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Support for Women who Experience Infertility: Providers' Perspectives

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by

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

The purpose of this study was to explore how providers can support women who are experiencing infertility. Seven licensed professionals including social workers, family and marriage therapists, psychologists and doctors with experience working directly with women experiencing infertility participated in this study. Using a qualitative design, participants were interviewed regarding their experience working with women going through infertility. Content analysis was used to analyze the recordings of the interviews and to identify themes that emerged throughout the data. Three major themes emerged from the data including the need for support, education, and continued care. The themes found in this study support previous research including the need for peer, partner and provider support as well as the need for education and integrative care within the fertility world. This study diverged from previous literature on the need for continued care for women following successful fertility treatment as they encounter the many challenges of motherhood and highlighted the need for future research. This study emphasizes the need for social workers to have a strong understanding of the impact that infertility has on women in order to provide effective care and support.

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Introduction

Although the psychological impact of infertility has been widely researched, how to support women throughout the infertility process is not well understood due to the stigma that infertility continues to carry, minimal research on the efficacy of interventions, and a general lack of understanding of long-term effects of unsuccessful treatment. Grief and loss associated with infertility can have profound effects on women and significantly impact their psychological wellbeing (Volgsten, Svanberg, & Olsson, 2010). As medical treatments for infertility have progressed greatly, concerns about the impact of these treatments on a women's psychological health have been greatly overlooked. Many women hide the losses they experience from an infertility diagnosis to avoid the social stigma around infertility that is so engrained in our culture (Thorn, 2009). Women experience feelings of guilt, depression and anxiety that greatly impact their identity and their relationships often leading to social isolation (Thorn, 2009). Despite the profound impact of infertility on a women's mental health, there is a lack of quality research and agreement on effective interventions for this population (Boivin, 2003). As research focuses on psychological interventions to help women with infertility, statistics show that most women do not seek specific psychological counseling. Women most at risk for long-term psychological distress are those who have either not sought treatment for various reasons or who have experienced multiple unsuccessful infertility treatments over the years (Volgsten, Svanberg, & Olsson, 2010).

Infertility profoundly impacts the lives of millions of women throughout the United States and globally. Current research suggests that around 12-15% of couples experience infertility during their childbearing years (Center for Disease Control [CDC], 2015). An estimated 4.3 million couples in the United States have difficulty naturally conceiving a child (Peterson, Gold & Feingold, 2007). Of the couples facing infertility, approximately 44% seek medical treatment. Infertility can have significant social, economic, psychological and physical effects for individuals and couples (CDC, 2015). Regardless of the cause of infertility, the diagnosis can have a profound impact on the couple (Volgsten, Svanberg, & Olsson, 2010).

The definition of infertility has changed over time from simply a medical diagnosis, to understanding it as a complex continuum that impacts women not just physically, but psychologically. Historically, infertility has been defined in a medically oriented manner as "not being able to conceive after one year of unprotected sex" (CDC, 2015, p.1). Medically, within infertility, there are different forms. *Primary infertility* is the inability to conceive with no previous children (CDC, 2015). *Secondary infertilit*y is the failure to conceive after previously conceiving and delivering an infant without fertility treatment (CDC, 2015). Infertility encompasses more than just the diagnoses. It includes the decisions about whether or not to pursue treatment, the treatment itself and the outcome whether it is conception or remaining childless. Infertility is variable in time, lasting on average five years, but for women who remain childless, the impact of infertility can continue throughout their life (Domar & Siebel, 1997).

Historically, interventions to support infertility have included medical interventions, alternative family building options, and psychological counseling around

infertility. Medical interventions include fertility education, medications that stimulate egg production in the ovaries and assistive reproductive technologies (CDC, 2015). Alternative family building options are sperm and egg donation, surrogacy and adoption (CDC, 2015). Psychological counseling around infertility involves preparatory psychosocial counseling for patients seeking medically assisted treatments or more intensive individual and group counseling around infertility for women regardless of whether or not they begin medical infertility treatments (Boivin, Scanlan, & Walker, 1999).

Although there have been many medical breakthroughs over the years regarding infertility treatments, barriers to addressing fertility remain problematic: cost, lack of access to treatment, and the psychological impact of fertility treatment (Bitler & Schmidt, 2001; Van De Broek et al., 2009). The cost continues to be substantial and can be a great barrier for women who wish to pursue treatment (Bitler & Schmidt, 2011). Despite the high cost, only 25% of health insurance plans cover any infertility treatment (Bitler & Schmidt, 2011). Lack of access to infertility clinics and higher average cost of treatments are more common in areas with low socioeconomic populations creating even greater barriers (Bitler & Schmidt, 2011. This highlights the socioeconomic implications of infertility treatments. Psychological impacts of treatment upon women suggest that the psychological burden of infertility treatments is not only a barrier to seeking treatment, but also the main reason women discontinue treatment (Van de Broeck et al., 2009).

The role of social workers in supporting women around infertility has included preparing clients for treatment, providing continuity of care, and providing structured psychological interventions when necessary. Infertility centers often do not offer

psychological support and doctors have minimal time to discuss options with their patients. Social workers can help prepare patients for the intensity of treatment and the difficult decisions they will need to make along the way (Greenfeld, 1997). Social workers can also provide continuity of care for individuals who are constantly seeing different providers. Some women need social workers to provide more structured psychological interventions throughout the infertility process including specific behavioral therapies, grief counseling and marital therapy (Greenfeld, 1997).

Problem Statement

The purpose of this study is to explore how providers can support women who are experiencing infertility.

Literature Review

This literature review is broken into four sections. First, context and definitions that pertain to infertility, infertility treatments, and current barriers to treatment shall be introduced. Second, research that examines the psychological impact of infertility section will be highlighted. Third, the impact of infertility, infertility treatments, and the unsuccessful medical treatment will be addressed through the exploration of existing empirical studies. Finally, given that the purpose of this research is to explore how providers can effectively support women experiencing infertility, the current psychological interventions will be explored as well as the specific needs of women going through infertility process.

Infertility, Treatment, and Barriers to Treatment

To understand how to meet the needs of women experiencing infertility, it is critical to define infertility and understand the treatments and possible barriers to treatment that women encounter. This section will define infertility and explore infertility upon a continuum of diagnoses and barriers. Secondly, it will look at current treatments including education, medical procedures, and third-party reproduction techniques. Lastly, it will address the barriers that many women face when considering infertility treatments including cost and the psychological burden of these treatments.

Definition of infertility. Infertility is defined as the inability to conceive after one year of unprotected sexual intercourse (CDC, 2015). Within infertility, there are different forms. *Primary infertility* is the inability to conceive with no previous children. Secondary infertility is the failure to conceive after previously conceiving and delivering an infant without fertility treatment (CDC, 2015). Although historically infertility is

commonly associated with women, it is estimated that only one-third of infertility is attributable to women. Another one-third is attributed to men, and the rest is a combination of the two partners or has no explainable cause (Peterson et al., 2007).

There are a variety of reasons why both men and women suffer from infertility. As women begin to delay child-birth into their 30's and 40's, their advancing maternal age can have an impact on their fertility. As women age, their number of eggs their body produces as well as the quality of egg begins to decrease (University of California Los Angeles [UCLA], 2014). This can make it more difficult for them to conceive naturally. Other common causes of infertility are ovulation disorder, tubal occlusion, uterine fibroids, endometrial polyps, and endometriosis (UCLA, 2014). In men, infertility is typically caused by abnormal semen. This can be a result of varicoceles, medical conditions such as diabetes, cystic fibrosis, exposure to chemotherapy or radiation or unhealthy habits such as heavy alcohol use, smoking and use of anabolic steroids (CDC, 2012).

Infertility treatments. Over the past 30 years, significant advances in the treatment of infertility have been developed including greater education around infertility, advanced medical procedures and third party reproduction techniques (UCLA, 2014). Treatment options for infertility range from basic education to costly and invasive procedures. For many couples, education is the first step. Helping couples understand the reproductive process can greatly impact their ability to conceive (UCLA, 2014). If couples continue to have trouble conceiving, many doctors prescribe women a medication that stimulates the ovary to develop eggs for ovulation. The most common medication prescribed oral medication is Clomiphene, which is taken for four days during

the menstrual cycle to stimulate egg development. Gonadotropins are another commonly prescribed medication, which consists of injections that are prescribed for some women and are typically taken daily for five to 10 days usually beginning on the second or third day of the menstrual cycle to prompt the ovaries to produce eggs. When medications are not successful, doctors often suggest intrauterine insemination (IUI). Sperm is taken from the man's semen and placed directly into the uterine cavity. Another option that doctors suggest is in vitro fertilization. During this procedure, women often begin by starting gonadotropin injections. Pre-ovulation the eggs are retrieved in the operating room. The eggs are then fertilized with sperm in the laboratory, and the embryos are transferred directly into the uterus. Other Assistive Reproductive Technologies include Zygote Intrafallopian Transfer, Gamete Intrafallopian Transfer, and Intracytoplasmic Sperm Injection. Some of these technologies can use donor eggs, donor sperm or previously frozen embryos (Center for Disease Control, 2012). If these options are unsuccessful, not possible given specific medical conditions or a couple simply wishes to pursue options, third party reproduction methods are another possibility (CDC, 2012).

Barriers to infertility treatment. Despite the medical advances that have been made over the years, there continues to be significant barriers to infertility treatment. Currently in the United States, only 25 percent of insurance plans cover even a portion of infertility treatment (Bitler & Schmidt, 2011). Costs vary widely in different states and different clinics. The average price of one Intrauterine Insemination cycle is 865 dollars. The average price for one cycle of In Vitro Fertilization is 8,158 dollars, which does not include the price of the necessary medications. The average additional add-on cost of intracytoplasmic sperm injection is 1,544 dollars (Resolve, 2014). It is important to note

that many couples go through multiple cycles of treatments before they can conceive (CDC, 2012). The Center for Disease Control reports that success rates of Assistive Reproductive Technologies (ART) are 40 percent in women under the age of 35 (CDC, 2012). The success rate of ART for women 35-40 is estimated to be between 22-31 percent. Studies estimate that approximately 30-40 percent of women remain childless five years after initial infertility diagnosis (Pinborg, Hougaard, Anderson, Molbo, & Schmidt, 2009).

Current research has sought to address other possible barriers women face when considering infertility treatment beyond the cost and time commitment. Domar and colleagues looked specifically at the emotional barriers women faced when deciding whether or not to seek treatment. Through an online survey of women who had experienced infertility (n = 445), but chose not to seek treatment, researchers found that the two biggest barriers to treatment were a women's age and anxiety over the treatment (Domar et al., 2012). Researchers found that women over 35 were reluctant to seek treatment. Many women also felt anxious over injections and medications involved in the medical treatments for fertility.

Another study looked specifically at the reasons that women chose to discontinue treatment by interviewing women from a hospital-based fertility center (Van De Broek, Holvoet, Enzlin, Bakelants, Demyttenaere, & D'Hooghe, 2009). Van De Broek and colleagues (2009) interviewed women (n = 25) who had decided to discontinue treatment and found that the psychological burden of the treatment was the most predictive factor of women dropping out. Physical burden, age, perceived lack of staff expertise and negative impact on social relationships also impacted their decision (Van De Broek et al.,

2009). Current research suggests that women experience significant barriers when considering infertility treatment including finances, time, and the psychological burden of treatment.

Emotional/Psychological Experience of Infertility and Infertility Treatments

As medical treatments continue to progress around infertility, a substantive body of research has begun to focus on the emotional and psychological impact of infertility and infertility treatments. Empirical studies to be discussed have focused on the psychological effect of the initial diagnosis, the impact of specific infertility treatments and the possible consequences of unsuccessful treatment. The following section will first look at four empirical studies to explore the research on the psychological and emotional impact of infertility and initial treatments. Secondly, research around the long-term psychological and emotional impact of unsuccessful infertility treatments will be addressed.

Psychological/ emotional impact of infertility. The many losses that individuals experience when they are faced with infertility can greatly impact their emotional and psychological wellbeing. Many women experience increased rates of depression and anxiety immediately following an infertility diagnosis (Lechner, Bolman & Van Dalen, 2007; Slade, O'Neil, Simpson, & Lashen, 2007; Newton & Sherard, 2013). Many different factors can impact a women's level of anxiety and depression while going through the complex process of infertility.

In one study, Slade, O'Neill, Simpson, and Lashen (2007) looked specifically at the factors that influenced symptoms of depression and anxiety in women experiencing infertility. Perceived level of social support was the greatest predictor of symptoms of

depression in women experiencing infertility (Slade et al., 2007). In this study, women who were attending an infertility clinic for the first time (n = 87) were given questionnaires focused on stigmatization, disclosure, social support, and psychological distress. Researchers also found that for these women, the perception of stigma was related to low social support.

A second study completed by, Galhardo and colleagues (2001) looked at the impact of shame and self-judgment and their association with psychopathology in women. The study compared couples experiencing infertility (n =100), couples without known fertility problems (n =100) and couples with infertility challenges applying for adoption (n = 40). Similar to Slade et al. (2007), the study found higher rates of depression and anxiety in women experiencing infertility treatment than those with known fertility problems. In addition to depression and anxiety, they also found higher levels of external and internal shame and self-judgment. These studies suggest that perceptions of stigma and feelings of shame are related to elevated levels of depression and anxiety in women experiencing infertility.

In a third study, Newton, Sherard and Glavec (1999) looked at other possible predictors of depression in women experiencing infertility. Their prospective study of women referred for assessment and infertility treatment (n = 1,153) found that sexual and relationship concerns are more effective predictors of the onset of depression during infertility (Newton et al., 1999). Researchers hypothesized that this could be because these concerns have the most immediate impact on the couple facing the infertility diagnosis (Newton et al., 1999).

Qualitative research studies have looked deeper into the emotional impact that infertility has on women. Loftus and Andriot (2013) interviewed women experiencing infertility (n = 40) and found that following an infertility diagnosis many women experience feelings of guilt and self-blame. Women often feel that their bodies are defective, or they are damaged in some way because they cannot conceive (Loftus & Andriot, 2013).

In interviews with Australian women experiencing infertility (n = 28), Bell (2013) found similar themes. Women described feelings of inadequacy, disempowerment, and guilt. Women in the study also described feelings of anger towards other women who had children as well as avoidance of situations that could be reminders of their childlessness (Bell, 2013). Research clearly suggests that infertility can have a significant impact on a women's psychological and emotional well-being.

Long-term impact of infertility treatment/unsuccessful treatment. The long-term psychological impact of infertility varies greatly based on whether or not treatment is successful. Women who can conceive following treatment have a lower risk of long-term psychological implications (Holter, Anderheim, Bergh, & Moller, 2006**)**. In a longitudinal study of couples seeking infertility treatment (n = 117), Holter and colleagues found that women who conceive following treatment rated their wellbeing higher after treatment than before. However, the study also suggests that for women who experience unsuccessful treatment, the emotional and psychological effects can be profound and long lasting.

Other studies also support the long-term effect of failed treatments on psychological well-being. Volgsten, Svanberg, and Olsson (2010) interviewed women (*n*

= 10) to look at the experience of women who had undergone unsuccessful IVF and remained childless three years later. The researchers found themes in the experience of the women studied including feelings of worthlessness, lack of self-esteem, loss of control and feelings of guilt (Volgsten, Svanberg, & Olsson, 2010). Feelings of grief and depression were enough to make them discontinue treatment altogether for women in the study (Volgsten et al., 2010). Looking at the long-term impact of unsuccessful IVF, this research suggests that three years later many women have not adapted to childlessness and continue to experience unresolved grief (Volgsten et al., 2010).

In a large longitudinal cohort study of Danish women (n = 51,221), researchers studied whether women who were unable to conceive following an infertility diagnosis were at a greater risk for suicide than those who had been able to conceive. Using population registries, researchers found that the women studied who were unable to have a child after an initial fertility evaluation were at greater risk for suicide than woman who were able to have a child (Kjaer, Jensen, Dalton, Johansen, Schmiedel, & Kjaer, 2001) The study also suggests that women experiencing secondary infertility are also at a higher risk of suicide than women who can conceive.

Qualitative studies have also looked retrospectively at the experience of unsuccessful infertility treatment. Ferland and Caron (2013) interviewed women (n = 12) who were postmenopausal and had remained childless due to unsuccessful interventions. Researchers used two hour-long interviews focused on the journey of infertility from the diagnosis to the present time to understand the women's experience. Years after unsuccessful treatment, women reported themes of hopelessness, insensitive doctors, and feeling as though no one understood what they were going through (Ferland & Caron,

2013). Current research suggests that unsuccessful infertility treatments can have a long-term impact on a women's mental health and wellbeing.

Psychological Interventions for Infertility and Women's Needs

Given the profound effect that infertility can have on a women's psychological well-being, research has begun to address the efficacy of a variety of psychological interventions as well as explore the needs of women throughout the infertility process. This section will look at two empirical studies related to the efficacy of individual and group therapy as well as specific therapeutic interventions. Secondly, it will review the current research on the needs of women throughout the infertility process by exploring three qualitative studies.

Psychological interventions for infertility. Many psychological interventions are used to support women with infertility. However, there are minimal quality research studies addressing their effectiveness. In a review of the current literature on psychological interventions, Boivin (2003) found a significant lack of quality studies around the impact of psychological interventions on infertility-related distress. Of the 380 studies he looked at, only eight met criteria, which included a control group and minimum quality research standards.

Despite the lack of studies, researchers have come to relatively consistent findings around the specific style of psychotherapy that is the most effective in helping women with infertility**.** The main psychotherapy method that research supports as being effective in promoting well-being and decreasing depression and anxiety in women experiencing infertility is group-based cognitive behavioral therapy (Facchinetti, Tarabusi, & Volpe, 2004; Domar, Clapp, Slawsby, Kessel, & Orav, 2000). Multiple studies have shown that

when women are provided with group-based CBT, their rates of both depression and anxiety decrease significantly more than women who did not receive the therapy (Facchinetti et al., 2004; Domar et al., 2000).

In their study, Faramarzi and colleagues (2008) also looked at the effectiveness of Cognitive Behavioral Therapy (CBT) and pharmaceutical interventions such as anti-anxiety and anti-depressant medication. Findings from the study suggest that CBT may be more beneficial that pharmaceuticals in decreasing depression in women undergoing infertility treatments (Faramarzi et al., 2008). Although research has begun to explore effective interventions for women experiencing infertility, there is a lack of quality studies as well as consistent results.

Women's needs throughout the infertility process. Given that research suggests that only around 18-21% of women choose to seek out professional counseling throughout their infertility experience (Boivin, 1999), researchers have begun to address if and how women are getting their needs met throughout the infertility process. Zargham-Boroujeni and colleagues interviewed women experiencing infertility (n = 17) and found that personal empowerment and sense of adequacy were fundamental needs of these women. These included needs of self-efficacy, being valued and self-esteem, sense of confidence and trust, access to information and financial support (Zargham-Boroujeni, Jafarzadeh-Kenarsari, Ghahiri, & Habibi, 2014). Women in the study also expressed that they expected to receive more hope and psycho-emotional support from their doctors as well as a consistent provider throughout their treatment.

Gameiro, Canavarro and Boivin (2013) also looked at how to best meet the needs of women throughout the infertility process. The focus of their study was on the role of

patient-centered care in infertility health care. Using the questionnaires of women undergoing infertility treatment (n = 322), they found that when women felt they had all the information and an understanding of the medical procedures, they had decreased symptoms of anxiety and depression**.** This study supported findings from Zargham-Boroujeni and colleagues around the importance of continuity of care. The study suggests that when women have one consistent member of their team throughout the infertility process, their psychological distress decreases (Gameiro et al., 2013).

Other research has looked at the level of satisfaction reported by women following infertility treatment. Malin and colleagues (2001), distributed questionnaires to women who had experienced infertility (n = 344) to investigate the experiences they had with the infertility process. They found that less than half of the women studied were satisfied with their treatment. The most common reason for negative experiences was a poor relationship with healthcare personnel. This included not being taken seriously, feeling as though they had been treated as an object and staff not taking psychological aspects of infertility treatment into consideration (Malin, Hemminki, Raikkonen, & Sihvo, 2001).

Problem/Purpose of study

Existing literature suggests that women with infertility experience significant psychological and emotional distress. This distress appears to be even greater in women who do not seek treatment or experience unsuccessful medical interventions. Research has focused on psychological support for women following the initial diagnosis; however major gaps are present in how providers can support women throughout the infertility process including women who choose not to seek out treatment. This study will focus on

provider perspectives of how to meet the needs of women throughout the infertility process whether or not they are involved in medical infertility treatments.

Conceptual Framework

Ambiguous loss

The infertility that many couples and individuals face can be viewed from the framework of an *ambiguous loss*, which Boss (2006) defines as an unclear loss that defies closure. There are two types of ambiguous loss including *ambiguous presence* and *ambiguous absence*. *Ambiguous presence* refers to situations where an individual or loved one is physically present, but psychologically absent. Examples of *ambiguous presence* include individuals with traumatic brain injuries, dementia, addiction and mental illness (Boss, 2006). Fravel, McRoy, and Grotevant (2000) applied ambiguous loss to adoption in that the birthmother experiences a psychological presence of their child, but a physical absence. *Ambiguous absence* refers to when an individual or loved one is physically absent, but perceived as psychologically present (Boss, 2006). This is often applied in situations involving missing children, soldiers who are deployed and divorce.

Grief/Loss Models

Historically, experience of grief has often been looked at through the Kubler Ross stages (Hooyman & Kramer, 2006). Although the stages were created to look specifically at the process of dying, many have applied them to grieving. The stages include: shock, denial and anger, resentment and guilt, bargaining, depression and adjustment and acceptance (Hooyman & Kramer, 2006). An individual must go through every stage in a linear fashion. Critics of this stage theory express that grief is not a linear process nor is it critical for an individual to experience every stage.

In recent history, theorists have created a new set of phases to more appropriately look at the process of grief following loss. These phases are not necessarily sequential and individuals move back and forth throughout the grieving process. The three agreed upon stages are avoidance, confrontation and accommodation (Hooyman & Kramer, 2006). The final stage accommodation occurs when an individual is able to "move on." In this model, "moving on," means living a meaningful life without the deceased. The great majority of current frameworks for grief continue to emphasize the need for closure and/or detachment from the loss as part of the process for "normal grieving" (Boss, 2006).

Although these three stages are appropriate for many types of grief, the ambiguity of the losses involved in infertility complicate the grieving process. Ambiguity in loss has a high potential for causing symptoms that conventional theories could see as unresolved grief (Boss, 2006). Infertility often has no closure and the nature of the loss is unresolvable. Using traditional grief and loss models, the ambiguity and ongoing grief of infertility often goes unrecognized. Providers either do not provide the support or tools women needs or immediately jump to pathologizing their grief response. As Boss states, "ambiguity coupled with loss creates a powerful barrier to coping and grieving and leads to symptoms such as depression and the relational conflict that erode human relationships" (2006, p.1). Understanding the ambiguity involved in infertility is critical to supporting women throughout the infertility process.

Loss and infertility

Women experiencing infertility can face loss in many different ways. When faced with infertility, couples may struggle to find meaning and identity when they are no

longer able to follow the societal expectations for their life (Peterson et al., 2007).). Infertility can also lead individuals to have doubts in their ability to achieve any of their dreams for the future because a dream they thought was so attainable was taken from them (Cook, 1987). Many women experiencing infertility feel a strong loss of personal identity. They often struggle to reconcile their ideal identity as a mother with their sense of self as being infertile (Thorn, 2009). This identity adaptation can be further complicated when women accept that they may remain childless (Thorn, 2009). Infertility can create loss in a woman's close relationships. Many women feel left out of the shared experience of pregnancy and birth that the women around them are a part of. They can begin to feel like outsiders with the people that are close to them (Ferland & Caron, 2013). Women can feel a loss in the relationship with their partner due to issues of blame, differing coping styles and varying opinions on privacy (Cook, 1987). Some couples may want to avoid sex all together because it is associated with failure. If they have not been able to conceive, sex is simply another reminder of their shortcomings (Thorn, 2009).

Infertility is a loss that is hard to define because it is not concrete. Unlike the grief that is caused by miscarriages or stillbirths, infertility is not the loss of a specific child, but rather the future promise of children. Not only is infertility in itself ambiguous, there is also ambiguity in the diagnosis, causes and treatment in infertility. Often doctors struggle to definitively determine whether a couple will in fact be able to conceive naturally which can cause many months of living in uncertainty. The cause of the infertility is unknown in 20% of infertility cases, which can complicate the grieving process for couples that need a concrete reason for their struggles (McQuillan, Greil,

White, & Jacob, 2003). The different infertility treatments also are full of ambiguity given their mixed success rates and outcomes.

Ambiguous presence/ ambiguous absence

The framework of ambiguous loss more appropriately describes the grieving process for women faced with infertility because not only does it acknowledge the ambiguity involved in the loss, but also gets away from pathologizing the on going grief that women experience as unresolved or complicated grief. Ambiguous loss can be applied to the grief process of women experiencing infertility in a variety of ways. *Ambiguous presence* can be seen in infertility in that women often mourn the psychologically presence of a child that may never have been physically present. A woman or her partner may also experience *ambiguous absence* during or after the infertility process. The psychological impact of infertility and its treatments may cause either individual in the relationship to emotionally withdraw leaving their partner to feel as though they are physically there, but psychologically absent. This *ambiguous absence* may also be experienced in regards to women's social relationships. Although their friends may still be physical present, many women feel that they can no longer identify, relate and share experiences with them making them feel as though they are psychologically absent.

Professional and Personal Lens

My previous professional experience working in women's mental health has influenced this project. Through my work with women in the postpartum period, I have seen the impact that infertility and pregnancy can have a woman's physical and

psychological wellbeing. I have also gained a greater understanding of the limitations in psychological support present within the traditional medical setting.

My personal experiences have also impacted my interested in the topic and desire to pursue this project. I have family and friends who have experienced infertility and have begun to understand the profound impact it can have on all aspects of a woman's life. Through their stories, I have begun to gain greater knowledge of the physical, psychological and educational needs they experience during the infertility process and potential barriers to having those needs met.

Methods

Research Design

The purpose of this study is to explore provider perspectives on how to support women who experience infertility. Since little research has been done specifically focused on the how to meet the needs of women throughout the infertility process, this study is exploratory in nature. The study used a qualitative research design to gather information about provider perspectives on how to effectively support women through the infertility process. *Qualitative studies* seek to understand the personal and subjective experiences of individuals (Monette, Sullivan, & Dejong, 2001). The study used a semi-structured interview that will address providers' perspective on the impact of infertility, perceived needs of women faced with infertility, and the effectiveness of current supports (see Appendix B). Seven licensed professionals that work with women throughout the infertility process were interviewed. The researcher created the interview with feedback from both her MSW research board and the University of St. Thomas Institutional Review Board**.** The interview will be recorded, transcribed and analyzed using grounded theory,

Sample

The sample included seven licensed professionals who had direct experience working with women going through infertility. All participants for this study met inclusion criteria including being a licensed professional and having minimally three years of experience working directly with women experiencing infertility. The sample included a licensed family and marriage therapist, three licensed psychologists, two licensed clinical social workers and one medical doctor. All of the participants were Caucasian, female and lived in an urban setting.

Recruitment

A purposeful, strategic sample was used for this study. The researcher contacted providers who worked directly with women experiencing infertility. Contact information for the potential participants was found on publically available sites. The providers were contacted directly by email and phone. A recruitment script was used for the initial contact and included the purpose of the study, rationale for why potential participants were chosen, risks of benefits of the study, and expectations for the participant should they choose to be a part of the study. If the participant demonstrated an interest in being a part of the study, a follow-up letter of introduction was emailed or sent to the individual. The participants then contacted the research to schedule an interview. All seven of the potential participants who contacted the researcher met criteria for the study and completed an interview.

Protection of Human Subjects

To protect participants in this study, many protections are in place. A letter of consent was provided before the interview that was approved by the University of St. Thomas Institutional Review Board (see Appendix A). The letter of consent clearly described the relevant background information, the purpose of the study, risk and benefits of participating in the study, the rights of the participant and confidentiality. The researcher also verbally explained the right rights of the participant, the voluntary nature of the study and factors related to confidentiality. There were no known identified risks or benefits of participating in this study. To mitigate any potential risk, only licensed providers were recruited for this study. Following the interview, participants were also given a list of resources around support to use if needed. The study was voluntary in

nature, and participants could skip any questions or choose not to participate at all. The participants' names were omitted from the records. The records were kept confidential and secure on a password-protected file on the researcher's computer. The interviews were recorded and transcribed to ensure appropriate analysis. The data will solely be used for this study. The recording of the transcription will be destroyed by June 1, 2017**.** The names of the participants will be replaced with pseudo names in the findings section to ensure anonymity.

Data Collection and Instrument Process

Before participating in the interview, all participants provided consent both verbally and through signed the consent form. Participants were informed that the study had not direct benefits to the participant and were reminded that they could end the interview at any point. Interviews took place in a private, mutually agreed upon location. The interview used a semi-structured format and lasted between 30 and 48 minutes. The interviews were recorded to ensure accurate analysis of the information. The questions were approved before the interview by the University of St. Thomas Institutional Review Board and Protection of Human Subjects to ensure they met appropriate guidelines. The interview consisted of nine questions that were compiled based on a review of literature focused on the psychological impact of infertility and intervention strategies (see Appendix B).

The sequencing of the questions went from broad questions about women's experience with infertility to more specific questions regarding perceived effectiveness of therapeutic supports. Follow-up questions were used throughout the interview to gain further information about perspectives regarding effective therapeutic interventions.

Following the interview, the entire recording of the interview was be transcribed by the researcher. This transcription was used for coding purposes. The entirety of the transcription was analyzed to identify codes and themes.

Data Analysis Plan

Content analysis was used to analyze the recordings of the interviews and to identify themes that emerged throughout the data. Content analysis is defined as a, "method of transforming the symbolic content of a document from a qualitative unsystematic form into quantitative, systematic form" (Monette et al., 2014). During the data analysis, qualitative interviews were audiotaped, transcribed, and analyzed for themes using a content analysis data reduction approach (Monette et al., 2014). Two of the qualitative interviews were conducted through Skype, and the remaining five were conducted in person. The primary researcher of this project transcribed interviews. Data analysis was conducted in several phases: (1) data was read through, and notes were written; (2) data was coded; (3) data was further described and summarized using *open coding* strategies where categories were found; (4) common themes and smaller subthemes were developed throughout the coding.

Findings

Data analysis of the seven interviews resulted in the development of three main themes. The themes included support, education, and continued care. Within in the three themes, subthemes also emerged. In the theme of support, subthemes included provider support, peer support, and partner support. Within the theme of education, three subthemes emerged including therapist education of medical infertility treatments, medical professionals education on the psychological impact, and education on integrative care. The final theme, continued care, contained two subthemes including the impact of ending treatment and the impact on motherhood. These themes are outlined in Table 1.

Table 1

Themes/Subthemes and Sample Response

Category	Thematic category	Sample Response
Theme 1:	Support	
S1	Provider Support	Instead of trying to minimize the negative feelings or trying to make it better, sit with her in the 'yuck.'
S2	Peer Support	Whether it is immediate friends and family, online support groups, resolve…there is so much value in knowing we are not alone.
S3	Partner Support	'You have different experiences, but you are still in it together, and it sucks'. So trying to get them to have compassion for themselves as a unit and help them build empathy between them
Theme 2:	*Education*	
E1	Therapist education on medical procedures	Educate yourself on the process so that you can speak intellectually and understand all those steps she is going through, so she doesn't have to explain it.
E2	Medical professionals education on psychological impact	They are experts on the women's body, but when that woman is crying on the table in frustration, they don't know how to help them.
E3	Education on integrative care	If we could bridge a little more in the therapy world and medical world about helping people have space to do some therapy and work around infertility.
Theme 3:	*Continued Care*	
C1	Impact on motherhood	The belief that they are defective or faulty doesn't go away after a successful pregnancy. Clients need to prove to themselves that they can do something right
C2	Impact of ending treatment	It has to be a personal decision, but there is a definite pressure to keep going. This is where I really think it is necessary to have therapy around it. Somebody who is not in it to talk to.

Support

Provider support. All seven of the participants in this study addressed the importance of provider support throughout the infertility process. The participants agreed that women needed to feel that they were not alone in the process. Women needed to feel like someone else was on this journey with them. Rebecca shared that women need support, "*just the sense that there is someone walking with you and is in this with you whether it is a doctor, therapist or nurse*."

The seven participants all discussed the profound impact that infertility has on a women's feeling of self-worth. They shared the importance of addressing the feelings of shame, sadness, and anxiety that women often experience both with the initial diagnosis and throughout the infertility treatment. They all stated that clients often brought up the idea that their body was "defective" in some way. Jane said, "*I think there is such a huge shame and grief piece. What is wrong with me? My body is defective. Angry with themselves."* She also discussed that many women start to express guilt over past experiences such as feeling that they had too many partners, put their career ahead of motherhood, or feel guilt over the abortion they had when they were young. Anna shared that many women feel that having a baby is a biological process that millions of women have done. Trying to cope with why their body cannot naturally produce a child is incredibly hard to take and often brings up intense feelings of shame. Jane described infertility as a loss of both innocence and control that can be extremely hard for women to understand.

All of the participants agreed that supportive therapy was necessary when working with women throughout the infertility process. They discussed the need to

empathize, validate and normalize what women were experiencing. Both Mary and Jessica expressed the need just to provide a space for women to share their experience. They both emphasized the importance of providing empathy and allowing women to feel truly heard. Anna also expressed that women need empathy and for someone to just listen. She stated that,

> *Women need to talk about their experiences, and they don't want it downplayed or dismissed. And they don't want a thousand pieces of advice, 'Oh just calm down.' 'If God wants to have a baby, you will have a baby.' They just need someone to listen.*

Anna shared that women often feel that their experience and struggle is minimized by the people around them and just need someone to acknowledge that what they are going through is a terrible experience. She shared that,

> *Instead of trying to minimize the negative feelings or trying to make it better, sit with her in the 'yuck.' Empathizing that this is a terrible experience, and I can't imagine how hard this must be. Truly being with the person rather than trying to change their mood.*

Jessica shared that there was a need for supportive therapy not only within therapy room but also in the medical setting. She explained that too often the conversation is solely centered on medication and procedures. Although this is the focus of these appointments, she felt that providers need to be compassionate and empathetic providing a space where women can talk about what they are feeling in a way where they feel heard and understood.

Peer support. All of the participants in the study discussed the feeling of isolation that many women face throughout the infertility process. The providers interviewed all felt that addressing the experience of feeling isolated was one of the most critical ways to support women through the diagnosis and treatment. Anna discussed the

strain that infertility can have on relationships with family and friends. Often peers and family members try to be supportive, but do not always know the best way to offer help. She shared that,

> *infertility is common, but not having infertility is more common. I hear clients describe the platitudes that get said around infertility, and they are meant to be supportive but are incredibly invalidating. It is another way that women feel isolated because no one understands their experience. It is a lonely thing.*

Rebecca similarly felt that infertility could strain friendships because women who have experienced infertility have such a different experience than women who became pregnant easily. Many of the providers shared that signs of fertility, pregnancy, and babies surround women in their childbearing years. These reminders can be extremely painful for women experiencing infertility because they are constantly faced with this dream that they are trying so hard to achieve. Multiple participants in this study stated that women often do whatever it takes to avoid these reminders, which can greatly isolate them from their family friends. Many women feel left out of the shared experience of pregnancy and birth. They can begin to feel like outsiders with the people that are close to them. Rebecca expressed that there could be feelings of jealousy, frustration, envy and even anger, which can further isolate women from their support system.

Given the feeling of isolation that many women experience, all seven participants stressed the importance of peer support. Four of the providers discussed the need for peer support whether it be existing friends and family or seeking out other women who have similar experiences. Rebecca stated,

> *just having one friend who calls you and asks how you are doing and you can cry with. That builds back resilience. And if you can just keep hope alive whether it is internally or someone else to hold you in it, it can make a positive impact.*

Anna and Laura agreed that having peer support had a positive impact on resilience and suggested that peer support can come from many places. Anna shared, "*whether it is immediate friends and family, online support groups, resolve…there is so much value in knowing we are not alone. This is tremendous medicine for the human soul. That will boost resilience."*

The three remaining participants felt that although peer support is helpful, women specifically need support from others with similar experiences. Jane shared that during an intake she divides a women's support system into people who have been through infertility and those who have not because she feels it makes such a difference in the type of support they can provide. Jenny shared that she tries to connect women with others who have experienced infertility in a variety of ways including support groups, online groups, blog, and podcasts just to help them feel less alone in their journey. Jessica agreed that it did not matter how women connected with others who shared their experience, the important piece was that they could share their struggles with people who understood what they were going through.

Partner support. All of the participants in the study stressed the importance of partner support if a partner was involved in the infertility treatment. They all agreed that getting partners on the same page is always the first step. Both Anna and Jessica expressed that it is not easy for men to fully understand what their partner is going through. Although they experience the stress, grief, and disappointment of each unsuccessful pregnancy, their experience differs because the treatments and procedures are often not happening directly to their body. Rebecca shared that it is important to get partners on the same page because infertility causes significant stress, which is even

further complicated if the partners cannot work together throughout the process. The need to build empathy as a couple was expressed by Mary. She stated that she often tells couples that, "'y*ou have different experiences, but you are still in it together, and it sucks.' So trying to get them to have compassion for themselves as a unit and help them build empathy between them is incredibly important."*

All of the seven participants agreed that part of encouraging partner support is involving the partner throughout the infertility process. This could include inviting them to medical appointments or getting them into the therapy room. Mary and Rebecca shared that they always try to get the partner into the therapy room even when it just one member of the couple seeking support. Jessica felt strongly about having partners involved in the medical appointments to understand both the process and what the woman is going through. She stated that partner involvement is,

> o*ften overlooked and I think even if there is nothing wrong with them, they need to be more involved in care. When women ask me if I think their partner should come in, I always say yes because it is helpful for them to understand better the process and what you are going through. When they are willing to come even if they have no struggles, it has a great impact on the partner and the relationship*.

Support summary. All of the providers interviewed felt strongly that support was the most critical component when helping women throughout the infertility process. The participants agreed that providers should allow space for women to tell their story. Providers also need to provider empathy and support throughout the process and help a woman through the feelings of shame, sadness and grief. Participants also agreed the women need peer support through the diagnosis and treatment of infertility. While some providers felt peer support of any kind was beneficial, others stressed the need for women to seek out others who had been similar experiences. All seven participants felt that

partner support was a critical component to increasing a women's resilience through the infertility process. They stressed that helping the couple understand the other's experience and including the partner in each step of the infertility process had beneficial effects for both the woman's wellbeing and the relationship as a whole. Participants agreed that support from providers, peers, and partners were essential to a woman's overall health and wellbeing throughout the infertility experience.

Education

Therapist education on medical treatments. All of the providers discussed the importance of education in providing effective integrated care to women throughout the infertility process. Each participant explained that infertility could be complicated because it involves both medical and mental health concerns. As Rebecca stated, "*what makes infertility different from other concerns that clients present is that infertility is in between the medical and mental health world*." Education was discussed in three ways including the need for of mental health professionals to be educated on medical treatments for infertility, medical professionals education on the psychological impact of infertility, and education to bridge the gap between the medical and mental health world.

All of the participants in the study discussed the importance of being educated on current medical procedures and treatments for infertility. Four of the participants felt that this is important because it should not be the client's job to help the therapist understand the infertility process. Rebecca shared that it is important to understand the procedures that women are going through. She stated as a therapist one needs to, "*educate yourself on the process so that you can speak intellectually and understand all those steps she is going through, so she doesn't have to explain it."* Four of the participants also felt that

understanding and being up to date on the current medical treatments was important because it allowed them to provide some guidance to their clients. Mary shared that,

> *clients need some guidance so that is where the therapists knowledge and experience working with people and knowing more about what treatments might be effective and which ones may not be extremely helpful. Knowing the statistics about treatments can help by giving them the facts to help them make decisions. For instance, just because your insurance pays for IUIs and not IVF does not necessarily mean that is the best choice.*

Jane and Rebecca felt strongly that providers should refer clients to therapists that specialize in infertility because of its complexity. They agreed that it was too hard for more generalized therapists to be up to speed on the ever-changing fertility world. Jane and Rebecca felt that referring clients to a therapist who has met criteria set by the American Society of Reproductive Medicine could ensure that clients receive the best care possible.

Medical professional's education on the psychological impact. All of the participants agreed that it would be beneficial for medical professionals to be educated on the psychological implications of an infertility diagnosis and infertility treatments. The seven participants discussed the profound impact that infertility treatments have on women and the need to have doctors and nurses who understand the impact and can support them. Mary felt that often medical professionals do not know how to help women emotionally. She stated, "*infertility treatments are humiliating and make people feel like they are being objectified or science experiments. Not real loving people. So it is dehumanizing, and not all medical professionals understand that piece. They are scientists and not therapists."* Jessica felt that because fertility clinics are always busy, and people are moved in and out quickly, they leave little space for a woman's emotional needs. Rebecca agreed that often there is not space for psychological support in fertility

clinics, but stressed the importance of educating medical providers to refer clients to providers who could provide that support. She stated medical professionals, "*are experts on the women's body, but when that woman is crying on the table in frustration, they don't know how to help them. They don't think to have a list of mental health providers, and it's frustrating*."

Education on integrative care. All seven of the participants also agreed that there is a need to bridge the mental health and medical worlds to provide more effective care to clients. They all discussed the lack of communication between the medical and mental health fields around infertility. Jenny stated,

> *if we could bridge a little more between the therapy and medical world, it could allow people more space to do some therapy around infertility. Having a doctor say, 'here are some providers' and following up. Not just making the initial referral, but continuing to bring it up at subsequent appointments.*

Anna shared that she felt it is important to have therapist embedded within OB/GYN clinics and fertility clinics. She believes that having them in the clinic not only eliminates barriers but also takes away some of the anxiety that women feel when seeking out mental health treatment. Jane and Laura agreed that therapists should be accessible on-site at fertility clinics, but felt that in places where this already happens, therapists are underutilized. They stressed that mental health providers within clinics need to have a more central role rather than simply completing psychological assessments on patients and donors. All of the participants agreed that having a stronger focus on integrated care would be greatly beneficial to the women they see.

Education summary. All of the participants in this study felt that there was a strong need for education on all aspects of infertility. The seven providers discussed the need for therapists to have a solid understanding of the medical factors involved in

infertility as well as the infertility treatments. Some providers felt that given the medical complexities of infertility, there was a need for therapists to refer out to providers who specialize in this field. The participants in this study also agreed that there is a need for medical providers to have a strong understanding of the psychological impact of infertility as well as knowledge of when women need more support. The participants in this study also felt that there was a need for greater education on integrative care within the community of infertility providers. Some suggested that therapists should be embedded in OB/GYN clinics and fertility clinics and utilized for not only assessments but ongoing therapy as well. Participants in this study felt that there is a strong need for education regarding the medical and psychological components of infertility.

Continued Care

Impact of ending treatment. All of the participants in this study felt that there was a need for providers to offer continued care to women after infertility treatment whether or not the woman was able to conceive. Anna shared that, "*all of my patients who have gone through infertility, whether they have a child or not, need aftercare*." Five of the participants discussed the need for women to be supported through the decision to end treatment as well as after. All five of the participants who discussed ending treatment emphasized the intense grief that women feel when making this decision. Anna shared that women feel a profound amount of grief and loss when making the decision to end treatment even if they come to that decision on their own. The participants also agreed that women and couples often need support to make the decision to end treatment. Jessica stressed from the medical perspective it is important to be honest and realistic with a

couple. She felt that a provider should only have this conversation if she or he already has an established relationship. Jessica stated,

> *this is not a conversation you rush into. From my experience, most women or couples know deep down when it is time to stop treatment or explore other options. I think being open, honest and allowing space are the most important things to keep in mind.*

Other participants stressed the need for women and/or couples to have therapeutic support around this decision. Jenny shared that her clients often tell her that they constantly feel pressure to keep trying. She explained that some of this pressure comes from the client and the desire to get this thing they want so badly, but women also experience added pressure from providers to continually try other options. She shared that, "*it has to be a personal decision, but there is a definite pressure to keep going. This is where I really think it is necessary to have therapy around it. Somebody who is not in it to talk to*." Rebecca also felt that therapist can help couples through the decision-making process. She shared that so often infertility and it its treatments comes at a huge cost, and eventually couples realize that they cannot continue down this path forever. Rebecca stated,

> *you always hear the phrase, 'a baby at any cost.' The cost is money, time, effort, loss and avoidance. So within therapy, I try to bring the dollar side of it and emotional side of it together. People often rush couples to make that decision. If you are going to tell a couple it is time to step away, there has to be so much empathy, kindness, and compassion and it needs to be slow.*

Participants also felt that women need continued support not only through the decision-making process but also for the months and in some cases years after ending treatment. The five participants shared that when treatment is unsuccessful, women often feel they have no control over their lives and experience great guilt because they feel they must have done something in their past to deserve this. Laura shared that,

> *for women who decide to end treatment, the grief does not just go away overnight. The loss of the life they dreamed of is an ongoing grieving process, and it is so important for them to have someone by their side. It is hard for them to find people who understand what they are going through and therapists need to not only be a strong support but also connect them with women who have similar experiences.*

Impact on motherhood. Five of the seven participants discussed the ongoing impact that infertility can potentially have on a women's view of herself and motherhood if she is able to conceive. Mary felt that there is not enough attention paid to the impact that the infertility process has on motherhood. She shared,

> *I think we have to have an eye on what state is this woman or couple in going into being a parent and what are they setting themselves up for postpartum. Going through infertility or having multiple losses is a risk factor for perinatal illness so I talk about that a lot and people do not want to hear it. They think once I have a baby everything will be fine, and then they get slammed.*

Jenny and Jessica also shared that women who have experienced infertility often struggle throughout pregnancy and following the birth of their child because of the high expectations they put on themselves and the experience. They both shared that women often have unrealistic expectations about the perfect birth plan, breastfeeding, and the immediate bond they will have with their child. Anna shared that,

> *the belief that they are defective or faulty does not go away after successful pregnancy. Clients need to prove to themselves that they can do something right. One of my clients I have is bending over backward in such a strenuous way to breastfeed her baby to ultimately a psychological detriment.*

Three of the participants also discussed that women often struggle with parenting because they feel they have worked so hard to have this child and should now love every minute of motherhood. Mary shared that women feel great shame around any small struggle they have with their children and put enormous pressure on themselves to be the perfect mother one hundred percent of the time. Laura agreed that women who have

conceived through infertility treatments often have unrealistic expectations of motherhood. She felt strongly that,

> *therapy cannot just end once the baby is born. Working through the shame that many women feel as well as helping them come to terms with the 'myths of motherhood' is so important. Helping them avoid jumping to, 'I'm a failure' or 'bad mom' every time they are not the idealized version of what a mother should be.*

Continued care summary. All of the participants in this study felt that there was a need for continued care following the end of infertility treatment. Five of the participants discussed the process of ending treatment as well as the impact that this decision has on women. They agreed that women often need support and guidance during the decision-making process. The five participants also felt women needed support to work through the profound feelings of loss, grief and shame that ending treatment can cause. They also stressed the importance of providing ongoing support to women after they have made that decision to help them throughout their grieving process. Five of the participants discussed the continued impact that infertility and infertility treatment can have on a woman even after they conceive a child. They agreed that women need support following the birth of their child to continue to work through feelings of shame and "defectiveness." Other participants stressed the need for continued therapy to help women face the challenges of motherhood in ways that did not immediately trigger feelings of inadequacy. The participants in this study felt that women need ongoing care whether or not they have a baby following infertility treatment.

Discussion

This research study looked at provider's perspectives on how to support women experiencing infertility through an ambiguous loss lens. The views of the providers in the study both supported and departed from current research on the impact of infertility. This section will examine both the consistencies and differences of findings of this study compared to current literature. This section will also look at emerging themes that came through in this research.

Support

The need to support women psychologically and emotionally throughout the infertility process was stressed by all participants in this study. They agreed that the infertility diagnosis and treatments could have profound impacts on a women's overall well-being. Every participant interviewed shared that women often feel as though their body is defective. These findings were consistent with research done by Loftus and Andriot (2013) who found that following the diagnosis, women viewed their bodies as defective or damaged in some way when they could not conceive naturally. Findings from this study were also consistent with previous research that found that following an infertility diagnosis women often experience symptoms of depression and anxiety as well as anger and self-blame (Lechner et al., 2007; Loftus & Andriot, 2013). Participants in the current study stated that women often feel intense sadness and anxiety when they are faced with an infertility diagnosis. Some participants discussed that women often blame themselves for past choices they have made and feel great shame that they are not able to produce a child when women have been doing this for millions of years. Research by

Galhardo and colleagues (2001) supports the idea that women who experience infertility may have higher rates of external and internal shame as well self-judgment.

All participants in this study emphasized the need for supportive therapy for women going through infertility. Each participant discussed the need for women to have space to tell their story and feel heard. They agreed that women need someone to sit with them in their grief and loss rather than immediately trying to begin fixing the situation. There is limited research on the need for supportive therapy with women experiencing infertility. As Boivin (2003) found, however, there are limited quality studies (n=8) around effective interventions in this area. The research that has been done has suggested that the most effective approach when working with women who are experiencing infertility is Cognitive Behavioral Therapy (CBT). Multiple studies looking at a variety of intervention techniques found that CBT was the most effective in improving overall well-being as well as decreasing symptoms of depression and anxiety (Facchinetti et al., 2004; Domar et al., 2000; Faramarzi et al., 2008). Although some of the participants in the current study felt that CBT could play a role in the intervention, most felt that providing support, education and increasing a women's connection to others were more important.

Peer support was considered a critical component to a women's well-being throughout the infertility process by all of the participants in this study. Each participant felt that infertility could often lead a woman to become isolated. Some of the participants stated that women often felt that their peers and family could not understand what they were going through. They shared that some women have feelings of jealousy, frustration, and anger directed at those who can get pregnant easily. This supports previous research

by Bell (2013) who found that women often have feelings of frustration and anger when they are unable to conceive. The study found that these feelings often lead women to avoid social situations that might remind them of the life they want so badly, but struggle to achieve.

Given this isolation, participants in this study stressed the importance of connecting women to social support whether it is friends, family, or support groups. Participants agreed that social support significantly impacted a woman's well-being and resilience. The importance of social support is prevalent throughout previous research. Slade and colleagues (2007) found that perceived level of social support was the greatest predictor of depression in women experiencing infertility. Participants from this study had varying ideas on whether or not support should come from women with similar experiences or existing peers and family members. Some participants in the study felt that women needed support from people who had also experienced infertility and infertility treatments in order to feel understood and less alone. There is limited research on the impact of varying types of peer support, however the need for women to feel supported and understood is present throughout the literature.

Throughout the interviews, the importance of partner support was continually discussed. Many participants shared that men and women experience infertility differently, but there is a need for them to come together as a couple. Participants felt that a critical component of therapy was working with the couple to build empathy as a unit. They felt that infertility is incredibly stressful in itself, and if a couple is unable to function as a supportive unit, it can be extremely hard for either partner to cope with this stress. Previous research has primarily addressed the different ways that men and women

cope with infertility. Research has also looked at the impact that relationship concerns and lack of sexual intimacy can have on a women's wellbeing. Newton and colleagues (1999) found that a woman's concerns about her relationship and sexual intimacy with her partner throughout infertility treatment had the greatest impact on symptoms of depression. There is little research, however, on how therapists and providers can help couples understand the other's experience and support each other throughout the process. Another technique that participants in the current study discussed for uniting couples throughout the infertility process is involving men in therapy and medical appointments. Many participants shared that they tried to involve men in the process even when they are not the one's seeking treatment. Participants shared that not only did this help the partner understand what the woman was experiencing, but also positively impacted their cohesiveness as a couple. Previous research has not specifically addressed partner involvement in the infertility process.

Education

Participants in this study agreed that therapists need to be educated on infertility related medical treatments and diagnoses to provide the best care possible for their clients. They felt that having this knowledge not only allowed them to help educate and guide their clients but also took the pressure of the client to have to explain what they were experiencing medically. There is limited research on the importance of therapist knowledge of the medical aspects of infertility; however, previous research has shown that when women feel they are educated on their options and the treatment process, they have lower levels of anxiety and depression (Gameiro et al., 2013). Some participants in the study felt that women should be referred to therapists that specialize in infertility due

to the medical complexity of the diagnosis and treatment. Previous research has not addressed the importance of women seeking out providers with an infertility specialty.

Throughout this study, participants continually discussed the need for medical professionals to be educated on the psychological impact of infertility. Some of the participants in the study expressed that infertility could be a dehumanizing experience where women can feel more like science experiments than real people. They stressed the importance of supporting women emotionally throughout procedures and treatments and suggested that this was often overlooked in busy OB/GYN and fertility clinics. This aligns with previous research suggesting that psychological support from doctors was an area that women felt needed to be improved (Zargham-Boroujeni et al., 2014). Research by Malin and colleagues (2001) also supports finding from the current study. This study found that women often felt dissatisfied by the infertility process because they felt as though they were treated as objects and their emotional needs were not addressed.

Participants in the study agreed that there is a need for a greater focus on integrative care within the infertility community. Embedding mental health professionals in OB/GYN and fertility clinics and utilizing these professionals for more than just psychological assessments were both discussed by many of the participants. Research is just beginning to emerge about the effectiveness of integrative care. Although little research has been done on having mental health professionals embedded within clinics, research has shown that women feel they need greater emotional and psychological support during medical appointments (Zargham-Boroujeni et al., 2014). Previous research also has shown that when women have a consistent member of the care team and a strong understanding of their options and the treatments they have a reduction in psychological distress (Gameiro

et al., 2013). The consistency of providers was not addressed specifically in the study, however the participants did emphasize the importance of finding ways for mental health providers to be more accessible and embedded in the fertility process.

Continued Care

Many participants in the study discussed the process of ending treatment and the need for guidance and support throughout the decision-making process. Participants acknowledged the enormous pressure that women feel when making the decision to end treatment and the importance of having a therapist or provider to offer not only guidance but also empathy and compassion. Participants felt that providers needed to be honest and realistic while still giving a woman space and time to come to her own decision. There is limited research on how to support women in the decision process. However, previous research has explored the impact of ending treatment when a women or couple is unable to conceive. Volgsten and colleagues (2010) found that women often experience feelings of worthlessness and guilt when they decide to end treatment as well as a loss of control of their life. Ferland and Caron (2013) similarly found that even years after unsuccessful treatment, women report feelings of hopelessness and that no one understand what they are going through. Findings from this study align with previous research as participants felt that women who are unable to conceive following treatment experience feelings of guilt around past decisions, strong grief reactions and a lack of control over their preferred life. They stressed the importance of continued care following treatment and the need for women to connect with others who had similar experiences to feel that they are not alone.

One area that deviated greatly from previous research is the impact that infertility has on motherhood. Previous research suggests that women who can conceive have a lower risk of psychological implications following infertility treatment (Holter et al., 2006). The study by Holter and colleagues (2006) also found that women who conceive following treatment rate their wellbeing higher after treatment than before. Although participants in this study felt that women who are able to conceive may have fewer ongoing psychological concerns, they stated that many women continue to struggle. Many of the participants felt there was a great need for continued care to help support women through the birthing experience and motherhood. Participants felt that some women need support to work through the ongoing shame that they continue to feel and to address the ways these feeling of shame may impact their expectations of themselves as mothers. The ongoing psychological and emotional impact that infertility treatments have on motherhood is an issue that has not been addressed in previous research.

Strengths and limitations

Strengths. The two main strengths of this study were the use of qualitative design and the participants involved in the sample. Using qualitative semi-structured interviews allowed for a deeper looked at provider perspectives on infertility. This design provided opportunities for follow-up questions and greater room for elaboration to expand on response and address areas that may not have been considered. The second strength of this study was the quality of the sample. All of the providers interviewed had at least four years of experience working directly with women who were involved in the infertility process. The participants also came from a variety of disciplines and settings, which allowed for a broader understanding of the impact that infertility has on women.

Limitations. There were three limitations to this study including the sample size, the lack of diversity in the sample and the face-to-face nature of the data collection process. The first limitation was the sample size. The sample size of seven was small in relation to the number of providers who work with women experiencing infertility. The small sample makes it difficult to generalize this data to the broader population of providers. The second limitation was the lack of overall diversity in the sample. The participants in this study were self-selected which could indicate that they have a greater understanding of the impact of infertility as well as how to support women throughout the process compared to other providers. Although the sample came from a variety of disciplines, the majority (n=6) were mental health providers, which also could impact the results. The sample also was entirely Caucasian and living in urban areas. This lack of diversity in the sample limits the generalizability of the results. Finally, the face-to-face nature of the study may have impacted the way participants responded to specific questions, which could have skewed the findings.

Recommendations for Future Research

The impact of infertility on women is an area that research is beginning to explore. Through this study, three areas for future research emerged including specific interventions to support women experiencing infertility, how to provide ongoing support for women after treatment and how to support men and children impacted by infertility and fertility treatments. The first area for future research is the need to further understand what specific techniques can be helpful in supporting women throughout the infertility process. Although some research has begun to look at specific therapeutic models, more quality studies need to be done. Although previous studies indicated that Cognitive

Behavioral Therapy was the most effective treatment, researchers have looked at the impact of very few alternative therapeutic models concerning supporting women through infertility (Faramarzi et al., 2008; Facchinetti et al., 2004; Domar et al., 2000).

The second area of future research that emerged from this study is addressing how to meet the long-term needs of women following infertility treatment. Previous research addressed the long-term impact of failed treatment, but researchers have yet to look at how to support these women when they are no longer seeking treatment (Volgsten et al., 2010; Holter et al., 2006; Kjaer et al., 2001). More research should be done to explore ways to provide ongoing support for women to help them through their grief and loss. This study also suggests that women need help even when they can conceive. There is minimal research looking at the way infertility treatment impacts the way a woman perceives her children and her identity as a mother. Studies looking at the impact of infertility on motherhood would be helpful to increase providers understanding of how to support women as they raise their children.

The third area for future research that emerged during the study is the need for more studies around the impact of infertility on men or partners and the impact of infertility treatment on the children who are conceived. Many participants in this study felt that male partners need significant support throughout the infertility process, and there are currently limited resources available. Research that explores the needs of men throughout the infertility process as well as how to provide support would great benefit both men and the couple as a whole. The impact that new treatments and third party reproduction have on the children who are conceived has also not been looked at within the research community. Understanding the experience from the child's side would be an

important area for research to explore to gain knowledge on how to support these children as they grow up.

Implications for Social Work Practice

Findings from this study have three implications for social work practice. The first implication is the need for providers to be knowledgeable about infertility and its impact on the women they encounter. Research shows that the grief and loss associated with infertility can have profound effects on a woman's psychological well-being (Volgsten et al., 2010). Clinical social workers who are in clinics, hospitals and therapeutic settings all need to have a basic understand of infertility and the way it impacts women so that they can either provide support or refer them to individuals who can.

Secondly, findings from this study emphasize the need for the medical and mental health worlds to collaborate. Social workers who are currently embedded in settings that provide direct services to women experiencing infertility need to find opportunities to break down the barriers between themselves and medical professionals. Based on findings from this study and previous research, women often report feeling as though they were not taken seriously and the psychological aspects of infertility were not considered throughout their treatment (Malin et. al., 2001). Social workers have the responsibility to integrate themselves into the fertility world to ensure these needs are met more effectively. Integration could include consulting with medical teams, educating themselves on the medical process and advocating for social workers to have a more central role (beyond assessments) within OB/GYN and medical clinics.

The final implication is the need for social workers to advocate for universal access to infertility treatments. Infertility raises many important issues around social policies and the disparities within the current healthcare system. Many participants in the study shared that they primarily see Caucasian, upper-middle-class women because they are the only ones who can afford infertility treatments. Even within this population, participants shared stories about clients who had given up their retirement, houses and overall financial stability to pursue treatments. Currently, only 25 percent of insurance plans cover any infertility treatment (Bitler & Schmidt, 2011). Studies also show that areas with lower socioeconomic populations have less of access to infertility clinics and higher average cost of treatments (Bitler & Schmidt, 2011. Given this limited access and that fact that one round of in-vitro fertilization costs around eight thousand dollars (Resolve, 2014), the great majority of people in the United States cannot pursue treatment. Support, education, and infertility treatments should not be available solely to individuals with great wealth. These apparent disparities around access to care demonstrate the importance for social workers to advocate for policies around healthcare and access.

Conclusion

The current study expanded upon previous research looking at the impact of infertility by looking at provider perspectives on how to support women throughout the infertility process. The themes found in this study supports previous findings including the need for peer, partner and provider support as well as the need for education and integrative care. This study also supports previous literature on the impact of unsuccessful infertility and expanded on ways to support women throughout their

grieving process. Findings from this study diverged from previous literature on the need for continued care for women following successful fertility treatment as they encounter the many challenges of motherhood. The current study also pointed out numerous areas for future research including the importance of considering the impact of infertility treatment on men and children who are conceived through these methods.

The impact of infertility on women is incredibly complex. Although infertility treatments can give women great hope and joy, infertility can also lead women to feel profound feelings of shame, grief, and disappointment. An infertility diagnosis can impact the women's peer and partner relationships as well as the way they view the world. This study showed the importance of support, education and continued care when working with women throughout this process. Social workers need to have an understanding of the impact that infertility can have on women to provide effective care and support to their clients.

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Appendix A

CONSENT FORM
UNIVERSITY OF ST. THOMAS
GRSW681 RESEARCH PROJECT

Support for Women who Experience Infertility: Providers' Perspectives

I am conducting a study focused on provider perspectives for supporting women who experience infertility. I invite you to participate in this research. You were selected as a possible participant because of your work in the area of women's health and infertility. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Mackenzie Landbloom, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by Kari Fletcher, PhD, LICSW

Background Information:
The purpose of this study is to understand provider perspectives on how to support women who are experiencing infertility. The interview will address the perceived impact of the infertility diagnosis and treatment as well as current and potential future supports for women who are going infertility. The interview will also address the possible impact of culture and resilience factors on a women's experience with infertility.

Procedures:
If you agree to be in this study, I will ask you to do the following things: Participate in a 45-60 minute interview consisting of 9 open-ended questions around your experience with working with individuals experiencing infertility. The interview will take place at a private location of your choosing. The interview will be recorded and transcribed. The transcription of the interview will be analyzed to identify themes in the data. The summary of these findings will be discussed in my research paper as well as presented at a graduate research day in May.

Risks and Benefits of Being in the Study:
Overall, risk for this study is minimal. The semi-structured questionnaire will open-ended in nature, and reflect knowledge of the current impacts and supports for women who are experiencing infertility that is commiserated with theoretical/conceptual literature as well as empirical studies in this topic area. This researcher's 682 clinical paper committee, as well as, the University of St. Thomas IRB will review the content of semi-structured interview questions prior to conducting the interviews. A resource list will also be provided to all participants prior to the interview. There are no direct benefits of this study.

Confidentiality:
The records of this study will be kept confidential. I will protect your identity in my study and in papers or presentations that result from my study by carefully disguising any information that would compromise your confidentiality and privacy. Written and recorded information with only be shared with members of my research committee. I will keep all data and

consent forms in a secure location for a period of three years as required by federal guidelines and all data will be stored electronically will be password protected.

Voluntary Nature of the Study:
Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. You are free to withdraw from the study after the interview has been completed. You may also call the researcher one week after the interview was completed to remove your information from the present research study. Should you decide to withdraw, data collected about you will not be used. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work.

Contacts and Questions
My name is Mackenzie Landbloom. You may ask any questions you have now. If you have questions later, you may contact me at _____ or Kari Fletcher at . You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:
I have read the above information. I am at least 18 years old. My questions have been answered to my satisfaction. I consent to participate in the study and to be audiotaped.

_____ _____
Signature of Study Participant **Date**

_____
Print Name of Study Participant

_____ _____
Signature of Researcher **Date**

Appendix B

Semi-Structured Interview Questions

1) What is your current job role?
2) What is your experience working with women going through infertility?
3) In what ways are women impacted by the infertility diagnosis? The infertility treatment?
4) Does a women's culture impact her experience with infertility? If so, in what ways?
5) What factors influence a women's resilience throughout the infertility process?
6) What is the best way that providers can support women going through infertility?
7) What recommendations would you give to others who are supporting women going through infertility?
8) Are there any other points you feel are important to address?
9) Is there anyone else you think I should talk to? If so, how can contact them?

Appendix C

Letter of Introduction

Date

Dear, (Name of provider)

My name is Mackenzie Landbloom, and I am a Masters student at St. Catherine University/University of St. Thomas School of Social Work conducting research for my final research project. As you may recall, I am conducting a research study focused on the needs of women who are experiencing infertility. Specifically, I am looking at how providers can support women throughout the infertility process. My study will address the perceived impact of the infertility diagnosis and treatment as current and potential future supports for women who are going through infertility. I am hoping to get a broad perspective of this topic from a variety of providers who work closely with women experiencing infertility. Information gathered through my study will help to identify these needs for support and address how they may be met. My research will be completed as a final research project and presented during a University research day in May.

I want to thank you for expressing interest in being a part of my study. I would like to schedule a time to meet with you at your earliest convenience either in-person or by phone. Once our interview is scheduled, I will send you a consent form that you can sign and have for your records. If you have questions, please feel free to contact me by email at _____ or by telephone at _____..

Thank you for your time and consideration.

Sincerely,

Mackenzie Landbloom, MSW student

School of Social Work
St. Catherine University/University of St. Thomas
2115 Summit Avenue, St. Paul, MN 55105

Appendix D

Resource List

Resources For Women Experiencing Infertility

Minnesota Resource	Internet Address
Center for Reproductive Medicine	http://www.ivfminnesota.com/
Reproductive Medicine & Infertility Associates	https://www.rmia.com/
Center for Grief, Loss and Transition	http://www.griefloss.org
National Resource	
Resolve: The National Infertility Association	www.resolve.org
Resolve Online Support Communities	http://www.resolve.org/support/online-support-communities.html
Massachusetts General Hospital Center for Women's Health: Reproductive Psychiatry Resource Information Center	https://womensmentalhealth.org/specialty-clinics/infertility-and-mental-health/
American Society for Reproductive Medicine	https://www.asrm.org
Creating a Family: The National Infertility and Adoption Education Non-Profit	https://creatingafamily.org