

Primary and Secondary Infertility and Post Traumatic Stress  
Disorder: Experiential Differences Between Type of  
Infertility and Symptom Characteristics

A DISSERTATION  
SUBMITTED TO THE FACULTY  
OF  
THE SCHOOL OF PSYCHOLOGY  
SPALDING UNIVERSITY

BY

Allyson Bradow

IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE  
OF  
DOCTOR OF PSYCHOLOGY

Primary and Secondary Infertility and Post Traumatic Stress  
Disorder: Experiential Differences Between Type of  
Infertility and Symptom Characteristics

A DISSERTATION  
SUBMITTED TO THE FACULTY  
OF  
THE SCHOOL OF PSYCHOLOGY  
SPALDING UNIVERSITY

BY  
Allyson Bradow

IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE  
OF  
DOCTOR OF PSYCHOLOGY

APPROVED: \_\_\_\_\_ Date: \_\_\_\_\_

Brenda Nash, PhD

\_\_\_\_\_ Date: \_\_\_\_\_

Thomas Bergandi, PhD

\_\_\_\_\_ Date: \_\_\_\_\_

Ann Lyons, MSN, PhD, RN, NCE

Copyright 2011 by Allyson Bradow

## Acknowledgements

I would like to thank the members of my dissertation committee. Without their guidance and support, this process would have seemed insurmountable. They allowed me to learn on my own and develop my ideas and abilities while steering me in the appropriate direction. My committee's invaluable knowledge and methodology was much appreciated. My chair, Dr. Brenda Nash, was especially important in my work on this dissertation. She provided unwavering support and encouragement throughout my own journey and the dissertation process. She has been and continues to be a mentor and exceptional role model.

I would also like to thank my family and sitter, who allowed me to dedicate many hours to this dissertation. Without their support and understanding, I would not have been able to finish. Finally, I would like to thank my husband, who has walked on many a journey with me. He has given me unconditional support not only throughout our own struggles, but also throughout my academic process. It is to him, my two beautiful daughters, and my dissertation chair, that I dedicate this dissertation.

## ABSTRACT

An investigation was conducted to assess the prevalence of Post Traumatic Stress Disorder (PTSD) in those who are diagnosed with infertility and/or are receiving treatment for infertility. Both primary infertility, defined as those who have never been able to conceive, and secondary infertility, defined as those who had previously been able to conceive and carry a child to term, were included in this investigation. The Post Traumatic Stress Disorder Checklist- Civilian version (PCL-C) was modified to include demographic information and associated features. Overall, 46% of the participants met criteria both cut off score and pattern criterion for PTSD (N=65), which is significantly higher than the prevalence of PTSD in the general population. The means scores of those with primary infertility and secondary infertility were compared to determine if there was a significant difference. Of the 115 participants with primary infertility, 49% met both cut off score and symptom pattern criterion (N=56) and 33% of the 27 participants with secondary infertility met both criterion (N=9). Due to the small sample size of those with secondary infertility, significant statistical power could not be attained. A T-test resulted in no significant difference in mean score between those with primary

infertility (X=46.45) versus secondary infertility (X=43.52). Individual characteristics of PTSD were evaluated for prevalence and severity. Several individual features from each criterion and associated features of PTSD were endorsed at a clinically significant rate. T-tests determined that there was no significant difference in the prevalence and severity of the individual characteristics of PTSD between those with primary infertility and those with secondary infertility. In addition, open ended responses were collected and reviewed. The qualitative data suggests infertility diagnosis and treatment is a traumatic event which can lead to the experience of PTSD symptoms.

TABLE OF CONTENTS

ACKNOWLEDGEMENT.....iv

ABSTRACT.....v

TABLE OF CONTENTS.....vii

LIST OF TABLES.....ix

CHAPTER

I. LITERATURE REVIEW

    Introduction.....1

    Infertility: Definition and Treatment.....2

    The Psychological Aspects of Infertility.....10

    Secondary Infertility.....20

    Acute Stress Disorder and Post Traumatic Stress  
        Disorder.....24

    Medical Diagnoses and PTSD/ASD.....28

    Summary.....33

    Rationale of Current Investigation.....33

    Hypotheses.....35

II. METHODS

    Participants.....36

    Procedure.....37

    Hypotheses and Analyses.....39

III. RESULTS

    Introduction.....43

    Demographic Information.....43

Prevalence of PTSD in Those Diagnosed with	
Infertility.....	50
Primary Infertility Compared to Secondary	
Infertility.....	51
Symptom Prevalence.....	53
Associated Features.....	57
Open Ended Responses.....	61
IV. DISCUSSION OF RESULTS	
Demographics.....	62
Previous Mental Health Diagnosis.....	64
Overall Prevalence of PTSD.....	65
Difference in PTSD Between Primary and Secondary	
Infertility.....	68
Symptom Presentation.....	69
Associated Features.....	77
Open Ended Responses.....	85
Study Limitation.....	90
Conclusion.....	91
Implications for Psychology.....	92
REFERENCES.....	95
APPENDICES.....	104
BIOGRAPHY.....	116

## LIST OF TABLES

TABLE 1	Educational Status
TABLE 2	Employment Status
TABLE 3	Income
TABLE 4	Time Trying to Conceive Prior to Diagnosis and in Treatment
TABLE 5	Financial Investment
TABLE 6	Individual Item Descriptives (N=142)
TABLE 7	Individual Item Analysis Dependent on Fertility Diagnosis
TABLE 8	Associated Feature Criterion
TABLE 9	Associated Features in Primary versus Secondary Infertility
TABLE 10	Associated Features Individual Item Endorsement (N=142)
TABLE 11	Associated Feature Endorsement Dependent on Diagnosis

## Chapter I

### Literature Review

#### *Introduction*

Survival of the species, or reproduction, is one of the basic biological drives in the human species. As children, most people expect to grow up, find a mate and have children. For close to 10 percent of those in the reproductive age of the population, conception and pregnancy does not occur as expected (Organon, 2006). For couples struggling with infertility, or the inability to conceive naturally within a 12 month period without contraception, the many considerations regarding treatment choice can be overwhelming (Mosher & Pratt, 1990).

Whether to continue on without treatment, seek fertility treatment to pursue having a biological child, or to choose alternative forms of having children such as adoption or surrogacy are the primary questions. Couples must decide how their own values will impact treatment choices, as infertility treatment can be very invasive financially, physically and psychologically. When a couple has conceived a child previously, either with or without medical assistance, the decision involves more than just them, it involves consideration of the effects of fertility treatment on the existing child/children present.

Fertility treatment is a significant commitment that offers no guarantees for the desired outcome. The energy expended on actual medical treatment procedures, thoughts about infertility and treatment, and the financial burden may lead to significant psychological disturbances that were not present prior to treatment. The present investigation intends to review infertility, the treatment options that are available, and the psychological impact of infertility that has been explored in recent research. The intent is also to explore the possibility that common symptoms of Post Traumatic Stress Disorder provide an accurate description of the psychological experience of infertility diagnosis, and to determine if there is a difference between symptom presentation in primary and secondary infertility for assistance in treatment.

*Infertility: Definition and treatment*

Infertility is defined as the inability to conceive a child after one year of unprotected intercourse (Mosher & Pratt, 1990). Many different sources cite the national infertility average at approximately 10% of the reproductive population (Organon, 2006; American Society for Reproductive Medicine, 1998; World Health Organization, 1992). Trying to conceive without success is separated

into two different categories: primary infertility and secondary infertility. According to Jordan and Ferguson (2006), primary infertility is defined as the inability to conceive within a 12 month period without the use of contraception in a couple who does not have any prior biological children. Neither the man nor woman in the relationship has conceived a child in the past. Jordan and Ferguson define secondary infertility as the inability to conceive a child within a 12 month period without the use of contraception in a couple who has previously conceived, or when either partner has previously conceived and/or carried a child to term. Whether the diagnosis is primary or secondary infertility, the reality of not being able to successfully conceive a child without assistance carries both medical and psychological considerations. A couple will often seek services after trying to conceive unsuccessfully, hoping to identify the reason for not conceiving and to find a solution in order to be able to become pregnant.

There are several different medical reasons underlying infertility, the most common are discussed in the following section. Statistically, women's reproductive malfunctions represent half of fertility problems. Malfunctions of the female reproductive system most commonly consist of

ovulatory issues or malfunctions in the uterus itself. Anovulation is one concern, which is the failure to ovulate. Oligoovulation is another concern, which is irregular ovulation (Ovulation Induction, 2007). Some women do not ovulate regularly because of an insufficient amount of specific hormones such as follicle stimulating hormone (FSH) and luteinizing hormone (LH), essential to either successful maturation of a follicle or the release of a mature egg. The most common problem related to the uterus itself that affects the ability to conceive is endometriosis. Endometriosis is defined as scar tissue either in the uterine lining itself or on the outer surface of the uterus (Weschler, 2002). Thickening of the lining or development of scar tissue on the lining creates difficulty in implantation when an egg is released and fertilized. An egg may be released and fertilized; however, when it travels down the fallopian tube to implant, it is not able to do so because of the condition of the uterine lining.

Reproductive issues in men contribute to roughly one third of infertility issues (Advances in Fertility Treatment, 2006). The male reproductive system, specifically sperm amount, quality and mobility, has an effect on the ability to conceive a child. Sperm

agglutination is another concern, which is defined as clumping of the sperm (Weschler, 2002). Approximately 10% of couples identified as infertile are categorized as unexplained even after extensive medical evaluation. Those with unexplained infertility have no identifiable malfunctions with either reproductive organs or processes (Fertility Journey, 2008).

A diagnosis of infertility requires a plethora of medical procedures, including blood work, external and internal examinations, semen analysis, and possible surgical interventions. While many of the tests are not thought of as physically invasive, the time spent in the testing process, as well as the emotional toll of the preparation and waiting for the results, can feel extremely invasive. Fertility endocrinologists and/or urologists are typically responsible for the bulk of the testing, as this is often beyond the scope of practice for a general gynecologist or primary care physician. If and when a diagnosis is confirmed, decisions about the best treatment options to conceive begin.

When a woman's reproductive system is not functioning well, there are several treatment options to choose from, ranging in invasiveness. There are two main issues when dealing with infertility; hormonal and structural.

Fertility specialists will often begin with the least invasive, likely hormonal interventions, moving through treatments if previous attempts are not successful. Initially, doctors will often prescribe medications to either induce ovulation, regulate the ovulatory process, or support the uterine lining depending on the diagnosis. Medications may include Clomiphene citrate, which is used to stimulate the pituitary gland to release hormones necessary for ovulation such as follicle stimulating hormone (FSH) and luteinizing hormone (LH). Progesterone may be used to help increase and support the uterine lining. Finally, Bromocriptine may be given to women who have high levels of prolactin, which stops ovulation (Fertility Journey, 2007). However if there are structural issues, surgical intervention may be required to repair abnormalities or blockages in the ovaries, fallopian tubes, or uterus. Often, these interventions lead to conceptions, implantations and viable pregnancies.

Using medications that interact with naturally occurring hormones may cause many different side effects. Follistim AQ, a synthetic form of FSH used to stimulate the production of follicles in the ovaries, has several side effects associated with its use. According to the patient information leaflet given with the Follistim AQ Cartridge,

FSH can produce "stomach pain, gas, pelvic pain, nausea, breast pain, injection site problems, enlarged stomach area, back pain, constipation, headache and ovarian pain." Other more serious side effects include ovarian hyperstimulation syndrome (OHSS), which is essentially when the ovaries produce too many follicles. After ovulation, these follicles may fill with fluid, producing ovarian cysts. Approximately 33% of women will experience some degree of OHSS during their treatment. Symptoms of OHSS are "severe pelvic pain, nausea, vomiting, sudden weight gain, and reduced urine output" (Ovarian hyperstimulation syndrome, 2010). Because of the time sensitive nature of fertility treatments, doctors may choose to treat OHSS by reducing the amount of estrogen in the woman's system. One of the treatments for OHSS is birth control pills, which seems to negate the fertility process.

Once the woman's ovaries have produced enough follicles, human chorionic gonadotropin hormone (hCG) shots will be given to induce ovulation (Ovulation induction by hCG, 2010). As with the other drugs used to treat infertility, hCG also has side effects. According to the drug information pamphlet that accompanies the medication Pregnyl, side effects of hCG can be "headache, irritability, restlessness, depression, fatigue, edema,

precocious puberty, gynomastia, and pain at the site of injection." Progesterone has similar side effects as FSH including breast tenderness, irritability, nausea and depression (Adverse Reactions, 2008). It is important to consider the side effects of the medication woman are given during treatment, as they undoubtedly play a part in the psychological experience of infertility, which will be discussed later in the present investigation.

Assisted reproductive technologies (ART) are more advanced treatment options for infertility. The first step in any ART treatment is over-stimulation of a woman's ovaries in order to produce numerous follicles with medication called gonadotropins. Several procedures accompany the over stimulation of ovaries. The goal of ART is to have the woman's body produce substantially more follicles, leading to eggs, than would normally happen during a typical menstrual cycle. The increased number of follicles allows for any of the following procedures to utilize more than one egg, increasing the likelihood of implantation and pregnancy. The more eggs a woman produces, the more likely at least one will be fertilized and lead to a successful pregnancy. Intrauterine insemination (IUI) is when sperm is collected, rinsed and injected directly into a woman's uterus. In in-vitro

fertilization (IVF), eggs are retrieved from the woman's ovaries and combined with a man's sperm in a petri dish to result in fertilization. The resulting embryos are then transferred into the woman's uterus in hopes of implantation. Intracytoplasmic sperm injection (ICSI) often partners with IVF. During ICSI, a single sperm is injected into the egg to increase the chances of fertilization. Gamete intrafallopian transfer (GIFT) is a treatment that is similar to IVF; however the retrieved eggs and the sperm are inserted back into the woman's fallopian tubes instead of combining the egg and sperm in a laboratory dish. Finally, zygote intrafallopian transfer (ZIFT) combines elements of both IVF and GIFT. The sperm and egg are placed together in the laboratory dish and are injected back into the fallopian tubes instead of the uterus (Fertility Journey, 2007).

As treatments become more complex and intricate, they become more invasive. Many of the drugs require the woman to self administer daily injections, as well as submit for weekly blood work and office visits to monitor the ovaries and uterine lining via internal ultrasound. When IVF, GIFT or ZIFT are used, extraction of eggs from the ovaries is completed. The man's role remains constant during this process, involving masturbation for semen analysis, wash,

and injection into the woman's uterus, fallopian tubes or directly into the egg. As the technology of the treatments for infertility increases, and the invasiveness increases, so does the cost. Super-stimulation with IUI costs around \$1300 for the services alone, with an additional \$400-\$1000 for the medication. In vitro services are significantly more expensive typically costing \$10,000 or more (IVF Cost Information, 2009). Along with the increased physical, financial and time commitment, the psychological cost is high. Psychological symptom presentation can occur in the individual as well as create or exacerbate struggles within the couple, and in the broader realm, with extended family and society.

### *The Psychological Aspect of Infertility*

Current research unanimously recognizes the emotional toll that a diagnosis of infertility carries. Several aspects of the psychological impact of infertility are important to assess. Actual emotional reactions to infertility exist for both men and women, however research indicates that women exhibit more emotional based responses to infertility and the treatments associated with infertility than men (Hart, 2002; Jordan & Ferguson, 2006). According to Pasch and Christensen (2000), men tend not to

be as involved or invested in treatment. Women are often more inclined to seek treatment and will likely suffer greater emotional distress because of the invasiveness of the medical procedures and the greater investment of their emotional resources. The effect of infertility on life expectations, as well as other areas of the couple or individual's life, is also important to consider when examining the outcome of an infertility diagnosis.

Confounding the individual's and/or couples' response to infertility and treatments is the expectations and reactions from friends, family, medical professionals and society in general to the couples struggle with infertility. Both internal and external responses should be considered when exploring the psychological impact of infertility.

Menning (1988) identified external factors of stress related to infertility which included a desire to avoid tactless advice and pity that others offer in response to a couple's infertility. Ridenour, Yorgason & Peterson (2008) also discussed the idea of advice giving from relatives and friends leading to negative feelings. Friends and family will often comment on when the couple should have a baby or negate the couple's thoughts or opinions because they do not have children (Bridges, 2005). Unsolicited advice

will overflow, such as "you are too worried about it, relax and it will happen" or "you just need to quit trying." These often times well-meaning but devastating comments likely contribute to the hesitance of couples to let friends and family members know about their family planning and infertility issues. The community in which one lives, including immediate family as well as the larger cultural community, can have a detrimental effect on the definition of infertility to the individual and couple. The individual may feel a loss of connection with peers in the same stage of life and may feel unable to officially differentiate from his or her family of origin, which is often completed by starting a family. Cultural expectations also create stress for couples suffering from infertility, specifically cultures that place a great deal of emphasis on children and child-rearing practices. Similarly, couples with significant religious affiliations may feel more negative support from this community for the similar reason that so much attention is given to raising children and families (Ridenour, Yorgason & Peterson, 2008). For example, in the Catholic ritual of marriage, the idea of openly accepting children into the marriage is stated as one of the expectations of marriage. While it seems clear that there are multiple sources of distress for

couples and individuals suffering from infertility, much of the current research focuses on broad internal characteristic responses instead of differentiating between specific symptoms that people experience. Researchers group psychological responses to infertility and treatment into three general descriptions: stress, anxiety or depression.

Stress, anxiety and depression are common descriptors of the psychological experiences of both couples and individuals experiencing infertility (Hart, 2002). Jordan and Ferguson (2006) found that 90% of the couples identified as struggling to conceive reported experiencing stress about their struggle. Gibson and Myers (2007) found that infertility in general created stress regardless of the cause of the infertility. According to Chen, Chang, Tsai and Juang (2004), depression and anxiety were found to be common in women engaged in treatment for infertility. Clay (2006) extended the identification of stress and anxiety to the couple as well. The emotional impact of fertility treatments has an effect on the functioning and health of the individuals going through the treatments, and on their relationships. Liz and Strauss (2005) cite past studies by Strauss, Argiriou, Buck and Mettler (1991), Strauss, Bettge, Bindt, Felder, Gagel, Goldschmidt, Henning, Ittner, Kentenich and Ningel ( 2000),

and Strauss, Stading, Hepp and Mettler (2001) indicating that anxiety and depression are common emotional responses to failed reproductive procedures. There is no denying that couples and individuals diagnosed with infertility have a significant amount of psychological stress, in addition to the stress associated with the treatment of infertility.

The emotional toll that infertility has on an individual or a couple is long term and cyclical. Not only is the immediate result of an infertility diagnosis or the failure of a treatment a concern, lasting negative emotional responses are also reported. Verhaak, Smeenk, Minnen, Kremer and Kraaimaat (2005) found that anxiety and depression were common after treatment that did not result in a pregnancy, and that psychological distress did not cease at follow up interviews. Menstruation often becomes a trigger for distress as it is a constant and regular reminder that conception did not occur. Menstruation creates distress on its own, however when the woman "felt" pregnant (feelings the required medications produce), this distress is often exacerbated. Having a period becomes exponentially devastating. The side effects of the medication that is often used to treat infertility (as noted above) also provide constant reminders of the

diagnosis and the side effects can mimic early pregnancy symptoms, including mood swings, swollen and sore breasts, bloating, and weight gain.

Due to the nature of the prevalence and depth of the psychological impact of infertility, determining what the individual or couple is feeling and experiencing is important for successful treatment. Verhaak et al. (2005) indicate that it is difficult to differentiate between depression and anxiety symptoms and that both depression and anxiety require different interventions. Anxiety and depressive disorders are not commonly differentiated in the research on the psychological symptoms of infertility; however a select few articles reviewed specific symptoms experiences by those diagnosed with infertility.

Bridges (2005) discussed several specific symptoms as described by Berg and Wilson (1994) and Exley and Letherby (2001) including isolation, fear, feelings of personal responsibility, and helplessness. Gonzalez (2000) identified several specific negative emotional experiences related to the experience of infertility. Powerlessness in relation to bodily experiences and future planning was often felt by couples, more specifically women, experiencing infertility (Forrest & Gilbert, 1992). Alienation, feelings of loss, mourning, and failure were

also identified as prominent feelings when dealing with infertility. Pasch and Christensen (2000) identified internal experiences of loss in regards to the opportunity to parent and to plan for the future.

The standard expectation of life progress is stereotypically: attending school, dating, marrying/partnering, having children, growing older, and then having grandchildren. People struggling with infertility not only have to face the immediate implications of their situation, the possibility of not having a biological child, but will inevitably have to ponder what the distant future looks like for them beyond their own children. They have to face the reality that what they defined as a successful life may not exist for them. For those struggling with infertility, the realization that they may not be able to have a biological child, or if they do it will be with medical intervention that has no guarantee, can be traumatic. Often times, those on the outside of this experience cannot relate or empathize. Hart (2002) and Spector (2004) describe avoidance of social situations where reminders of fertility are present, such as situations where there will be pregnant women or infants, because of the visceral reaction that is created by these sights. These situations become

triggers for the individual and/or couple suffering from infertility. Tearfulness is a common reaction, which is difficult to explain to those outside the infertility world (Hart, 2002). Social experiences can thus create more turmoil for those suffering from infertility, which exacerbates the already excruciatingly isolating experience of not being able to conceive or bear a child.

Social interactions and the comments that follow, become triggers for distress. Seeing family members who are pregnant or have babies can especially trigger trauma responses (Edelmann, Connolly & Robson, 1989). Whether directly or inadvertently, they experience cues that trigger distress when the individual and/or couple is out trying to live a "normal" life. Couples and individuals are likely to avoid social situations where they will be scrutinized for their lack of children, or where there are constant reminders of their own infertility. Couples and individuals may also make lifestyle decisions, such as vacationing, as a way to compensate for the lack of ability to have children. Many viewing their choices from the outside may comment on their choice to lead a more extravagant lifestyle, while the couple or individual feels the activities are a poor substitute for the ability to have a child (Spector, 2005).

Others outside of the situation often have expectations for overcoming stress or trauma, which can add to the negative psychological experience of the individual or couple. People expect that others should overcome issues in a specific pattern, within an allotted amount of time, and with a certain amount of emotional display (Wortman & Silver, 1989). Additionally, the expectation of grief does not often occur in cases of infertility. The loss that infertility brings is one of the potential to bear a child, to fulfill a life-long dream. People outside of the infertility crisis often do not understand how these losses can be so painful (Forrest & Gilbert, 1992). Furthermore, the process of being diagnosed as infertile and the treatments that follow take a significant amount of time, rendering stereotypic responses to grief and loss inappropriate. When grief surrounds the loss of a loved one, the loss is time-limited and specific; the loved one has passed on or a relationship has ended. Infertility diagnosis and treatment is an ongoing process that creates trauma each month that requires emotional attention. There is not one specific event leading to grief and loss, instead there are numerous events that occur over and over again during infertility diagnosis and treatment.

Reactions and professionalism by physicians is another social influence on a couple's or individual's reaction to infertility. A significant amount of trust and hope is placed in a physician that is treating a couple for infertility. If the physician does not understand the magnitude of the emotional aspect of infertility, the couple or individual can feel more traumatized. "The medically based view on the different reasons for infertility give General Practitioner's a narrow-minded image of the infertile couple" (Himmel, Ittner, Schroeter, & Kochen, 1998, p. 17). Practitioners may not give much thought to the emotional implications of a diagnosis of infertility or the treatments that accompany the diagnosis.

Unfortunately, lack of attention to the psychological aspects of infertility is not uncommon (Spector, 2004). If the psychological effects are to be attended to in any way, it is likely from a mental health professional and not medical professionals treating the individual or couple. The clinician is thus responsible for the caretaking of the emotional needs, however Dingfelder (2006) reports that not many couples need extensive psychological services. Pengelly, Inglis and Cudmore (1995) found that 62% of the couples that were offered psychological services accepted these services, with only 10% taking more than three

sessions. Two issues not discussed in the article, however, were avoidance and time constraints. An individual and/or couple who are already investing a large amount of time and money into medical treatment may not be able to afford mental health services or be able to take off of work or travel for additional "doctors" appointments. Avoidance of the trauma and the factors surrounding the event are also common and typical of persons suffering from a traumatic experience. This knowledge should be considered when evaluating the reason why therapeutic services are not accepted. Another issue remains; services offered to those dealing with infertility continue to be mostly medical without much acknowledgment or attention paid to the psychological aspect of infertility. All of these stressors and treatment constraints are likely most felt by couples who already have children. In these families, the additional stress of being a parent and dealing with the stress and anxiety of secondary infertility likely increases the need for attention to mental health concerns.

### *Secondary Infertility*

Much of the research on infertility and the psychological impact of diagnosis and treatment focuses on

primary infertility. The experiences of women and couples dealing with secondary infertility have been neglected from both a research aspect as well as the possible different psychological implications. Sarrel and DeCherney (1985) looked at couples who had previously been successful in conceiving but had no medical explanation for their current infertility. They found that enmeshed relations with the female's mother and fear of pregnancy were two common themes the participants displayed. The authors maintain that their study should be looked at as an exploration not one that indicates causes of infertility. "The main implication of this experience is that psychotherapy that deals directly with pregnancy-related conflicts may affect physiologic factors and thereby enhance reproductive potential" (p. 900). Allison (1979) suggested that secondary infertility can be associated with a change in expectation of roles and life demands. This study indicated that women who suffer from infertility have more tradition ideas about role expectation and conflicts; however, it is not clear as to whether these differences were viewed as a result or a cause of infertility. The acceptance of psychological assistance could prove to be beneficial both for the treatment of infertility as well as

for dealing with the ramification of the diagnosis and medical interventions.

White and McQuillan (2006) hypothesized that since couples or individuals suffering from secondary infertility already had a biological child, they would not suffer as much when deciding to stop trying to conceive as those suffering from primary infertility. However, they found no significant difference in distress between primary and secondary infertility. This study only evaluated the possible difference between distress when the couples decided to stop trying to conceive, not what the couples experienced during diagnosis and treatment. What seems to be missing in the literature is the evaluation of symptom experiences with couples who already have children during diagnosis and treatment of secondary infertility. In the literature reviewed, it seems that studies either focus solely on primary infertility or do not differentiate between primary and secondary infertility. However, having one child can have either a positive or a negative, compounding effect on infertility. In addition to the internal struggles that a couple facing infertility diagnosis and treatment must endure, societal views on woman who chose to pursue treatment for secondary infertility can be quite harsh. Comments that have been

expressed, such as "you already have one beautiful child, you should just be grateful for that" can result in increased feelings of guilt and isolation. The more negative reactions received, the more likely that social situations may be avoided and that distress and anxiety will increase.

Infertility diagnosis and treatment undoubtedly leads to some degree of psychological distress, for people who have never conceived and for those who have successfully borne children in the past. The research thus far has focused mainly on primary infertility and the broad categories of anxiety and depression to address the psychological issues associated with infertility. When looking further into those broad categories, many other symptoms emerge. Many of these symptoms are very similar to those presented by people who have experienced or witnessed a more traditional sort of trauma such as a car accident, abuse or combat. While the traditional definition of trauma has included exposure to a life threatening event, it stands to reason that changes in life expectancy could also lead to trauma responses. Trauma symptoms have been discussed in the literature, but they have not been associated with the idea of infertility, which instead continues to be linked with overall anxiety

and depression. There are two main disorders that include trauma symptoms, Acute Stress Disorder and Post Traumatic Stress Disorder.

#### *Acute Stress Disorder and Post Traumatic Stress Disorder*

Trauma is defined "as emotional shock following a stressful event or a physical injury, which may be associated with physical shock and sometimes leads to long-term neurosis" (New Oxford American Dictionary, 2008, 874213). According to the Diagnostic and Statistically Manual 4<sup>th</sup> Edition Revised Text (2000), the core presentation of Acute Stress Disorder is the "development of characteristic anxiety, dissociative and other symptoms that occur within one month after exposure to an extreme traumatic stressor" (p. 469). Dissociative symptoms can include a physical sense of numbing in the body, lack of emotional response, depersonalization. An avoidance of situations that may cause a remembrance of the trauma, significant anxiety and an exaggerated level of arousal are also signature symptoms of the disorder. The DSM-IV-TR identifies several associated symptom presentations including irritability, problems with concentration, hopelessness, guilt, excessive responsibility for the loss, sleep disturbances, dreams about trauma, and distress when

stimuli is reminiscent of the traumatic event (American Psychological Association, 2000).

According to the DSM-IV-TR (2000), Post Traumatic Stress Disorder (PTSD) occurs when certain characteristics develop following an event. The events identified include military combat, abuse, assault or the diagnosis of a medical condition that is life threatening. The first category involves experiencing or witnessing a life threatening event and feelings of fear or helplessness in reaction to that event. The second category addresses re-experiencing the trauma by intrusive thoughts, dreams, reoccurrences, and exaggerated responses to cues that trigger memories. The third category contains symptoms of avoidance and psychological numbing such as avoiding activities, places and people that remind one of the traumatic event, and feeling detached and exaggerated change in ability to express feelings. The fourth category deals with arousal such as difficulties with concentration and irritability. The DSM-IV-TR also describes several associated features (American Psychological Association, 2000):

Individuals with Post Traumatic Stress Disorder may describe painful guilt feelings about surviving when others did not survive or about things they had to do to survive. Avoidance patterns may interfere with interpersonal relationships and leads to marital

conflict, divorce or loss of job. The following associated constellation of symptoms may occur and are more commonly seen in association with an interpersonal stressor : impaired affect modulation; self-destructive and impulsive behavior; dissociate symptoms; somatic complaints; feelings of ineffectiveness, shame, despair or hopelessness; feeling permanently damaged; a loss of previously sustained beliefs; hostility; social withdrawal; feeling constantly threatened; impaired relationships with others; or a change from the individual's previous personality characteristics. (p. 465).

Response to trauma and stress differs from person to person, however there are several somewhat common presentations that are associated with PTSD. These presentations include depression, grief, and anxiety. In some occasions, repeated exposure to a single type of traumatic event, or different traumas that occur over time, result in a presentation that is referred to as complex PTSD. Complex PTSD is thought to stem from repeated traumatic events, the characteristics of which are of a more interpersonal nature (Briere & Scott, 2006). PTSD also relies more heavily on interpersonal features as well as avoidance features. PTSD takes at least four weeks after a traumatic event has occurred. ASD, on the other hand, focuses more on dissociative features and is more immediate, occurring shortly after a traumatic event.

Both PTSD and ASD can be diagnosed in response to the diagnosis of an illness that is life-threatening. There is

little consideration for medical diagnoses that are not life threatening, but that lead to significant changes in life expectation and threat to life as planned. Yet, Freeman, Boxer, Rickels, Tureck & Mastroianni (1985) found that over half of woman and a fourth of men engaged in infertility treatments felt that being infertile was the most distressing event in their life. It is important to note that these men and women obtained normal scores on the Taylor Manifest Anxiety Scale prior to treatment. They were also given the Minnesota Multiphasic Personality Inventory (MMPI) and approximately half of them had high scores on the Ego Strength scale, indicating that they were functioning well and were equipped to handle distress. Although being diagnosed with infertility and proceeding with treatment is not life threatening in the traditional sense of the phrase, it does alter life expectations and plans.

Hobfoll (1989) discusses a definition of stress that extends beyond the definition of life-threatening. He maintains that actual or perceived loss of resources is the key component when defining stress. "Resources are defined as those objects, personal characteristics, conditions or energies that are valued by the individual or that serve as a means for attainment of these objects, personal

characteristics, conditions or energy" (p. 516). In this theory, resources hold not only an objective meaning, but also a subjective one as well. Applying Hobfoll's theory of stress to infertility and PTSD then, fertility and reproduction is a resource. It is valuable to society on a macro scale, and to individuals on a micro scale. The loss of fertility or inability to procreate constitutes a stressful event, likely creating a stress response, which in certain circumstances, could be considered a post-traumatic response.

Resources are threatened in many ways, not just in the external environment, but also internally as well. Stress responses and PTSD symptoms have been well documented in victims of crimes, war, abuse and medical diagnoses. When thinking in terms of assessing PTSD symptoms in those with infertility, it is useful to look at some of the scant literature available that juxtaposes psychological symptoms associated with infertility and those that are associated with other medical conditions.

#### *Medical Diagnoses and PTSD/ASD*

Domar, Zuttermeister and Friedman (1993) found that the psychological symptoms expressed by individuals suffering from infertility are similar to those suffering

from other medical illness such as cancer, hypertension and Human Immunodeficiency Virus (HIV). Several studies have been completed evaluating ASD and its relationship to cancer diagnosis. Most of these studies look at the predictive power of ASD to later Post Traumatic Stress Disorder (Kangas, Henry, & Bryant, 2005a, 2005b). Both studies found that while ASD had limited predictive value for future PTSD, a diagnosis of cancer did leave individuals more susceptible to ASD. Kangas, Henry and Bryant also found that dissociation, numbing, and re-experiencing were the most common symptoms experienced by persons after a cancer diagnosis. They hypothesized that the future development of PTSD may be due to the limited ability to consolidate and process emotions and experiences as a result of the dissociation and numbing. The limited research of ASD as a result of cancer diagnosis confirms that this sort of medical diagnosis leaves a person more vulnerable to distress, not unlike the specific symptoms reported by individuals and/or couples suffering from infertility.

Symptoms of PTSD have been found in other medical conditions that require diagnostic testing and invasive treatments. Kwekkeboom and Seng (2002) reported that patients with cancer experience PTSD symptoms, with up to a

fifth of cancer survivors meeting full criteria for diagnosis. Cordova, Andrykowski, Kenady, McGrath Sloan and Redd (1995) found that breast cancer survivors reported symptoms of PTSD and that up to 10% met full diagnostic criteria. Kornblith and Ligibel (2003) found that PTSD symptoms in cancer survivors were more similar to those that had experienced events that were more typically defined as trauma than the national average of PTSD prevalence, such as war, abuse or a car accident. Alter, Pelcovitz, Axelrod, Goldenberg, Harris, Meyers, Grobois, Mandel, Septimus and Kaplan (1996) found that women who had survived cancer displayed PTSD symptoms at a significantly higher rate than normal populations. One of the contributing factors to the development of PTSD symptoms was the unexpected nature of the traumatic event, in this case, diagnosis of a medical illness. The unexpected nature of a medical diagnosis contributes to trauma symptoms, but the ambiguity about the future is also a contributing factor to the development of symptoms.

Mehnert and Koch (2007) found that while the diagnosis was distressing, feelings about life expectations and what the future had to offer after such a diagnosis were as distressing. Kangas, Henry, and Bryant (2005b) found that a cancer related diagnosis indicated a greater

susceptibility to psychological distress and trauma response. In another study completed by Kangas, Henry and Bryant (2005a), it was found that the most prevalent characteristic presentation post cancer diagnosis was numbing and re-experiencing the trauma. While cancer diagnosis appears to be the main medical diagnosis associated with PTSD symptoms, other diagnoses have also been explored.

Peterlin, Tietjen, Brandes, Rubin, Drexler, Lidicker and Meng (2009) investigated the relationship between PTSD symptoms and migraines. They found that the occurrence of PTSD among those who experienced migraines was higher than the occurrence of PTSD in the general population. De Leeuw, Schmidt, and Carlson (2005) also found that headache sufferers reported PTSD symptoms with more frequency than the general population.

The many symptoms reported by studies examining the psychological experiences of diagnosis and treatment of a medical condition are strikingly similar to those reported in investigations that study the psychological aspects of infertility. Medical diagnosis of any kind may lead to ASD or PTSD symptoms, specifically diagnoses that threaten the patient's life or future life experiences. Treatment often becomes a trauma trigger, serving as a constant reminder of

the diagnosis and the psychological implications that follow.

Gonzalez (2000) identified many of the symptoms that are typically associated with PTSD and ASD displayed by participants in a study who had been diagnosed with infertility. "The participants in this study described a sense of alienation, powerlessness, stigma, and personal failure in their struggle with infertility. Additionally, many suffered from depression, anxiety, anger and obsessive thinking at a time when they are required to make decisions regarding invasive and costly procedures" (p. 630). Hart (2002) reported similar findings including dissociation, inability to concentrate, isolation, bothersome dreams, and social avoidance. Clay (2006) suggested the experience of infertility creates sadness, shame, and guilt. The majority of research has lumped all of these symptoms into one broad category of anxiety and depression. An examination of the specific symptoms experienced by both men and women during diagnosis and treatment of infertility is lacking. Examining the criterion for ASD and PTSD along with the limited research on the specific symptom experiences of those struggling with infertility clearly indicate that there is more than simply anxiety and depression.

### *Summary*

The overall acceptance of psychological issues associated with infertility diagnosis and treatment consists of stress, depression and anxiety. A lack of consideration of the specific symptoms and response to infertility can affect appropriate screening and intervention. "The therapist has an important role to validate the emotional, social and physical difficulties of infertility treatment" (Spector, 2004, p. 99). The emotional turmoil that a couple or individual dealing with infertility experiences can be difficult to comprehend. The psychological reactions to infertility testing, diagnosis and treatment are typically beyond the scope of what the medical profession assumes (Van Hall, 1983). While research consistently identifies certain psychological responses, the depth and degree of the impact is not fully understood, especially by medical professionals. Further, the degree to which previous fertility success relates to the psychological experience of infertility has not been well explored.

### *Rationale of Current Investigation*

The purpose of this study was to investigate the specific symptoms experienced by those struggling with

infertility, both primary and secondary and to assess for post-traumatic responses. While the research regarding medical diagnosis and trauma symptom experience supports both ASD and PTSD, the criterion for each diagnosis is slightly different. As previously discussed, PTSD focuses more on interpersonal difficulties and avoidance of situations and stimuli whereas ASD relies more heavily on dissociative features. Thus, a diagnosis of PTSD is a better fit for the symptom presentation reported by the research investigating psychological symptoms associated with infertility diagnosis and treatment. PTSD also requires a longer time frame for symptom presentation, also more appropriate for those struggling with infertility.

Thus, the present investigation explored what symptoms included in the diagnosis of PTSD occur in people struggling with the infertility experience, the prevalence of these symptoms and the effect of that symptom presentation on daily life. The study also sought to determine if a difference exists in symptom experience and presentation between people struggling with primary compared to secondary infertility. A final goal of this study was to increase awareness about the psychological impact that infertility has on those who have been diagnosed and/or are being treated. A documented

connection between specific symptoms related to infertility and the diagnosis of PTSD should assist in treatment availability and implementation.

### *Hypotheses*

The null hypothesis was that any findings of this investigation occurred simply by chance. The alternative hypothesis of this investigation was that those suffering from infertility experience symptoms of PTSD at a higher rate than those in the general population. A second hypothesis was that there is a difference in symptom presentation and severity between participants who experience primary infertility and those with experience secondary infertility.

## Chapter II

### Methods

#### *Participants*

Participants were recruited via online social network support groups. The networks used were Care Girls and Infertility Friends, both through Yahoo groups, and infertility support groups through Baby Center and What to Expect. The examiner posted the same information regarding requirements for participation and requirements of the study in a new discussion group weekly for one month from July 2010 through August 2010. The participants were able to click on a link that led them directly to the informed consent and survey for them to complete (See Appendix A).

Participant demographics were collected and included gender, ethnicity, age range, relationship status, educational status, employment history, family status such as number of children and whether these children were biological, adopted or other. Participants were also asked about previous mental health diagnoses, treatment if appropriate, previous trauma experiences, and infertility history (primary versus secondary infertility). In addition to the basic inclusion criteria of volunteering for the study, criteria for participation was as follows: at least 21 yrs of age and past or current experience with

infertility diagnosis and treatment. Certain characteristics were exclusionary such as participants with serious mental illness (untreated schizophrenia, thought disorder, or current suicidal ideations or attempts), participants under 21 years of age and those with limited cognitive abilities. These exclusionary factors were identified by the participants' self-report answers to a question that inquires about a mental health diagnosis as well as certain symptom presentation.

The survey was viewed 687 times. From the participants recruited from the support groups, 157 participants began the survey, with 150 participants completing the survey, indicating a 95% completion rate. While 150 surveys were completed, only 142 were able to be used in this investigation due to missing data. Analysis of demographic variables is detailed in Chapter III.

### *Procedure*

Participants who consented to participate in the study were provided with a slightly revised form of the Post-Traumatic Stress Disorder Checklist- Civilian version (see Appendix A). This self-administered checklist was designed by Weathers, Huska, and Keane in 1991. The PCL-C has established psychometric properties and is public domain

through the National Center for Post-Traumatic Stress Disorder. Many studies examining symptoms of PTSD have utilized this checklist (Resnick, Kilpatrick, Dansky, Saunders, & Best, 1993; Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995; Peterlin, Tietjen, Brandes, Rubin, Drexler, Lidicker, & Meng, 2009; Peterlin, Tietjen, Meng, Lidicker, & Bigal, 2008; De Leeuw, Schmidt, & Carlson, 2005) for medical diagnoses including migraines and cancer. The wording of the instruction was to complete the PCL-C with the items revised to reflect the infertility diagnosis and treatment as the traumatic event. Certain questions intended to gather demographic information as well as items to assess associated features were also added to the revised PCL-C (see appendix A).

QuestionPro was used to allow a greater number of participants to be able to participate in the study. It allowed the participants to easily access the survey, anonymously, and at their own leisure. Having the survey available to the participants on their own schedule instead of a mandated time hopefully increased the number of participants. Allowing participants to take the survey via QuestionPro likely aided in the honesty of symptom endorsement, presentation and severity. It also allow the

author to obtain data in a more timely fashion to aid in the analysis of data.

Participants who were recruited via the on-line support groups were asked to click on a link that led them to the informed consent (see Appendix A) and study questionnaire (PCL-C plus demographic and PTSD associated features questions). After they completed the questionnaire, it automatically submitted back to the author for analysis.

#### *Hypothesis and Analysis*

The purpose of this study was to investigate the occurrence of PTSD in those who are suffering from and/or receiving treatment for infertility. The first hypothesis was that those who are diagnosed with infertility and who are currently or who have sought treatment in the past will experience symptoms of PTSD at a higher percentage rate than the general population. According to Friedman, Keane and Resick (2007) the prevalence of PTSD in the general population is 7.8%, and the DSM-IV-TR (2000) reports the prevalence at 8%. Thus was hypothesized that the rate of PTSD in people with infertility will be higher than that of the general population. Using the most stringent scoring criteria for the PCL-C, the rate of PTSD was determined for

the sample population, then compared to the documented occurrence of PTSD in the general population. The second hypothesis of this study was that there would be a significant difference in the symptom presentation between those with primary and secondary infertility. Many different factors account for symptom presentation in PTSD, similar to the many factors that are involved in a person's/couples' experience of infertility. Those suffering from secondary infertility may experience more social symptoms than those suffering from primary infertility. There seems to be a greater stigma to pursuing fertility treatments with secondary infertility; family and other social systems may have stronger opinions about pursuing treatment compared with those associated with primary infertility. The financial burden of choosing to seek treatment may have more of an effect on a larger family than that of one with no children. In addition, a person who has already experienced the birth of a child may have the disadvantage of knowing what conception, pregnancy and birth is like. This prior experience may influence their trauma responses when they cannot experience it again. Further, when bodies have already done what they are supposed to do, and then fail to do so it is a loss of expected body function.

Using SPSS 18.0 and Microsoft Excel 2003, items that represented criteria of PTSD categories such as re-experiencing (Criterion B) symptoms, mood symptoms (Criterion C), and social symptoms (Criterion D) were grouped together. Overall analysis was conducted using Excel to determine total PCL-C score and each criterion score. According to the PCL-C scoring criteria, the most stringent way to investigate PTSD diagnosis is to use a total score cut-off, ranging from 30-50, and an analysis to determine whether an individual meets specific criteria. Individuals who endorsed a given symptom at a level "3" or higher were considered to be endorsing that symptom at a significant level. Individuals must have endorsed at least one symptom at a significant level in Criterion B (questions 1-5), at least three at a significant level in Criterion C (question 6-12), and at least two at a significant level in Criterion D (questions 13-17) to receive a diagnosis of PTSD. Using the most stringent scoring methods for this investigation, participants must have received a total score of at least 44 and endorsed the specified number of symptoms in each criterion subgroup to meet criteria for a PTSD diagnosis (Blanchard, Jones-Alexander, Buckley & Forneris, 1996).

Participants who identified themselves as suffering from either primary or secondary infertility were grouped together and compared on the different symptom categories. An independent samples t-test was conducted on the total PCL-C scores to determine if there was a significant difference in symptom experience and type of infertility. In addition, independent samples t-tests were conducted on each PCL-C symptom, and the associated features added to the PCL, to determine if there was a difference between the symptom presentation of those with primary infertility and those with secondary infertility.

## Chapter III

### Results

#### *Introduction*

The purpose of the current investigation was to determine the prevalence of PTSD in people diagnosed with infertility and/or who are receiving treatment for infertility. This survey, a modified version of the PCL-C which included associated features of PTSD as defined by the DSM-IV-TR, was made available to potential participants through QuestionPro, an online survey resource (see Appendix A). A brief explanation and invitation to take the survey was posted on online support groups for infertility.

Over 600 participants viewed the survey, 157 participants began the survey, with 150 participants completing the survey, indicating a 95% completion rate. While 150 surveys were completed, only 142 were able to be used in this investigation due to missing data. Participants were not considered in the current investigation if their survey contained more than one missing answer in each section of the survey. The PLC-C addresses each criterion of the PTSD diagnosis as defined by the DSM-IV-TR and specific groups of questions are presented to assess the presence of certain symptoms. If a

participant omitted more than one question in each of the criterion groupings, the data was removed from the analysis.

*Demographic Information*

A total of 142 surveys were included in this investigation. Questions gathering demographic information were added to the PCL-C questions in order to report accurate participant information (see Appendix A). Of the 142 surveys included in this study, 97.2% were female (n=138) and 2.8% were male (n=4). Participant data indicated that 86.6% were married, 3.5% were partnered, 9.1% identified as single and less than 1% indicated "other." Demographic questions also included education level (see Table 1).

Table 1  
Educational Status

<i>Educational Status</i>	<i>Number of Participants</i>	<i>Percentage of Participants</i>
GED	1	.7%
High School	6	4.2%
Some College	26	18.2%
Associates Degree	7	4.9%
Bachelor's Degree	45	31.7%
Some Graduate	6	4.2%
Graduate Degree	51	35.7%

A question about current employment status was also added to the demographic portion of the questionnaire (see Table 2).

Table 2  
Employment Status

<i>Employment Status</i>	<i>Number of Participants</i>	<i>Percentage of Participants</i>
Non-employed	19	13.3%
Part-time	23	16.2%
Full time	100	69.9%

Finally, income level was added to the portion of the survey that collected demographic information (see Table 3).

Table 3  
Income

<i>Income Level</i>	<i>Number of Participants</i>	<i>Percentage of Participants</i>
Under \$25,000	3	2.1%
\$26,000-\$40,000	14	9.9%
\$41,000-\$70,000	33	23.4%
\$71,000-\$120,000	54	38.3%
\$120,000 +	37	26.2%

Information was collected about time spent trying to conceive prior to treatment, time to receive diagnosis, and overall time in treatment as seen in Table 4.

Table 4  
 Time Trying to Conceive Prior to Diagnosis and in Treatment

<i>Time</i>	<i>Number of Participants</i>	<i>Percentage of Participants</i>
Trying to Conceive		
0-6 months	32	22.54%
7-12 months	38	26.76%
1-2 years	46	31.51%
2 or more years	26	17.81%
Diagnosis		
<1 month	30	20.55%
1-2 months	25	17.60%
2-4 months	15	10.27%
4-6 months	9	6.16%
6 or more months	29	20.42%
No diagnosis made	34	23.94%
Total Time in Treatment		
<1 month	5	3.45%
1-3 months	11	7.59%
3-6 months	14	9.66%
6-9 months	14	9.66%
9-12 months	14	9.66%
> 1 year	83	58.45%

Overall monetary cost for diagnosis and treatment was also queried (see Table 5).

Table 5  
Financial Investment

<i>Money Spent</i>	<i>Number of Participants</i>	<i>Percentage of Participants</i>
Under \$1000	23	16.19%
\$1000-\$3000	27	18.62%
\$3000-\$6000	20	14.08%
\$6000-\$9000	5	3.45%
> \$9000	66	46.47%

Of the 142 participants that participated in this survey, 50% indicated that they did not have any children ( $n=72$ ), 25.2% reported that they had one child ( $n=36$ ), 16.1% indicated that they had two children ( $n=23$ ) and 7.7% reported having more than two children ( $n=11$ ). The next question asked about the origin of children in the family. 5.6% of the participants reported that their child/children were adopted ( $n=8$ ), 40.1% indicated that their child/children were biological ( $n=57$ ), 1.4% reported that they had both biological and adopted children ( $n=2$ ) and 50% indicated that this question was not applicable, as they did not have a child or children ( $n=72$ ). Participants were then asked about their infertility diagnosis. 19% of those who participated in this survey reported that they were able to conceive and carry a child prior to their infertility diagnosis ( $n=27$ ). Those who were able to conceive and carry a child prior to diagnosis were

considered to have secondary infertility. 81% of the participants indicated that they had never been able to conceive or carry a child prior to their infertility diagnosis (n=115). Those who indicated that they had never been able to conceive or carry a child were considered to have primary infertility. See Chapter I for detailed explanation.

The participants were asked about their healthcare providers' gender, temperament and empathy level. Over half, 70%, of the participants reported that their physician was male (n=99) and 30% indicated that their physician was female (n=43). Most of the participants indicated that their physician was pleasant and helpful or even tempered (62% and 28% respectively). 9% reported that their physician was distant or disconnected and two participants reported that their physician was either unpleasant or that they were unsure.

The participants were also asked several open ended questions, one pertaining to previous mental health diagnosis. Of the 142 surveys completed, 32 reported that they had previously received a mental health diagnosis. These diagnoses included anxiety disorders, depression, eating disorders, and addiction.

### *Prevalence of PTSD in Those Diagnosed with Infertility*

According to the National Center for PTSD (2010) there are several ways to score and interpret the PCL-C in order to determine if a diagnosis of PTSD is appropriate. As mentioned in Chapter II, this study used the most stringent scoring method, the combination scoring method, to assess if participants met criteria for a PTSD diagnosis. The combination scoring method includes both a total symptom severity score and a criterion pattern score.

A total symptom severity cut off score of 38 is suggested for diagnosis in the civilian primary care population, a total cut off score of 44 is suggested for screening of PTSD in those who have had motor vehicle accidents. For the purpose of this investigation, a total PLC-C cut off of 44 was used as it is stringent and specific. Of the 142 surveys, 53% of the participants ( $n=75$ ) obtained a PCL-C total score of 44 or higher.

The criterion pattern portion of the combined scoring method mirrors the defining characteristics of PTSD according to the DSM-IV-TR. Criterion B consists of re-experiencing symptoms such as intrusive thoughts and nightmares. Criterion C consists of avoidance symptoms such as dissociation and feeling detached. Criterion D consists of increased arousal symptoms such as difficulty

with concentration and sleep disturbances. The combined scoring methods dictates that in order to meet criteria for a diagnosis of PTSD, one must have at least one symptom from Criterion B, at least three symptoms from Criterion C, and at least two symptoms from Criterion D. Of the 142 surveys completed, 46% of participants met PTSD diagnosis criterion for both pattern of symptoms and suggested total cut off score ( $n=65$ ). The average rate of PTSD in the general population is 8% (American Psychological Association, 2000). Thus, the null hypothesis is rejected and the alternative hypothesis is accepted; participants in this investigation, who were diagnosed with infertility, met criteria for PTSD at a higher rate than the general population.

#### *Primary Infertility Compared to Secondary Infertility*

Of those who identified as having primary infertility ( $n=115$ ), 49% met both criterion and a total PCL-C cut off score ( $n=56$ ), and 33% of those who identified as having secondary infertility ( $n=27$ ) met both criterion and a total PCL-C cut off score of 44 ( $n=9$ ).

A second goal of this investigation was to determine if there was a significant difference in diagnosis and symptom presentation between those suffering with primary

infertility compared with those suffering from secondary infertility. In order to run analysis with significant statistical power, each group (those with primary and those with secondary infertility) should have had at least 65 participants to obtain a medium effect size with a Power=.80 at  $p < .05$  (Cohen, 1992). However, a large effect size can be seen with at least 26 participants in each group at the  $p < .05$  level. The participants that indicated primary infertility ( $n=115$ ) had a mean PCL-C score of 46.45 with a standard deviation of 13.72. Those indicating secondary infertility ( $n=27$ ) had a mean PCL-C score of 43.52 with a standard deviation of 9.78.

While the number of participants was less than desirable, statistical analysis of the data provided preliminary results. An independent sample t-test was used to compare the mean scores of each group. The results indicated that there was not a statistically significant difference in the mean scores of the PCL-C of those with primary infertility ( $M= 46.45$ ) compared to those with secondary infertility ( $M=43.52$ ) with  $t= -1.289$  ( $p=.203$ ). Thus, the alternative hypothesis is rejected and the null hypothesis is accepted; there is not a significant difference in PTSD symptom prevalence and presentation between those diagnosed with primary infertility and

secondary infertility. Due to the small sample size of participants indicating they suffered from secondary infertility, it is possible that a significant difference may exist, however was not detectable in this comparison.

In addition to whole group analysis, analysis on specific symptoms was used to determine if those with primary infertility differed in experience and severity of symptoms from those with secondary infertility. Given the amount of survey questions and independent sample t-tests used to analyze the data, the possibility of experiment-wise error had to be taken into account. When running numerous analyses, it is more likely that some will be statistically significant simply by chance. In order to correct for multiple comparison, the Bonferroni method was used, making comparisons significant only if  $p < 0.002$ . Using the corrected analysis, none of the items yielded significant differences between those with primary infertility and those with secondary infertility.

#### *Symptom Prevalence*

The third goal of this study was to look at specific PTSD symptom presentation and severity in those who struggle with infertility. According to the National Center for PTSD (2010), a score of "3" or higher on the individual

items of the PCL-C is considered significant. The general score for each item was computed to determine overall rate of occurrence in the population that participated in this survey (See Table 6).

Table 6  
Individual Item Descriptives (N=142)

<i>Individual Criterion Item</i>	<i>Number of Significant Responses</i>	<i>Percentage</i>	<i>Mean</i>	<i>Standard Deviation</i>
B1 (Repeated Memories)	77	54.23%	2.85	1.13
B2 (Disturbing Dreams)	35	24.65%	2.08	1.16
B3 (Re-experiencing)	44	30.99%	1.98	1.48
B4 (Upset at Reminder Cues)	112	78.88%	<b>3.51</b>	<b>1.25</b>
B5 (Physical Reactions)	57	40.14%	2.27	1.23
C6 (Avoiding Thoughts and Talk)	68	47.89%	2.54	1.21
C7 (Avoiding Activities)	89	62.68%	2.91	1.26
C8 (Memory Trouble)	19	13.38%	1.59	0.81
C9 (Loss of Interest)	75	52.82%	2.73	1.25
C10 (Feeling Distant/Cut Off)	95	66.90%	<b>3.28</b>	<b>1.31</b>
C11 (Emotional Numbness)	59	41.55%	2.41	1.30
C12 (Shortened Future)	70	49.30%	2.71	1.46
D13 (Sleep Disturbances)	75	52.82%	2.69	1.33
D14 (Irritability)	102	71.83%	<b>3.13</b>	<b>1.10</b>
D15 (Difficulty Concentrating)	90	63.38%	2.98	1.19
D16 (Heightened Awareness)	41	28.87%	2.00	1.22
D17 (Jumpy or Easily Startled)	38	26.76%	1.86	1.09

\* **Bold** indicates clinical significance

Using the mean scores for all of the participants, three criterion items yielded clinically significant scores.

One item derived from Category B in the DSM-IV PTSD criterion had a mean endorsement of "3" or higher, "Feeling very upset when something reminded you of infertility diagnosis and/or treatment." One symptom from Category C had a mean endorsement of "3" or higher, "Feeling distant or cut off from other people." One symptom from Category D was endorsed at a "3" or higher, "Feeling irritable or having angry outbursts."

In addition to total individual item analysis determining mean and standard deviation for each item regardless of diagnosis, each item was assessed given the diagnosis, primary versus secondary infertility. Scores of "5", "4" or "3" were counted as clinically significant responses for each diagnostic category (primary and secondary infertility) and then totaled for each individual symptom on the PLC-C. Percentages were then derived from each group's total for comparability (see Table 7).

Table 7  
Individual Item Analysis Dependent on Fertility Diagnosis

<i>Individual Criterion Item</i>	<i>Number of Significant Responses Primary Infertility (N=115)</i>	<i>Percentage Primary Infertility</i>	<i>Number of Significant Responses Secondary Infertility (N=27)</i>	<i>Percentage Secondary Infertility</i>
B1 (Repeated Memories)	64	55.65%	13	48.15%
B2 (Disturbing Dreams)	33	28.70%	6	22.29%
B3 (Re-experiencing)	38	33.04%	8	29.63%
B4 (Upset at Reminder Cues)	92	80.00%	20	74.08%
B5 (Physical Reactions)	46	40.00%	11	40.74%
C6 (Avoiding Thoughts and Talk)	55	47.83%	12	44.44%
C7 (Avoiding Activities)	72	62.61%	17	62.96%
C8 (Memory Trouble)	16	13.91%	3	11.11%
C9 (Loss of Interest)	62	53.91%	13	48.15%
C10 (Feeling Distant/Cut Off)	80	69.57%	15	55.56%
C11 ( Emotional Numbness)	52	45.22%	7	25.93%
C12 (Shortened Future)	60	52.17%	10	37.04%
D13 (Sleep Disturbances)	64	55.65%	11	40.74%
D14 (Irritability)	86	74.78%	16	59.26%
D15 (Difficulty Concentrating)	74	64.35%	16	59.26%
D16 (Heightened Awareness)	33	28.70%	8	29.63%
D17 (Jumpy or Easily Startled)	32	27.83%	6	22.22%

When comparing symptoms presentation and severity between those with primary infertility and those with secondary infertility, those with primary infertility endorsed almost all symptoms to the same degree or higher than those with secondary infertility.

### *Associated Features*

There is currently no assessment tool available to identify and score the associated features of PTSD. As mentioned above, the PCL-C identifies a score of "3" or higher as clinically significant on each item. In order to quantify the prevalence and severity of associated features, scoring criteria was created for "mild," "moderate," and "severe" associated features. Overall endorsement of the associated features were assessed using the "3" or more value, indicating the clinically significant experience of each associated feature (see Table 8).

Table 8  
Associated Features Criterion

<i>Number of Features Scored at "3" of higher</i>	<i>Classification</i>	<i>Modified Value</i>
0-2	None	1
3-5	Mild	2
6-8	Moderate	3
9-11	Severe	4

Participants who met criteria for PTSD using the combined scoring on the PLC-C were further examined to determine the level of associated features also endorsed. Overall of the participants who met PTSD criteria, 3% reported no significant associated features ( $n=2$ ), 20% indicated experiencing mild associated features ( $n=13$ ), 33% reported experiencing a moderate amount of associated features ( $n=22$ ), and 44% indicated a severe amount of associated features ( $n=28$ ). Thus the majority of those who met criteria for PTSD using the combined scoring method on the PCL-C also endorsed moderate to severe presence of associated features.

These participants' answers were then evaluated based on their infertility status (primary versus secondary infertility). Table 9 displays how those with primary infertility endorsed associated features compared to those diagnosed with secondary infertility.

Table 9  
Associated Features in Primary versus Secondary Infertility

<i>Infertility Diagnosis</i>	<i>No significant associate features</i>	<i>Mild associated features</i>	<i>Moderate associated features</i>	<i>Severe associated features</i>
Primary Infertility (percentage)	0	12 (21.34%)	18 (32.14%)	26 (46.43%)
Secondary Infertility (percentage)	2 (22.22%)	1 (11.11%)	4 (44.44%)	2 (22.22%)

Scores for each associated feature were also tallied to determine the rate of occurrence in the population that participated in the present investigation (see Table 10).

Table 10  
Associated Features Individual Item Endorsement (N=142)

<i>Associated Feature Item</i>	<i>Number of Significant Responses</i>	<i>Percentage</i>	<i>Mean</i>	<i>Standard Deviation</i>
A1 (Marital Conflict)	58	40.85%	2.40	1.25
A2 (Interpersonal Conflict)	69	48.59%	2.57	1.09
A3 (Less Control Over Emotions)	89	62.68%	2.96	1.16
A4 (Impulsivity)	36	25.35%	1.92	1.04
A5 (Shame)	72	50.70%	2.70	1.41
A6 (Hopelessness)	97	68.31%	<b>3.36</b>	1.29
A7 (Withdrawal)	83	58.45%	<b>3.00</b>	1.23
A8 (Hostility)	66	46.48%	2.52	1.13
A9 (Changes in Personality)	78	54.93%	2.91	1.28
A10 (Hallucinations)	9	6.34%	1.27	0.76
A11 (Change in World View)	83	58.45%	2.99	1.33

\***Bold** indicates clinical significance

In addition to the overall analysis of associated features, single items were examined dependent on diagnosis, primary infertility or secondary infertility. Individual associated feature endorsement was assessed for each group, then a percentage was rendered for each group given the number of participants (see Table 11).

Table 11  
Associated Feature Endorsement Dependent on Diagnosis

<i>Associated Feature Item</i>	<i>Number of Significant Responses Primary Infertility</i>	<i>Percentage</i>	<i>Number of Significant Responses Secondary Infertility</i>	<i>Percentage</i>
A1 (Marital Conflict)	52	45.22%	6	22.22%
A2 (Interpersonal Conflict)	56	48.70%	13	48.15%
A3 (Less Control Over Emotions)	71	61.74%	18	66.67%
A4 (Impulsivity)	30	26.09%	6	22.22%
A5 (Shame)	61	53.04%	11	40.74%
A6 (Hopelessness)	79	68.70%	18	66.67%
A7 (Withdrawal)	70	60.87%	13	48.15%
A8 (Hostility)	55	47.83%	11	40.74%
A9 (Changes in Personality)	66	57.39%	12	44.44%
A10 (Hallucinations)	8	6.96%	1	3.70%
A11 (Change in World View)	70	60.87%	13	48.15%

### *Open Ended Responses*

Of the 142 surveys completed, 74 participants (52%) gave comments in the section that provided the opportunity for additional information and feedback. Several themes were apparent in the participants' comments. The most common theme was expressing the participants' own emotional journey through infertility diagnosis and treatment. Another theme was hope and encouragement that research was being done on the emotional impact of infertility. Financial commitment and lack of insurance coverage was the third theme that manifested in the open-ended responses. Finally, suggestions for future questions and areas of research were indicated.

## Chapter IV

### Discussion of Results

#### *Demographics*

As reported in Chapter III, over 600 people viewed this survey, and less than one third of those who viewed the survey completed it. While there is not a way to assess rationale for why people who viewed the survey did not chose to complete it, there are several possible reasons. One of the main symptoms of PTSD is avoidance, specifically of things and situations that remind them of their trauma. One of the possible explanations for the low percentage of those who viewed the survey but did not finish it may be avoidance. It is quite possible that potential participants previewed the survey, but after seeing what was being asked of them, determined that the process of completing the survey would be too psychologically dangerous for them; the survey may have been viewed as unwanted stimuli, a trigger or reminder of their trauma.

Infertility can be a devastating diagnosis with treatment options that offer no guarantee of success. However, those who are officially diagnosed and receive treatment, may only represent a small portion of people who are actually struggling with being unable to conceive.

Many of the participants that responded to this survey were Caucasian females of higher socioeconomic status with advanced educations in married relationships. According to this study, infertility treatment appears to be culturally and economically limited. It is not surprising that those making more money access treatment, given insurance companies do not often cover infertility treatment.

The demographic data indicated that 46% spent over \$9000 on infertility diagnosis and treatment. People with lower paying jobs, poorer insurance coverage and limited access to resources would be much less likely to engage in infertility treatment. Further, lower paying jobs often do not have the flexibility needed to attend doctor's appointments and procedures that are required for treatment. In essence, infertility treatment is discriminative from the scheduling to the cost. The reality is that many more people are likely suffering from infertility, but do so without access to treatment. Future research utilizing people who are not in the position to access treatment would be necessary to be able to generalize results to other ethnic and socioeconomic populations.

### *Previous Mental Health Diagnosis*

Several participants reported having a previous mental health diagnosis. Most of the diagnoses reported were anxiety and depression. Research indicates that prior mental health issues can create a vulnerability to developing PTSD after experiencing a trauma (Briere & Scott, 2006). It is possible that those who have a risk factor for developing PTSD, like a prior mental health diagnosis, are more apt to develop PTSD as a result of infertility. However, only 7 of the 32 participants that indicated a previous mental health diagnosis, approximately 22%, met criteria for PTSD using the combined scoring method.

The present study assessed for this vulnerability by running an independent samples t-test to determine if those with a previous mental health diagnosis met criteria for PTSD as related to their experience with infertility at a higher rate when compared to those without prior mental health diagnosis. The mean PCL-C score for those with a previous mental health diagnosis was 46.03, and the mean score for those without a previous mental health diagnosis was 42.43. The differences in mean PCL-C scores between the two groups mean scores were not statistically significant,  $t = 1.506$  ( $p = .134$ ), thus indicating that

previous mental health diagnosis did not appear to inflate the prevalence of PTSD in the current study. As mentioned previously, the size of each group should be considered when analyzing differences in mean scores. These two comparative groups were not large enough for acceptable power. It is possible that a statistically significance difference could be found with a larger sample size.

#### *Overall Prevalence of PTSD*

One purpose of this investigation was to determine if PTSD is an accurate conceptual frame of the experience for those who suffer from infertility. Most of the research that has been completed studying the psychological effects of infertility diagnosis and treatment has focused on general anxiety, depression, and grief and loss symptoms. To this author's knowledge, viewing the diagnosis and treatment process as a traumatic event has not been considered. According to the data collected in this investigation however, it is clear that infertility diagnosis can be considered a traumatic event, even though it is not a life threatening experience as dictated by Criterion A in the DSM-IV-TR. The threat appears to be more about the unmet expectation of life and the future. The current data suggests that it is not the actual

threatening of life that is important in PTSD, rather the experience of the event that is paramount. How one views and reacts to an event is more important than how the rest of the world views the severity and importance of the event. And the current participants were loud and clear defining infertility as a traumatic event.

The process of infertility treatment can be viewed as a complex trauma due to its cyclical nature. Each month that treatment ensues, pills are taken, shots administered and procedures performed. For women, menses often begins regardless of intervention, giving evidence that pregnancy was not attained. Each of these events can be experienced as traumatic in and of themselves. Moreover they can be additive in the nature of their affect. Combining "mini" traumas of the multiple medical interventions, and the beginning of menses, can create another traumatic experience. Infertility, then, is not a single exposure to a traumatic event; but more like an earth quake with consistent aftershocks. Each appointment, each shot, each procedure, and each menses is an aftershock, contributing to the mounting emotional effect of infertility treatment. Anxiety, depression, grief and loss are good descriptives of the emotional experience of infertility, but they do not tell the entire story.

As reported, over half of the participants' surveyed met total PCL-C score criteria for PTSD. When adding the combined scoring method, just under half met criteria (46%). The Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> Edition Revised Text (2000) reports an 8% rate of PTSD in the general population. Thus, the current sample of individuals suffering from infertility met the criteria for PTSD at a rate almost six times as high as the general population.

Van der Kolk, McFarlane, and Weisaeth (1996) report the national average of PTSD in the population that has experienced a life threatening trauma ranges from 10.7% to 48.4% varying on gender and type of trauma. The occurrence of PTSD increases in populations that have experienced war which is roughly 15% according to the National Vietnam Veterans Readjustment Study (Kluka et. al, 1990). Those who have been prisoners of war experience PTSD at a rate between 60% and 70%. The abuse survivor population suffers from PTSD at a rate of at least 50% and those who witness or experience a catastrophic event at a rate of 3.6% to 59% depending on severity of disaster and sample group (van der Kolk, McFarlane, and Weisaeth, 1996). There is also evidence that other medical issues such as cancer and migraines are associated with PTSD symptom

occurrence (Domar, Zuttermeister & Friedman, 1993; Kwekkeboom & Seng, 2002; Peterlin, Tietjen, Brandes, Rubin, Drexler, Lidicker & Meng, 2009; De Leeuw, Schmidt & Carlson, 2005). Research consistently shows that experiencing trauma can produce PTSD. As the current PTSD rate is similar to the rate cited after other accepted types of traumatic events, further credence is given to considering infertility diagnosis and treatment a traumatic event. And, as many more people likely suffer from subthreshold PTSD, the prevalence of suffering is likely much higher even still.

#### *Difference in PTSD Between Primary and Secondary Infertility*

One of the main investigative questions of the present survey was to determine if there was a significant difference in PTSD occurrence between those with primary infertility and those with secondary infertility. As reported in Chapter III, there was not a statistically significant difference between the mean PCL-C scores of those with primary infertility (M=46.45) and those with secondary infertility (M=43.52). As mentioned, the sample groups were not large enough to have significant power. It

is possible that a larger sample group may have yielded a significant difference when comparing the two groups.

### *Symptom Presentation*

In addition to examining overall PTSD diagnosis, it was important to assess which symptoms presented most often in those suffering from infertility. The PCL-C contains items that mirror the specific criteria derived from the DSM-IV-TR. For the overall population in this investigation, over 40% of those who participated in this survey reported that they have significant issues with avoiding thoughts about infertility, experiencing emotional numbness and having a shortened sense of their future. Over 50% of the participants indicated that they have repeated memories surrounding infertility, become upset at cues that remind them of their infertility diagnosis or treatment, avoid activities that remind them of their infertility, have lost interest in things they once enjoyed, feel distant or cut off from others, have sleep disturbances, are irritable and have difficulty concentrating (see Table 6). Upon analysis of the individual items, three of the eighteen symptoms identified in the original version of the PCL-C, were consistently endorsed at a rate of "3" or higher. Each category was

represented in this group, including reexperiencing, avoidance, and increased arousal.

The reexperiencing symptoms can include reoccurring dreams, intrusive thoughts, flashbacks and distress caused by internal or external cues that remind the person of the trauma. One of the items that represented distress caused by cues reminding one of the traumatic event, "Feeling very upset when something reminded you of infertility diagnosis or treatment," was endorsed at a clinically significant level according to scoring criteria by 80% of the participants ( $n=92$ ). Twenty-eight of the participants reported that they were extremely affected by cues that reminded them of their infertility diagnosis and treatment. Forty-one participants reported that they were affected by cues reminding them of their infertility quite a bit, and twenty-three reported that they were moderately affected by cues.

Reexperiencing trauma as a result of cues that remind a person of infertility is clinically significant. Cues can include infertility treatment itself, but also social cues such as pregnant women, infants and babies that are encountered, or even remarks or comments made by friends and family. In this author's case, the task of working on this investigation served as a significant cue reminding of

the past trauma of infertility. The reality is that cues are everywhere; similar to cues that may be experienced by those who have been abused, assaulted or in a car accident. A significant difference between events that are typically defined as trauma, such as abuse or war, and infertility is that the treatment for infertility is often a consistent cue that evokes traumatic responses. In essence, the thing that may give individuals what they desperately want is also one of the things that will likely trigger a trauma response. Moreover, infertility treatments are not viewed as traumatic experiences. In effect, the treatment for infertility triggers trauma responses, but is necessary to reproduce, and the psychological impact of the experience is seen as invalid by both medical professionals and family and friends.

Avoidance characteristics include dissociation, diminished interest in enjoyable activities, feeling detached, or feeling as if the future is cut short. The item that represented the avoidance symptoms, "Feeling distance or cut off from other people" was endorsed at a significant level according to scoring criteria by 69% of the participants ( $n=79$ ). Twenty-six of the participants reported that they were extremely affected by feeling distance or cut off from others. Thirty-two participants

reported that they felt cut off or distance from others quite a bit, and twenty-one participants reported that they were moderately affected by feeling distanced and cut off from others. As previously mentioned, the mere sight of the questions asked in this survey may have triggered avoidance behaviors in potential participants who viewed the survey but did not participant.

Social support serves as a protective agent against developing PTSD. Conversely, lack of social support is a risk factor for developing PTSD (van der Kolk, McFarlane & Weisaeth, 2007). Feeling distant or cut off from others is common in those who are diagnosed with infertility and those who are seeking treatment for infertility. Not only are others in their lives ill-informed about infertility and the affects that infertility can have on those experiencing infertility, but they also likely hold the traditional values of society that children make life more complete. Friends and family of those diagnosed with infertility may directly contribute to the feeling of being isolated by expectations of the individual or couple having children, and further by giving advice on how to conceive.

Feelings of isolation can be exacerbated by others simply living their life; talking about getting pregnant, being pregnant and raising children. While it is unfair to

blame others for fulfilling their own dreams of having children, it is necessary to mention that those who suffer from infertility are significantly affected by others in their life. In addition, many people do not experience infertility, which leads to a lack of understanding of both the medical procedures and the psychological effect of infertility. Those who do not experience infertility likely do not know that their actions affect those who do suffer from infertility. If they do know about the diagnosis or understand the physical and emotional toll, they likely do not know how to support those experiencing infertility.

Increased arousal includes sleep disturbances, emotional dysregulation and difficulties with concentration. One of the items that represented increased arousal, "Feeling irritable or having angry outbursts," was endorsed at a significant level according to scoring criteria by 74% of the participants ( $n=85$ ). Fourteen participants reported that they were extremely affected by experiencing irritability or angry outbursts. Thirty-two participants reported that they experienced irritability and angry outbursts quite a bit and thirty-nine participants reported being moderately affected by irritability and angry outbursts. Feeling irritable and

having angry outburst likely contributes to the feelings of isolation and being cut off from others. It also affects relationships that do remain in tact. Infertility often produces negative emotions, and likely intensifies negative emotions that are already present.

Those suffering from infertility have to navigate emotions that while understandable may not be natural for them. The experience of infertility diagnosis and treatment can create irritability, but the role of medication side effects should also be considered. Emotional reactions are expected when one is told they cannot naturally conceive a child and should consider medical intervention to assist the process. The addition of synthetic hormones into an already emotionally stressed system only intensifies emotional arousal. Heightened emotion and increased arousal is difficult to deal with not only within the person, but also within the relationships in that person's life.

Several items, one from Category C, one from Category D, and two from the Associated Features, were within a tenth of a point of meeting the score of "3," which was the clinically significant cut-off score used in the current study. While these items were not endorsed at a high enough rate to be considered clinically significant

according to the scoring criteria, the symptoms would likely feel significant to those who endorsed them. One item, "Avoiding activities or situations because they remind you of infertility diagnosis and/or treatment," was endorsed by 62% of the participants ( $n=88$ ). Fifteen participants reported that they were extremely affected by feeling compelled to avoid activities, thirty-eight reported that they avoided activities quite a bit, and thirty-five participants indicated that they were moderately affected by their need to avoid activities that remind them of their infertility. Avoiding situations that may trigger strong emotional reactions is a common practice for those who have experienced a trauma. Avoidance allows the person to circumvent difficult emotions by not exposing themselves to experiences that may remind them of the trauma, and thus avoidance reinforces itself. Avoidance works in that it allows the person to control his or her exposure to stimuli, but it comes at a significant cost; damaging or losing relationships, changing daily life routines and experiences, and altering activities that provided enjoyment prior to the trauma.

Another item, "Having difficulty concentrating," was endorsed by 63% of the sample that participated in this survey ( $n=90$ ). Sixteen people reported that they were

extremely bothered by concentration issues, thirty-four participants indicated that they experienced difficulties in concentration and forty people indicated moderate issues with concentration. Concentration issues are not surprising given the extensive effect infertility treatment has on one's life. The reality of not being able to conceive a child would be enough to create distractibility. More over, treatment for infertility requires a significant time investment. Even if the emotional energy was not enough to create clinically significant distractibility, the logistics of treatment certainly could.

When looking at individual item endorsement between the two groups, those with primary infertility endorsed almost every item at a higher percentage than those who identified as having secondary infertility. In essence, those with primary infertility endorsed more symptoms in general, and endorsed symptoms at a higher level of occurrence or disturbance. It seems that those who suffer from primary infertility experience more symptoms of PTSD. These are people who have never been able to conceive or bear children. One possibility for this discrepancy may be that having had the positive experience of pregnancy and birth may help protect against PTSD. The memories and positive associations that are drawn from the prior

pregnancy may provide a sort of emotional safety net for those who cannot conceive or carry a child to term later in life. In addition, already having a child may mean that at least part of the life expectation has been fulfilled. Being a parent is a powerful motivator, and procreation is a biologically hard wired drive. It could be that those who have had a child have fulfilled this need or drive, even if it is not necessarily in the manner or quantity that they would have liked. Regardless, the emotional experience of the individual is most important, not how society defines an event or desire. While having a child may help somewhat protect someone from developing PTSD as a result of infertility, the individual's experience of infertility is most important to consider.

#### *Associated Features*

Given the amount of individual symptoms and pattern of endorsement, it is not surprising that a large portion of individuals suffering from infertility met criterion for PTSD. Emotions run high when life expectations are cut short. Traditionally, a trauma associated with PTSD has been defined as life threatening, but in the case of infertility, it is the expectation of life. Similarly,

assessment of trauma response has focused on the symptoms that have been identified in the DSM-IV-TR, including re-experiencing, avoidance and increased arousal. What is not typically explored is the occurrence of associated features, which are listed in a small paragraph beneath the description and criterion for the diagnosis of PTSD. The associated features have proven to be significant symptoms that affect those who have experienced trauma in their life (Litz and Roemer, 1996). It is more plausible to view infertility diagnosis and treatment as a complex trauma (one with associated features) due to the multiple occurrences, cyclical nature, personal definition and social factors that influence the psychological response to infertility.

Many of the associated features are linked to social supports such as marital and other interpersonal relationships. Infertility has a large social component not only because of the time commitment that often requires at least employers to know about the treatment, but also that friends and family likely know because of their expectation that the individual or couple will be or should be having children. As a result, it is important to extend the diagnostic symptoms of PTSD to include the associated

features, which were added to the traditional PCL-C in the present investigation.

Not surprisingly, most of the participants who met the diagnostic criterion for PTSD also endorsed a considerable number of associated features according to typical scoring criteria. The associated features identified in those who met criteria for PTSD are relational conflicts, emotional dysregulation, shame and hopelessness, hostility, and changes in personality. Over 40% of the participants indicated that they were experiencing clinically significant levels of marital and interpersonal conflict, feelings of shame and hostility. Over 50% of the participants reported significant feelings of hopelessness, withdrawal, decreased control of emotions, changes in personality and changes in world view (see Table 10).

When comparing the associated features that were endorsed by the two groups (primary versus secondary infertility), the previous PTSD findings were supported; those who identified as having primary infertility endorsed a higher percentage of individual associated features than those who reported having secondary infertility. Again, it is necessary to note that the sample size may have produced the difference simply because substantially more people with primary infertility participated in this investigation

than those with secondary infertility. It is also possible that those suffering from primary infertility truly do experience more symptoms at a higher intensity than those with secondary infertility.

Overall individual items analysis revealed that two associated features were endorsed at a clinically significant level according to scoring criteria. The first, "Feeling shameful since diagnosis/treatment of infertility," was endorsed by 68% of the participants (n=96). Thirty-four participants indicated that they were extremely affected by feelings of shame. Thirty-nine participants reported that they felt feelings of guilt quite a bit, and twenty-three people indicated that they were moderately affected by feelings of shame. Similar to feeling upset by cues that remind one of infertility, feeling irritable and having angry outbursts, and feelings of shame contribute to emotional isolation.

Shame suggests that one is to blame, one is at fault. Fertility is viewed as a biological given; humans are biologically built to procreate and have instinctual drives to do so. When conceiving a child is difficult and external interventions must be used, a sense of shame or inadequacy may develop. The individual may feel like it is her fault that she cannot conceive a child. In addition to

the personal responsibility that may be felt, lack of understanding and even stigma attached to infertility diagnosis and treatment from society can exacerbate feelings of shame. Not only is the individual blaming herself, but she also likely perceives blame from others, even if they are well meaning. Many comments made by those trying to support the individual or couple struggling with infertility trigger feelings of sadness, shame and hopelessness.

The second item included in the associated features of PTSD, "Feeling hopeless since diagnosis/treatment of infertility," was endorsed at a significant level according to the scoring criteria by 58% of the participants ( $n=83$ ). Twenty-three participants indicated that they were extremely affected by feelings of hopelessness. Twenty-five participants reported that they experienced feelings of hopelessness quite a bit, and thirty-five participants reported that they were moderately affected by feelings of hopelessness. Individuals seeking treatment for infertility have often tried to conceive a child for more than a year prior to seeking treatment. Months of unsuccessful attempts lead to questions about why pregnancy has not been achieved and hope for a future child begins to waiver. When treatment is initiated, feelings of

hopefulness may replace negative feelings for a time, however if pregnancy is not achieved as a result of treatment, feelings of hopelessness can quickly return.

For many, having children is not only a biological drive, but also a life dream. Those who suffer from infertility enter treatment because they long to have a child. Having that dream interrupted by biology not cooperating with the desire to have a child creates difficult emotions, one of which is hopelessness. Prior to medical intervention, there is little that one can do to encourage conception. Ovulation predictors and home remedies can be successful, however if there is a medical reason why conception is not occurring, these interventions will be ineffective. After time and time again of trying to conceive, being hopeful of conception and menses beginning while trying to conceive, positive outlooks and emotions are often replaced with frustration, anger and hopelessness. Dreams of having a biological child and not being able to fulfill that dream creates internal turmoil for the individual and/or couple, and social influences compound these emotional responses. Expectations from family members and friends influence the desire to have a child, and when that want cannot come to fruition without medical intervention, and sometimes still doesn't occur

even with treatment, hopelessness about the future that the individual/couple envisioned for likely occurs.

Two associated features approached the level of clinical significance according to the scoring criteria. The first addressed perceived changes in personality, "Feeling that your personality has changed since diagnosis/treatment of infertility," with 54% of the participants endorsing this item. Twenty-four people reported that they feel that their personality has changed extremely, twenty participants indicated that they feel their personality has changed quite a bit, and thirty-three people reported a moderate change in their personality. Experiencing trauma can have debilitating effects on a person's thoughts, feelings, behaviors and overall personal functioning, which can lead to permanent changes to the person who has experienced trauma (Herman, 1992). The initial understanding of not being able to conceive on your own is often devastating for people, but when combined with intensive and intrusive treatment, the trauma experience becomes cyclical and chronic. Consistent elevation of stress and negative emotions can lead to changes in core personality functioning. Optimists become pessimists, patience becomes impatience and mild mannered becomes easily angered. It is likely that the experience of

infertility and treatment is a large culprit of personality changes, but the side effects of hormonal based medicine must be considered as well.

The second associated feature that appeared to have significance according to the scoring criteria was related to changes in world view, "Feeling your beliefs about yourself and the world are different since diagnosis/treatment of infertility," with 57% of the population reporting a change in how they view the world (n=81). Twenty-five participants reported that they felt that their world view had extremely changed, twenty-eight participants indicated that they felt their world view had changed quite a bit, and twenty-eight participants reported that their world view had moderately changed.

Altering how one looks at the world is directly related to personality change. Whether the change in world view is primary or secondary to personality change, it greatly affects daily functioning. Seeing oneself differently has a dire effect on personality functioning. Seeing oneself as a competent, healthy and successful person likely changes when one discovers that he or she cannot meet one of his or her primary goals in life; bearing children. Questions about responsibility for infertility, self-blame and justice in the world come into

play and can often alter a previously fair and positive world view.

Sue (1978) identified four different world views that are formed by assessing locus of control and locus of responsibility. This theory is often associated with minority identity development, but is also important when looking at trauma and the residual affects of a traumatic experience on worldview. Those with an internal locus of control and an internal locus of responsibility fair better in general. They believe that success in life is up to them and that they control their own fate. This is also the world view of most Caucasians, which is consistent with the demographics of the present investigation. However when a trauma is experienced, internal control is often stripped, leaving the belief that one is at the mercy of the environment. In addition, self-blame is common in those who suffer from infertility. Adhering to an internal locus of responsibility and external locus of control creates a difficult place to function and leaves the person susceptible to mental health issues such as PTSD.

#### *Open Ended Responses*

Participants were given the opportunity to provide any other information that they would like the investigator to

know including details about their experiences, feedback or thoughts about future research. As previously reported, 74 participants provided open-ended feedback for the investigator. It is necessary to discuss the reality that half of the participants who completed this survey wanted to leave qualitative data. It is possible that this survey was one of the only outlets participants had to express their emotions and experiences with infertility. Clearly, people who are diagnosed with infertility and/or who are going through infertility treatments need an outlet, and likely psychological services from professionals who understand their experiences with infertility.

As discussed in Chapter III, several themes emerged such as further expression of the emotional experience of infertility, the financial burden of infertility diagnosis and treatment, and the lack of insurance coverage for treatment.

Many participants discussed the emotional toll that infertility takes. One participant stated "infertility consumes you, changes you and your partner." Another participant stated "It is isolating and numbing. If you allow yourself to feel, it hurts. It hurts to live with infertility, there are reminders everywhere. It is like a disability except that it's invisible to the eye. It's

like an open wound that no one can see." The emotional impact of infertility is clear and the specific experiences of infertility are painful to read. "I feel emotionally traumatized from the experience..." and "It has been completely devastating and absolutely the hardest thing I have been through in my life" are sentiments reported consistently in the open ended responses.

The sheer nature of the psychological impact of infertility is palpable. Other participants made it clear that infertility, regardless of outcome, provided lasting effects. "We managed to build our family, however our infertility experience remains the defining aspect of our lives." Another participant reported "It is a very long and tiring journey- one that never really ends even after you have a child(ren). I feel the impact is never really over. It is a life long diagnosis no matter if you get what you want or not." One participant stated "There is an empty, useless, and sad feeling in my heart nearly everyday. Some days I feel stronger and normal, but little everyday things... walking in a store, passing the baby section or a pregnant woman, a diaper commercial etc. will set me off and I'll feel broken all over again. This has been going on for over 15 years with me." As the former participants indicated, not only is there a re-experiencing

that is cued by stimuli all around, but the effects are long-term, for her lasting over 15 years.

Many participants commented on the social aspect of infertility, including the effect on interpersonal relationships. "Gone are the days of making love just for the sake of it. It becomes a business and is no longer a way to feel connected to your partner." "I always imagined creating offspring to be very intimate and private. Infertility strips that from couples. We were poked, prodded and were actually in separate rooms when our embryos were implanted." The idea of creating life is often associated with a loving and intimate relationship along with the social support of family and friends. Infertility treatment destroys that expectation of life and replaces it with cold medical procedures that are traumatic in and of themselves, along with a lack of understanding and support from the community. "Sensitivity is generally low, not just in the medical community, but in society as a whole- particularly the workplace."

The medical community often is dictated by the insurance companies, most of which do not provide coverage for infertility treatment. "Going through this healthcare system sucks!! I had a lady compare my (infertility) procedures to a facelift today..." Another participant added

"Where I live our medical will pay for a sex change b/c of the psychological related issues but they won't pay for any fertility treatments b/c they see it as a 'choice' to have children." The emotional turmoil is likely exaggerated by the fact that while the medical diagnosis is recognized, it is not severe enough to be granted coverage, and the recognition of the emotional effect of infertility is even less supported. In general, there is a stigma associated with mental health diagnoses and insurance coverage and reimbursement rates are substantially skewed towards the medical side of health. There appears to be a significant issue with lack of coverage to address both the medical treatment and the psychological impact of infertility.

Finally, some participants had suggestions for future research including examining the psychological impact of family and friends' pregnancies on those suffering from infertility, separating previous infertility experience from current infertility experience, the relationship between the cause of infertility and the prevalence of PTSD, and the effect of miscarriages on the psychological experiences of infertility.

### *Study Limitations*

This investigation had several limitations. First, the majority of the participants in this study were Caucasian ( $n=136$ ), female ( $n=139$ ), married ( $n=124$ ), with a Bachelor's degree or higher ( $n=103$ ), employed ( $n=124$ ), and having a household income of over \$40,000 ( $n=124$ ). As a result, it is difficult to generalize findings to other populations with different ethnic backgrounds and socioeconomic status. Being able to assess those who did not seek treatment, who continued to try and conceive without medical intervention would be valuable information. Including those who did not pursue medical intervention would help determine if the trauma of infertility in and of itself lead to PTSD symptoms or if the medical procedures and the psychological effects of those treatments have a compounding effect.

A second limitation of this investigation was the sample size of those with secondary infertility. It is possible that due to the large sample size of those with primary infertility, the number of endorsed items and percentages increased simply due to increased number of participants. The differences in endorsements may decrease if a larger sample size is attained. Although this investigation showed no statistically significant

difference in PTSD symptom presentation and severity between those with primary infertility and those with secondary infertility, it is possible that those suffering from primary infertility experience a larger number of PTSD symptoms and that those symptoms are more severe than those experienced by participants with secondary infertility.

One question to be raised is why there were not more participants with secondary infertility. Is it possible that those with secondary infertility talk about their struggle with infertility less or could it be that those suffering from secondary infertility simply do not need to reach out for support, or are perhaps too busy to reach out for support.

### *Conclusion*

It is clear from this investigation that infertility diagnosis and treatment is a trauma, likely a complex trauma, and that the psychological experience of infertility and the treatments that are associated with infertility can lead to PTSD symptoms in a large portion of the population that experiences infertility. The prevalence of PTSD in the sample recruited for this investigation who were diagnosed with infertility and/or were going through infertility treatment met criteria for

PTSD at a similar rate as those who have experienced other type of events that are traditionally identified as trauma and almost six times the rate of the general population. Many things likely affect the occurrence of PTSD symptoms including social stigma, which often causes withdrawal and isolation, lack of insurance coverage for treatment, and general ignorance and misunderstanding of the psychological impact of infertility. It is this authors hope that this investigation will increase the awareness of the prevalence of PTSD in those who suffer from infertility for society in general, and specifically for the medical community. The more awareness there is that infertility is a trauma which can lead to trauma symptoms and PTSD, the more likely there is to be support and treatment options for those living with infertility.

#### *Implications for Psychology*

As discussed numerous times in this investigation, infertility is not currently seen as a trauma event. The medical community treats it as a treatable condition, going through whatever interventions, including medications, surgeries and procedures, that will "fix" the problem without consideration of the psychological impact of the interventions. The general public views infertility as

something that is easily solved, and if not, should be gotten over with relative ease. Psychologists must understand that infertility is a trauma, and often a complex trauma. Month after month, the individual and/or couple is exposed to and reminded of her/their infertility by undergoing treatment, creating more trauma experiences. Not to mention the reminders of infertility, such as pregnant women, babies, friends and families questions and comments, and material goods related to infants and children are ubiquitous. It is important for therapist to change the conceptualization of infertility, and of trauma as well, so that treatment can be offered.

While anxiety, depression, and grief and loss are all a part of the psychological impact of infertility, there is much more to the experience which is defined by the individual. The definition of trauma needs to be expanded. Hobfoll (1989) discussed how the definition of stress and trauma should be extended to include not just threats to actual life, but also to life expectations and resources. He maintains that actual or perceived loss of resources is the key component when defining stress, thus defining a trauma response. Understanding that the threat of death does not necessarily define what a traumatic experience is, rather that the individual's subject experience is a more

reliable definition of trauma, is key to successfully  
intervening with this population.

## References

- Advances in fertility treatment: An educational guide.*  
(2006). Roseland, NJ: Organon USA.
- Allison, J.R. (1979). Roles and role conflict of women in infertile couples. *Psychology of Women Quarterly*, 4(1), 97-113.
- Alter, C.L., Pelcovitz, D., Axelrod, A., Goldenberg, B., Harris, H., Meyers, B., Grobois, B., Mandel, F., Septimus, A., & Kaplan, S. (1996). Identification of PTSD in cancer survivors. *Psychosomatics*, 37(2), 137-143.
- Assisted reproductive technologies: Patient guide.* (2003).  
Roseland, NJ: Organon USA.
- Berghuis, J.P & Stanton, A.L. (2002). Adjustment to a dyadic stressor: A longitudinal study of coping and depressive symptoms in infertile couples over an insemination attempt. *Journal of Consulting and Clinical Psychology*, 70(2), 433-438.
- Blanchard, E.B., Jones-Alexander, J., Buckley, T.C. & Forneris, C.A. (1996). Psychometric properties of the PTSD checklist (PCL). *Behavioral Research & Therapy*, 34, 669-673.

- Bridges, S.K. (2005). A constructivist approach to infertility: loss and meaning reconstruction. *Contemporary Sexuality*, 39(12), 10-13.
- Briere, J. & Scott, C. (2006). *Principles of trauma therapy: A guide to symptoms, evaluation, and treatment*. Thousand Oaks, CA: Sage Publications.
- Chen, T., Chang, S., Tsai, C. & Juang, K. Prevalence of depressive and anxiety disorders in an assisted reproductive technology clinic. *Human Reproduction*, 19(10), 2313-2318.
- Clay, R. (2006). Battling the self-blame of infertility. *Monitor on Psychology*, September 2006, 44-45.
- Cohen, Jacob. (1992). A power primer. *Quantitative Methods in Psychology*, 112(1), 155-159.
- Cordova, M.J., Andrykowski, M.A., Kenady, D.E., McGrath, P.C., Sloan, D.A., & Redd, W.H. (1995). Frequency and correlates of posttraumatic-stress-disorder-like symptoms after treatment for breast cancer. *Journal of Consulting and Clinical Psychology*, 63(6), 981-986.
- De Liz, T.M. & Strauss, B. (2005). Differential efficacy of group and individual/couple psychotherapy with infertile patients. *Human Reproduction*, 20(5), 1324-1332.

- De Leeuw, R., Schmidt, J.E., & Carlson, C.R. (2005).  
Traumatic Stressors and post-traumatic stress disorder  
symptoms in headache patients. *Headache*, 45(10),  
1365-1374.
- Dingfelder, S.F. (2006). How to handle a stubborn stork.  
*Monitor on Psychology*, September 2006, 48-49.
- Domar, A.D., Zuttermeister, P.C., & Friedman, R. (1993).  
The psychological impact of infertility: a comparison  
with patients with other medical conditions. *Journal  
of Psychosomatic Obstetrics and Gynecology*, 14, 45-52.
- Edelmann, R.J, Connolly, K.J, & Robson, J. (1989). The  
impact of infertility and infertility investigation:  
Four case illustrations. *Journal of Reproductive and  
Infant Psychology*, 7, 113-119.
- Edelmann, R.J, Connolly, K.J. (1987). The counseling needs  
of infertile couples. *Journal of Reproductive and  
Infant Psychology*, 5, 63-70.
- Fertility Journey.com. About fertility, today's treatment  
options (section). (2008). Kenilworth, NJ: Schering  
Corporation
- Follistim AQ*. (2005). Roseland, NJ: Organon USA.

- Forrest, L. & Gilbert, M.S. (1992). Infertility: An unanticipated and prolonged life crisis. *Journal of Mental Health Counseling*, 14(1), 42-58.
- Frank, D.I. (1984). Counseling the infertile couple. *Journal of Psychosocial Nursing*, 22(5), 17-23.
- Freeman, E.W., Boxer, A.S., Rickels, K., Tureck, R., & Mastroianni, L. (1985). Psychological evaluation and support in a program of in vitro fertilization and embryo transfer. *Fertility and Sterility*, 43(1), 48-53.
- Friedman, M.J., Keane, T.M., & Resick, P.A. (2007). *Handbook of PTSD: Science and practice*. New York, NY: The Guilford Press.
- Gibson, D.M. & Myers, J.E. (2002). The effect of social coping resources and growth-fostering relationships on infertility stress in women. *Journal of Mental Health Counseling*, 24(1), 68-80.
- Gonzalez, L.O. (2000). Infertility as a transformational process: A framework for psychotherapeutic support of infertile women. *Issues in Mental Health Nursing*, 21, 619-633.
- Hart, V.A. (2002). Infertility and the role of psychotherapy. *Issues in Mental Health Nursing*, 23, 31-41.

- Himmel, W., Ittner, E., Schroeter, M. & Kochen, M.M. (1999). The many facets of involuntary childlessness in general practice. *Scandinavian Journal of Primary Health*, 17, 25-29.
- Hobfoll, S.E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist*, 44(3), 513-524.
- IVF Cost Information. <http://www.socalfertility.com/ivf-cost-information.html> (2009).
- Jordan, C.B. & Ferguson, R.J. (2006). Infertility-related concerns in two family practices. *Families, Systems & Health*, 24(1), 28-32.
- Kangas, M., Henry, J.L., & Bryant, R.A. (2005). The relationship between acute stress disorder and posttraumatic stress disorder following cancer. *Journal of Counseling and Clinical Psychology*, 2, 360-364.
- Kangas, M., Henry, J.L., & Bryant, R.A. (2005). Predictors of posttraumatic stress disorder following cancer. *Health Psychology*, 24 (6), 579-585.
- Kornblith, A.B. & Ligibel, J. (2003). Psychosocial and sexual functioning of survivors of breast Cancer. *Seminars in Oncology*, 30(6), 799-813.

- Kwekkeboom, K.L. & Seng, J. S. (2002). Recognizing and responding to post-traumatic stress disorder in people with cancer. *Oncology Nursing Forum*, 29(4), 643-650.
- Litz, B.T. & Roemer, L. (1996). Post-traumatic stress disorder: An overview. *Clinical Psychology and Psychotherapy*, 3(3), 153-168.
- Mehnert, A. & Koch, U. (2007). Prevalence of acute and post-traumatic stress disorder and comorbid mental disorders in breast cancer patients during primary care: A prospective study. *Psycho-oncology*, 16, 181-188.
- Menning, B. (1988). *Infertility: A guide for the childless couples* (2<sup>nd</sup> ed.). Englewood Cliffs, NJ: Prentice-Hall.
- Mosher, W.D. & Pratt, W.F. (1990). Fecundity and infertility in the United States, 1967-1988. *Advance Data from the Vital and Health Statistics* (No. 192). Hyattsville, MD: National Center for Health Statistics.
- National Center for PTSD. (2010). Using the PTSD checklist (PCL). <http://www.ptsd.va.gov/professional/pages/assessment.ptsd-checklist.asp>

*Ovulation induction: Patient guide.* (2007). Roseland, NJ:  
Organon USA.

Ovulation induction by hCG. [http://www.ivf-  
infertility.com/infertility/treatment/ovarian7.php](http://www.ivf-infertility.com/infertility/treatment/ovarian7.php)  
(2010).

Pasch, L. & Christensen, A. (2000). Couples facing  
fertility problems. In K.B.Schmaling & T.G. Sher  
(Eds.), *The Psychology of Couples and Illness: Theory,  
Research and Practice* (pp. 241-267). Washington DC:  
American Psychological Association.

Pengelly, P., Inglis, M., & Cudmore, L. (1995).  
Infertility: Couples' experiences and the use or  
counseling in treatment centres. *Psychodynamic  
Counselling*, 1(4), 507-524.

Peterlin, B.L., Tietjen, G.E., Brandes, J.L., Rubin, S.M.,  
Drexler, E., Lidlicker, J.R. & Meng, S. (2009).  
Posttraumatic stress disorder in migraine. *Headache*,  
49(4), 541-551.

*Pregnyl.* (2008). Roseland, NJ: Organon USA.  
Progesterone.  
<http://www.drugs.com/pro/progesterone.html> (2008)

The psychological impact of infertility and its  
treatment. (2009, May). *Harvard Mental Health Letter*,  
25(11), 1-3.

- Ridenour, A.F., Yorgason, J.B., & Peterson, B. (2009).  
 The infertility resilience model: Assessing  
 individual, couple, and external predictive factors.  
*Contemporary Family Therapy*, 31, 34-51.
- Risks and complications of IVF treatment. [http://www.ivf-  
 infertility.com/ivf/standard/complications/ovarian\\_sti-  
 mulation/ohss.php](http://www.ivf-infertility.com/ivf/standard/complications/ovarian_stimulation/ohss.php) (2010)
- Sarrel, P.M., & DeCherney, A.H. (1985). Psychotherapeutic  
 intervention fortreatment of couples with secondary  
 infertility. *Fertility and Sterility*, 43(6), 897-900.
- Spector, A.R. (2004). Psychological issues and  
 interventions with infertile patients. *Women &  
 Therapy*, 27(3/4), 91-105.
- Sue, D.W. (1978). World views and counseling. *Personal  
 and Guidance Journal*, 56, 458-462.
- Van Hall, E.V. (1983). Psychosocial and emotional aspects  
 of infertility. *Journal of Psychosomatic Obstetrics  
 and Gynecology*, 2(4), 251-255.
- Verhaak, C.M., Smeenk, J.M.J., van Minnen, A., Kremer,  
 J.A.M., & Kraaiaat, F.W.(2005). A longitudinal,  
 prospective study on emotional adjustment before,  
 during and after consecutive fertility treatment  
 cycles. *Human Reproduction*, 20(8), 2253-2260.

- Weschler, T. (2002). *Taking charge of you fertility: The definitive guide to natural birth control, pregnancy achievement and reproductive health* (revised edition). New York: Harper Collins.
- White, L. & McQuillan, J. (2006). No longer intending: The relationship between relinquished fertility intentions and distress. *Journal of Marriage and Family*, 68, 478-490.
- World Health Organization (1992). Recent advances in medically assisted conception. WHO technical report series, 820. World Health Organization, Geneva.
- Wortman, C.B. & Silver, R.C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, 57(3), 349-357.

## APPENDIX A

### Revised PCL-C

My name is Allyson Bradow and I am a graduate student at Spalding University in Louisville, Kentucky. I am conducting a research project as part of my graduate program in Clinical Psychology. The general goal of my research project is to investigate the psychological symptoms associated with infertility diagnosis and treatment. There are no direct benefits to your participation. I am asking if you would volunteer to participate in my research. Your participation will require you to answer questions related to your experience with infertility. I expect that it will require about 10-15 minutes of your time. The results from your participation will be anonymous. Your name will not, and cannot be associated with your data. No identifying information is asked for, and therefore cannot be linked to your data. In addition, all data will be presented in grouped form, and the results from any one individual will never be presented. I judge the risks to your participation to be minimal. An emotional response may be elicited from the questionnaire and the request that you think about a time that may have been emotional for you. If you should experience something that causes significant distress as a result of your participation, please discontinue the survey and seek mental health assistance in your area. For assistance in finding a referral, you may use one of the following links: <http://locator.apa.org> or [www.abct.org/Members/?m=FindTherapist&fa=FT\\_Form&no1m=1](http://www.abct.org/Members/?m=FindTherapist&fa=FT_Form&no1m=1) In addition, please contact me at any time if you have any questions regarding this research. My name and e-mail address are given below. I will assume your return of the completed questionnaire is an indication of your willingness to participate in this research, that you are sufficiently informed of what is expected of you, that you are aware of the level of risk and you know how to contact me if should you have questions. Please keep this form for future reference if needed. Investigator Contact Information:

Name: Allyson Bradow, MA, LPA      E-mail: [allysonbradow@spalding.edu](mailto:allysonbradow@spalding.edu)

1. I consent
2. I do not consent

Gender

1. Male
2. Female

I consider myself

1. Caucasian
2. African American
3. Asian
4. Hispanic
5. Other

My age is

1. <20
2. 21-30
3. 31-40
4. 41-50
5. >50

My relationship status is

1. Married
2. Partnered
3. Single
4. Other

The highest level of education I have completed is

1. GED
2. High school
3. Some college

4. Associates degree
5. Bachelors degree
6. Some graduate school
7. Graduate degree

My employment status is

1. Not employed
2. Part-time employment
3. Full-time employment

I approximate my household income to be

1. under \$25,000
2. \$26,000-\$40,000
3. \$41,000-\$70,000
4. \$70,000-\$120,000
5. \$120,000 or more

I have \_\_\_ child/children

1. 0
2. 1
3. 2
4. 3
5. 4 or more

My child/children are

1. Adopted
2. Biological
3. Both
4. Not applicable

I was able to conceive and carry a child to term prior to my infertility diagnosis.

1. Yes
2. No

I have changed partners since I was able to conceive and carry a child to term

1. Yes, I have a different partner
2. No, my partner is the same as the one I conceived with
3. I have never been able to conceive

How long did you try to conceive without intervention prior to seeking treatment?

1. 0-6 months
2. 7-12 months
3. 1-2 years
4. 2 or more years

How long did it take for the medical specialist to make a diagnosis?

1. Less than one month
2. Between 1-2 months
3. 2-4 months
4. 4-6 months
5. 6 or more months
6. They still have not made one

How long have you been receiving treatments/intervention for infertility? (if you are no longer pursuing intervention, please indicate how long you did receive treatment prior to stopping)

1. Less than one month
2. 1-3 months
3. 3-6 months
4. 6-9 months
5. 9-12 months
6. A year or more

What would you estimate you have spent on infertility diagnosis and treatment?

1. Under \$1000
2. \$1000-\$3000
3. \$3000-\$6000

4. \$6000-\$9000
5. Over \$9000

My healthcare provider whom I had the most contact and interaction with during diagnosis and/or treatment of infertility was

1. Male
2. Female

I would consider my healthcare providers temperament to be

1. Pleasant and helpful
2. Even tempered
3. Distant and disconnected
4. Unpleasant
5. Not sure

I felt that my healthcare provider understood my emotional experiences and was sensitive to my situation

1. True
2. False
3. Some of the time
4. Not sure

Instruction to participant: Think about your experiences with infertility diagnosis and treatment. Please read each question carefully and select which category accurately indicates if and how much you have had each experience in relation to infertility diagnosis and treatment.

1.

Repeated, disturbing memories, thoughts, or images related to infertility diagnosis and/or treatment?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Repeated, disturbing dreams related to infertility diagnosis and/or treatment?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Suddenly acting or feeling as if experience were happening again (as if you were reliving it)?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling very upset when something reminded you of infertility diagnosis and/or treatment?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Having physical reactions (e.g., heart pounding, trouble breathing, or sweating) when something reminded you of infertility diagnosis and/or treatment?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Avoiding thinking about or talking about, or avoid having feelings related to infertility diagnosis and/or treatment?

1. Not at all

2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Avoiding activities or situations because they remind you of infertility diagnosis and/or treatment?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Having trouble remembering important parts of infertility diagnosis and/or treatment?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Losing of interest in things that you used to enjoy?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling distant or cut off from other people?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling emotionally numb or being unable to have loving feelings for those close to you?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling as if your future will somehow be cut short?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Having trouble falling or staying asleep?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling irritable or having angry outbursts?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Having difficulty concentrating?

1. Not at all
2. A little bit
3. Moderately

4. Quite a bit
5. Extremely

Being “super alert” or watchful on guard?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling jumpy or easily startled?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Experiencing marital conflicts since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Having difficulty with other interpersonal relationships since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling less able to control your emotions or react like you used to since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Finding yourself doing things impulsively or without thinking since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling shameful since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling hopeless since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Withdrawing from other people and things that you used to enjoy since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit

5. Extremely

Feeling hostile since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling that your personality has changed since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Hearing or seeing things that were not there since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Feeling your beliefs about yourself and the world are different since diagnosis/treatment of infertility?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely

Prior to your experience with infertility, were you ever given a mental health diagnosis?

1. Yes
2. No
3. Rather not say

If yes, what diagnosis have you been given?

How did you hear about this survey?

Is there anything that you would like me to know about your experience with infertility or with this survey?

## APPENDIX B

### Open Ended Responses

1. I'm only 21, have been trying to conceive for almost 2.5 years, and have stage 2 endometriosis.
2. I wanted to let you know that my infertility and mental diagnoses were related--It seems both are linked to a thyroid disorder. I went to three different doctors (one PCP, one OB/GYN nurse practitioner, and my female gynecologist) before I requested a referral to an endocrinologist. The endocrinologist took one look at me and said, 'I think you have PCOS). If you want more information about my experience, I would be happy to talk to you. My email is hmrich01@louisville.edu.
3. my experience is very different from other because I attended a special support group for infertility and I am part of it yet  
I live in Argentina
4. There are not a lot of people to talk to a out feelings during treatment. It is almost as if it needs to be kept secret. Very difficult to work and receive treatment.
5. it is a very long and tiring journey - one that never really ends even after you have a child(ren). we now have a son via IVF/ICSI and 1 naturally 7 years later(a complete surprise since we have a very large male factor problem) and even though we only ever wanted 2 kids, i feel that the impact is never really over. it is a life long diagnosis no matter if you get what you want or not. speaking up for fertility issues will be something i continue to do.
6. that this process has been a cycle of continuous grief-especially when treatments didn't work. since we have decided to stop treatments an pursue adoption, I have begun to feel so much better and am getting to the place of acceptance that this is just the way it is for us and we WILL be parents someday. Thank you for doing this research b/c I often felt that people at the clinic ( not my doctor) were really unsure as how to encourage and support me.
7. Infertility is an important area of research and I'm heartened that people are charting this territory, especially with regards to the psychological aspect of the experience. Thank you for your work.
8. Wish we had more surveys/studies like this. It's such a personal topic, and difficult to discuss with others (friends, work, etc) and such an emotional drain. The other topic that no one has addressed is once the hurdle of infertility is overcome is selective reduction, a) the fertility clinics don't explain well, or it's just 1 sentence in the area of risks, due to the nature of fertility drugs to generate numerous eggs b) the patient is faced with reducing from multiples (quints, quads, triplets), to achieve a healthy pregnancy oftentimes the safest decision is a singleton (this is an extremely traumatic experience as conveyed by women on the selective reduction list in yahoo groups - it has destroyed marriages). Glad to be part of this survey.
9. My infertility is because of my age. I 'waited too long' but circumstances made it that way. Women/couples should be aware of the impact infertility has on your life, so don't wait too long. Just because women have babies in their late 30's and 40's doesn't mean it's always possible or easy. Not sure if this helps your research but wanted to put it out there.
10. We were dealing with secondary infertility and it was so painful. After 2+ years of tears, prayers, and doctoring, and surgery, we became pregnant with baby #2 all on our own and just found out last month. There is hope for others out there going through this same thing. Although I have overcome the odds, this experience has forever changed who I am. I never thought I'd be on the other side and now I'm on my way there with a baby on the way! God is good!
11. You may want to add a question about insurance coverage. People going thru infertility treatment pay a physical, emotional and financial toll. Those with coverage are spared at least one of these three. Also, the amounts paid are too low...over the course of 5 years we have spent close to 30K and have had one child as a result of treatment.
12. Our biggest frustration since our diagnosis of Secondary Infertility has been lack of financial/ insurance support. We've used upwards of \$20,000 from our retirement and still weren't pregnant. We want to be parents again so desperately and to give our son a sibling (we have 2 children, but our second son was stillborn). We've moved on to adoption because at least we know that when all is said and done, we will bring a child home. Thanks for your time and best of luck to you with your research. There's not enough, especially for secondary infertility.
13. Most people have spent well over \$9000 for fertility treatments. We have exhausted our medical benefit (\$15000 and \$7000) and paid about another \$2000 out of pocket.

You don't ask how long about the diagnosis was given or if the symptoms persisted the whole time. For example, we have been trying for another child for 2.5 years. Though most of my symptoms are controlled well, I'm still sobbing about once

every other day. I spend a lot of time thinking about how old each of my m/c children would be if they lived to term. It's exhausting.

I found 'Wanting another child' to be helpful and interesting and very applicable, but it's over 10 years old. Most of the recent books are about miracle conceptions and ways to torture your body into producing better eggs (though nothing is proven to work.)

Thank you for choosing this as a research project. I think most of the women that sadly fall into this group are silent and suffering.

14. I suppose the two are similar but I wouldn't say it is the diagnosis exactly that has caused reactions in me but rather not being able to conceive. If I'd never gone to a specialist and didn't have a diagnosis I would still be very upset that my efforts are not working. I try to think of myself as sub-fertile, rather than INFertile. I have many signs of fertility, just not conceiving or implanting. I did have one miscarriage.

15. it's isolating and numbing. If you allow yourself to feel it's hurt. It hurts to live with infertility. there are reminders everywhere. it's like a disability except it's invisible to the eye. it's like an open wound that no one can see.

16. My children are my husband's biological children. I used an egg donor.

17. I now have 2 precious daughters. 1st via IVF and the 2nd a miracle of natural conception. My youngest is 5 y.o. so I tried to answer your questions by reflecting back to that time. I think it was unclear how to respond if this was from the past but I did my best. I felt emotional traumatized from the experience and still feel that I wish I had a support group for mothers post-infertility. I don't think other mothers can truly understand the anguish that I suffered or the tremendous appreciation I feel. This also placed me in an older category of mothers so I often feel like a mis-fit since my energy level and health are compromised both due to age and the years of taking all of the medications, etc.. Best wishes w/ your research.

18. Your survey assumed people are partnered (married, actually, as you ask about marital discord and didn't give an option of 'I'm not married'--as a Single Mother by Choice, I went through infertility treatments without a partner and skipped those questions relating to partners.

19. I am almost 20 years post treatment, and we managed to build our family, however our infertility experience remains the defining aspect of our lives. It also helped to prepare us for dealing with other health challenges that we encountered along the way.

A lot of the extreme reactions I noted in the questionnaire were valid at the time of treatment and in the immediate years, but a lot of that has since faded away. I can remember the pain, but I don't feel it anymore - if that makes any sense.

20. It has been completely devastating and absolutely the hardest thing I have been through in my life.

21. It is very strainfull emotionally. Especially when you know you are the problem. Steps have been taking to resolve that problem and still you cannot get pregnant. Though, I am not at the end of the road yet. In the province of Québec, Canada (where I am), there is now a government plan that offers 3 free tries of IVF (In vitro fertilization). This will keep me sane, thinking that I still have a chance.

22. I am very happy you are doing this. I run a fertility support group and am very concerned that fertility patients are misunderstood. I did a lot of work to get over my severe depression. I have come a long way. I am now 10 weeks pregnant. You might be interested in my blog: [www.dirtteaforayear.com](http://www.dirtteaforayear.com)

23. Dr. Glass has great bedside manner and ran the most comprehensive tests that, in turn, led to a strategy that got me pregnant. Now that I have a 13 day old daughter, I feel that 5 years of relentless stress and anxiety has been distilled.

24. I had a child at 19 who I placed for adoption and have now had 2 IUIs gotten pregnant both times but the ended in miscarriage.

25. It completely changes who you are.

26. Took four years to conceive and carry a baby to term after - 2 miscarriages, SEVERAL 'procedures', 5 failed IUI's, 2 failed IVF's - she is our miracle baby conceived with no medical assistance!

27. Experience of infertility was more than 20 yrs ago. I had habitual Abs (DES exposure) and no treatment beyond clomid. All 7 pregnancies occurred unrelated to treatment. We adopted a newborn and I had one unplanned, spontaneous pregnancy/delivery.

28. My diagnosis & treatment was 7- 9 years ago, and our treatment was successful, so I feel very blessed and do not have too many negative things to say.

However, prior to - and during several courses of treatment (for 2yrs.) it was a painful, emotional struggle that consumed me.

29. I think it's important for the public to know that infertility does affect quality of life. Where I live our medical will pay for a sex change b/c of the psychological related issues but they won't pay for any fertility treatments b/c they see it as a 'choice' to have children.

30. I also deal with pregnancy loss (3 miscarriages) as well as infertility, and that affects me more than the infertility itself.

31. My infertility was related to pregnancy loss.

32. About 6 months after the loss of our son that died shortly after birth I began having some physical issues such as my hair falling out in handfuls, aches and pains, missing cycles and some other issues that I just kept putting off. I finally went to my general practitioner for what I thought was a UTI. She ran some tests and did some blood work and I didn't have anything wrong with me. I told her about the other thing that were happening to me and she then diagnosed me with Adult Stress Response. I was put on antidepressants for about 8 months and things are much better now! We have since adopted a child and are trying to move on to the next chapter of our lives. Hope this helps! Good Luck :)

33. I actually had two separate bouts with infertility. The first was diagnosed in late 2006 after an early miscarriage in 2005. I was diagnosed with PCOS, and was given fertility drugs to help us conceive our daughter.

The second bout with infertility came in 2009 after two miscarriages, one being a set of twins. My husband and I went through thousands of dollars in genetic testing, which thankfully, showed all was normal. It wasn't until I had an x-ray type procedure of my ovaries that it was discovered that one of my fallopian tubes was partially blocked. I ended up getting pregnant after this procedure and now have a healthy little boy.

Thank you for taking the time to research such an important topic. We need more awareness in the area of infertility and miscarriage/fetal loss.

34. I had three miscarriages and was sent to an IS by my OB/GYN for further treatment. However, because I could not become pregnant, my insurer refused to consider me infertile and would not cover infertility treatment and we abandoned our course of action. After two more miscarriages, we successfully conceived and carried three pregnancies to term with no intervention. I did not have a good experience, but not because of the doctors involved. I don't think infertility can ever be easy, particularly when pregnancy or infant loss is involved.

35. Thank you for recognizing how difficult it can be.

36. I have not only gone through and am currently going through fertility treatments, but have also suffered the loss of my first and only child. I lost her when I was 22 weeks pregnant. I am sure this plays a role in my feelings about infertility.

I also experienced the death of my newborn prior to my experience with infertility, so I believe my responses indicate feelings of grief over her death as well as the grief of dealing with infertility.

37. There is an empty, useless and sad feeling in my heart every day. Some days I feel stronger and 'normal' but little everyday things ...walking in a store, passing the baby section or a pregnant woman, a diaper commercial etc. will set me off and I'll feel heart broken all over again. This has been going on for over 15 years with me.

38. One of the most helpful things is having people to talk to that have also experienced or are experiencing infertility. It is so helpful to know you are not alone in the way you are feeling and thinking. It is also helpful to know it is normal for thinking and feeling those things.

39. Infertility consumes you, changes you and your partner. Once we had my daughter and a natural conception 15 months later it was like we got our life back. We struggled with infertility for nearly 5 years. I went from a size 8 to 14 because of the drugs and I was counselling teen Mothers during the last part of my treatment. I counsel others going

through the process because I have walked in their shoes and know what it is like to be afraid and overwhelmed.....and poor as a result!!

Good luck with your paper :) If you have any questions please dont hesitate to contact me at sprouts@rogers.com

40. I have a 6 and a 7 year old (both conceived after the first try) and was unable to conceive until a hysterosalpingogram in Dec 2009. I lost that pregnancy 6 weeks later and became pregnant again in April and lost that pregnancy at 19 weeks.

41. Maybe how people who have been diagnosed and have no children at all How they react when friends/family have babies.

42. I was able to give birth through embryo adoption to twins and we have a child through international adoption

43. My experience ended with a hysterectomy. After trying medications and a ton of birth control to re-regulate my system. It didn't matter. The hysterectomy was only way to

Deal with non stop bleeding and submucosal fibroids x3 very large.

44. I am still trying to conceive, all hope is not lost acc to my RE. I have not undergone treatment (IVF, IUI) because I DO get pregnant but I have miscarried 3 times. My RE has added meds to my regimen because of clotting disorder and low folic acid with hopes that it may improve my egg quality for implantation and improve the environment for implantation.

45. It's possible that since I've ALWAYS known I would not be able to conceive on my own that it's made it easier to come to terms with. I imagine it being very difficult to find out suddenly that there was a problem and have no time to process it.

46. Its a emo roller coaster ride

47. Good luck

48. Yes, my wife and I found out that I was infertile about 2 years ago. After a few failed donor attempts, we put everything on hold. About 4 months ago my wife had an affair and we are now seperated.

49. I find myself so sad and angry. I have several friends who were 'infertile' for a year or two... and then had babies. I can never become pregnant. My uterus is messed up. And I get so angry when these people WHO HAVE CHILDREN tell me they know just how I feel because they've been through it. Yes, they've been through it, but they came out the other side as parents. I'm nothing. And I never will be anything.

50. We were pleased to finally have a diagnosis and plan. We were happy to hear that we needed IVF after trying for 2.5 years with no diagnosis. Our official diagnosis brought us relief and hope.

51. I was diagnosed with unexplained infertility, but refused to go down the path of IVF. Acupuncture and Traditional Chinese Medicine (herbs) worked for me, and I got pregnant naturally.

52. I have one son via my 3rd IVF after 3 miscarriages. I feel very lucky to have him. We have done 3 more IVF since he was born but none took. We are going to be doing the Egg Donor route next month. I think you should be asking questions regarding what someone has tried in the past as it will better give you perspective on the answers. my answers would have been different 3 yrs ago. my perspective has changed, I am not angry or much less so. I am not as anxious as I was when I first started treatments almost 4 yrs ago. I think that as you go thru the steps and make friends and talk the sting hurts less. I have more concerns now about what I am going to tell my child/ren when the time comes.

I wish you the best. if you want to ask me anything you can email me at redrubyfruit@gmail.com

53. You asked a lot of questions about emotions. I would have to say that a lot of those emotions are influenced by the drugs and hormones you are on.

54. I am currently in my 25th cycle of trying to conceive. I was diagnosed with a uterine septum, which has been surgically corrected. I am currently in my 4th cycle post-surgery and am currently diagnosed as having 'unexplained infertility.' I will now be moving on to IUI in addition to the Clomid. I am a Type A personality, and I feel that this whole process is throwing me for a loop because I can't control it.

55. I think in all of ways it is hard to deal with infertility especially after having a failed IVF, I thought no one understood. Since I do have one child that was conceived after almost 2 years of infertility treatment and 1 out of pocket IVF, I do know that it has made me a better parent and person!

56. I was blessed with a son from a natural pregnancy, while waiting to start my third ivf. During the 2.5 years of trying for him, I definitely had suicidal thoughts (if I can't have a child, why keep living). I still have a hard time dealing with women who easily get pregnant, even having now been successful.

57. Only fertility problem me and my husband have so far that I know is that we have both been fixed. Had one round of ivf which ended in a chemical pregnancy and miscarried. Starting another round of fet.

58. I got pregnant with my first IVF and lost the baby traumatically at 17wks. I went through 2 additional cycles 1 - had a chemical pregnancy and 1 - resulted in DD. I have attempted 4 cycles since my DD to get pregnant again with no luck.

59. I had a brain tumor, major surgery, and months of radiation. No longer have a working thyroid or pituitary. Told I would never get pregnant. Got pregnant with my daughter without trying - no birth control since I hadn't had a period in two years anyways. Decided we wanted another, but no go after nearly a year. Spoke to my doctor and my Endocrinologist - they frankly have no idea how or why I got pregnant the first time. Clomid 1 round with no ovulation. Now on my first round of Femara (2.5 cd 3-7) + Follistim (50 IU cd 8-12). Waiting to see if I ovulate (it is currently cycle day 11).

60. husband has ptsd from combat,

61. I have twins from previous infertility treatments and am still experiencing the same issue this time as well.

62. Even though you are just looking for how people have reacted to infertility, maybe knowing what is the reason behind it, and or what led to the infertility might help with the overall study. Where some might show less stress related outcome due to none production of eggs, compared to those who have gone through several rounds of IUI, IVF and no pregnancy in the end.

63. I was able to successfully conceive after my first IVF treatment. While thrilled and so grateful, I am still concerned about my future fertility. I don't know if I will ever be able to conceive a child naturally or if I will ever be able to have another child at all. Even when 33-weeks pregnant, I am still bothered by my 'unexplained infertility' diagnosis.

64. This question:

I have changed partners since I was able to conceive and carry a child to term

Yes, I have a different partner

No, my partner is the same as the one I conceived with

I have never been able to conceive

Doesn't take into account miscarriage or prior abortion in the answer choices. A woman may have been able to conceive without having carried a child to term.

65. I answered these questions based on my first experience with fertility treatments in 2007. I conceived a son in October of 2007. He was born in June of 2008. I have just completed another round of diagnosis and treatments. I am in my 2 week wait from our last round of IVF.

66. Thank you for doing this.

67. There are some gaps in this survey. I am by no means mental or defined by my diagnosis. I have emotional ups and downs and it has colored how I view the world and my interactions in it. Infertility takes a toll on a marriage. It can bond you forever while at the same time doing damage to intimacy. Gone are the days of making love just for the sake of it. It becomes a business and is no longer a way to feel connected to your partner. To truly look at the emotional effects of infertility these are things that need to be considered.

68. Switched infertility dr's after 4 years. Love the Dr I am seeing now!!

69. People struggling with infertility need to have this medical disorder recognized in society as a MEDICAL not a personal problem; particularly by insurance companies. I always imagined creating offspring to be very intimate and private. Infertility strips that from couples. We were poked, prodded, and were actually in separate rooms when our embryos were implanted -- far from intimate.

70. I'm glad you're researching the effects of IVF/Infertility on the mental health of individuals who have gone through this. As a veteran of infertility treatments, IVF and a successful adoption, I feel that society overlooks the painful journey and trials that those of us struggling with trying to conceive deal with on a day to day basis. Sensitivity is generally low, not just in the medical community, but in society as a whole--particularly the workplace.

71. Have endometriosis stage 4 and have tried IVF once with no success. We are going to adopt and try IVF once more within the next few months.

72. But through all the grief of infertility, I was able to conceive and carry almost to term a set of healthy twin boys.

73. Going through this healthcare system sucks!! people need to have a heart. Insurance companies are the devil and so are companies that don't pay for infertility. I had a lady compare my procedures to a facelift today, are you kidding me?!?!?

74. A lack of required Infertility coverage WITH IVF coverage in all but 15 states causes financial stress for those of us without the coverage. If money were not an issue, then this 'journey' would be so much easier to handle.

75. We had a miscarriage and things just got harder for us after losing our baby.

## BIOGRAPHY

Allyson Bradow earned her undergraduate degree in Psychology from the University of Louisville in Louisville, Kentucky, where she graduated *cum laude* in 2000. She worked for Maryhurst, a local non-profit agency until 2002, when she matriculated at Spalding University. Allyson earned her Master's degree in Clinical Psychology in 2002. She then worked for The Home of the Innocents until 2005, when she returned to Spalding University to complete her doctorate degree in clinical psychology. This dissertation is a result of her own journey with infertility. Allyson lives in Louisville, Kentucky with her husband and two children, and continues to work at The Home of the Innocents.