage, and these women are eligible to participate as well. Individuals who have ever been diagnosed with an intellectual disability will not participate in this study, due to the possibility of not fully understanding the risks and the impact of sharing their experiences.

Where will this study take place?

Interviews will take place in any location that is confidential and comfortable for you, but is not your own home. Location will be worked out with each person individually. If you were recruited via the Internet, the interviews will take place online or over the phone.

Western Michigan University

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HSIRB Office

What is the time commitment for participating in this study?

An estimated 2.75 – 3 total hours of your time is predicted. This is broken down over 5 points of contact:

- 1) initiating contact with me about your interest in the study (15 minutes);
- 2) going over informed consent and completing the demographic questionnaire (30 minutes);
- 3) sitting for the interview (60 minutes);
- 4) completing the first member check, verification of information (30 minutes);
- 5) completing the second member check, feedback of identified themes (30 minutes).

It is expected that you will be able to complete your participation within six months. Your ability to move from point of contact 3 to 4 and from point of contact 4 to 5 depends on my timeliness of providing you with the necessary transcript and information. I will make every effort to provide these materials to you in a timely fashion. It is possible that your participation may conclude in as little as 6-12 weeks; however, it is best to be prepared for the maximum length of time of six months.

What will you be asked to do if you choose to participate in this study?

If you choose to participate in this study, please contact Tristan McBain at (517) 574-3728 or tristan.d.hock@wmich.edu. You will be asked to complete one interview with me that is estimated to last about 60 minutes. The interview will be audio recorded and then transcribed. Additionally, you will be asked to complete two member-checks. After I transcribe your interview, I will email it to you and you will have the opportunity to read it over and add or clarify anything you feel will contribute to a more complete picture of your experience. You will then send it back to me and this will complete the first member check. If I do not receive this first member check from you within two weeks after sending you the transcript, I will proceed with data analysis. For the second member check, I will send you a copy of the emerging themes as I begin to see them as analysis progresses. Once I have emailed you the initial themes, you will have up to two weeks to examine these themes and provide feedback to me about whether or not you believe I have accurately captured your experience. If you do not have additional feedback for either member-check, please email me that information so I can mark your check as complete. Once you have finished this second member check, your participation in the study has been completed and you will receive a \$20 gift card. You will only receive a gift card if you complete both member checks after your interview. In the event that you do not provide a first and/or second member check, I will progress with the study using the transcript created from your interview.

What information is being measured during the study?

This study will not use any measurement instruments. Instead, this study will use data collected from interviews. The data will be analyzed through qualitative methods.

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What are the risks of participating in this study and how will these risks be minimized?

It is possible that the sensitive nature of the topic may spur emotional responses or psychological distress during the conversation. You have the right to decide at any point during the interview that you cannot or do not want to go on with the interview, and the interview will be ended immediately. You have the right to decide at any point during the interview that you cannot or do not want to continue with a specific topic or question, and you may stop and ask me to move on to another question. You will not be pressured or coerced to answer or discuss anything you do not want to. If I sense that you are under distress that may lead to emotional or psychological damage, the interview will be stopped immediately and you may be referred to your doctor or counselor.

What are the benefits of participating in this study?

A potential benefit is allowing you a place to express your grief. You may feel positively about telling your story and contributing to a greater awareness of grief surrounding reproductive loss. The potential benefit of the research may be an enhanced understanding of how grief surrounding infertility and miscarriage is disenfranchised and experienced. This knowledge may be beneficial to mental health and medical professionals by increasing understanding about how to best respond to grief when working with women who have endured these painful reproductive losses.

Are there any costs associated with participating in this study?

The cost to you will be your time in completing the study. If we are planning a face-to-face interview, you will also have the cost of your travel expenses, such as gas and mileage, required to get you to our agreed upon location.

Is there any compensation for participating in this study?

Upon completion of the second member-check, you will receive a \$20 gift card as a thank you for participating in this research study. You will be able to choose from a Biggby Coffee or Meijer gift card. In the event that you live in a geographical location that does not have a Biggby Coffee or Meijer business, you and I will discuss alternative gift card options. Please note that you will only receive a gift card if you complete both member-checks within each designated two-week time frame.

Who will have access to the information collected during this study?

The results of this study will be published in refereed journals and possibly presented or referenced for future use at professional conferences or in grant proposals. Confidentiality will be maintained to protect your privacy. I will change all names and other identifying information. Audio recordings, transcripts, and any work notes will be kept on encrypted storage devices. All materials will be packaged and stored in the university archives for at least 3 years after close of the study.

Western Michigan University

H.S.I.R.B.

Approved for use for one year from this date:

NOV 05 2018



 X _____
 HSIRB Office
What if you want to stop participating in this study?

You can refuse to participate or choose to stop participating in the study at anytime for any reason. You will not suffer any prejudice or penalty by your decision to stop your participation. You will experience NO consequences personally, professionally, or academically if you choose to withdraw from this study.

I also reserve the right to decide to stop your participation in the study without your consent.

Should you have any questions prior to or during the study, you can contact the primary investigator, Glinda Rawls at (269) 387-5100 or glinda.rawls@wmich.edu. You may also contact the Chair, Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298 if questions arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

I have read this informed consent document. The risks and benefits have been explained to me. I agree to take part in this study.

 Please Print Your Name

 Participant's signature

 Date

Appendix E

Demographic Questionnaire

Demographic Questionnaire

1. What is your age, race, and marital status?
2. Do you have any living children?
3. How many times in your life have you ever been pregnant?
4. Have you ever had a miscarriage at or before 19 weeks of pregnancy, and if so, how many have you had?
5. If you have had a miscarriage, at what gestation was your most recent miscarriage?
6. Have you ever experienced the inability to get pregnant despite actively trying?
7. Have you ever been diagnosed with infertility?
8. Have you ever undergone an assisted reproductive procedure (medication, IUI, IVF), and if so what and how many times?

Appendix F
Interview Protocol

A Phenomenological Investigation of Women's Infertility and Miscarriage Grief Experiences Interview Protocol

This is an interview protocol for the Research Question: What is the meaning of infertility and miscarriage grief experiences for women?

“Today I will be interviewing you as part of my dissertation study about women’s infertility and miscarriage grief experiences. Research shows that women experience grief reactions related to these areas of reproductive loss, but to date few studies have been conducted that investigate the grief itself. I am interested in any experiences you have had that involve grief related to your reproductive loss, and the meaning you make from these experiences.

Thank you for your time and willingness to participate in this research. Please start by telling me about the nature of your infertility/miscarriage.”

Reflection Questions:

What were your expectations for pregnancy and motherhood before your infertility/miscarriage?

How did you break the news of your infertility/miscarriage to others in your life? Did you experience any difficulties when sharing the news of your infertility/miscarriage?

What are/were the losses that you endured from your infertility/miscarriage?

Please describe the grief that you have felt related to your infertility/miscarriage.

At what time or what point was your grief the strongest? What did you need at this time and were you able to get it?

How has the grief that you experienced from your infertility/miscarriage differed from grief that you have experienced in the past or in other areas of your life?

How or where have you found support for your infertility/miscarriage?

Can you think of a specific time when you felt supported and describe it for me?

Can you think of a specific person who was particularly supportive and describe characteristics of what made them supportive?

In what ways were you not supported during or after your infertility/miscarriage?

Can you think of a specific time when you did not feel supported and describe it for me?

Can you think of a specific person who was particularly unsupportive and describe characteristics of what made them unsupportive?

How did the grief impact your relationship with your partner?

A funeral after the death of a loved one is considered to be a type of ritual that facilitates the grieving process. Have you created or participated in any rituals to help you manage your grief?

How does/did infertility/miscarriage grief affect your life in the short term and in the long term?

What type of medical or mental health resources have you pursued for assistance in dealing with your grief? What barriers have you encountered to attaining these resources?

What do you believe your family and friends do not understand about infertility/miscarriage? What do you want them to know?

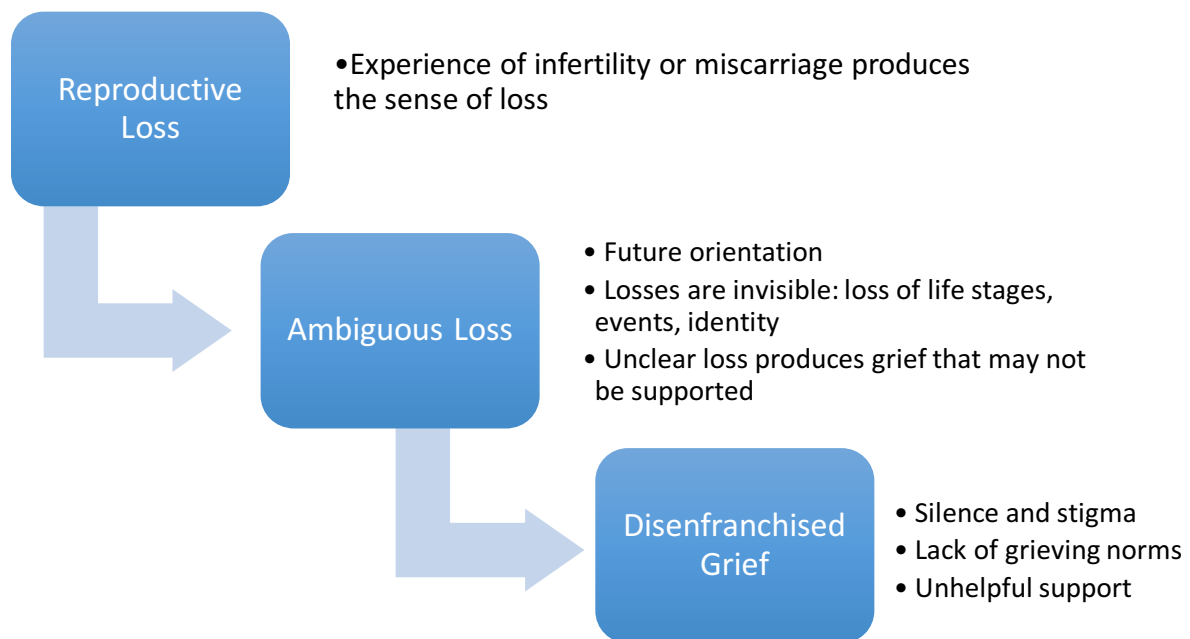
What do you believe counselors do not understand about infertility/miscarriage? What do you want them to know?

What do you believe doctors do not understand about infertility/miscarriage? What do you want them to know?

How can resources and support be improved for women affected by infertility/miscarriage?

Appendix G

Visual Thematic Map



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