

**THE EXPERIENCES OF WOMEN WHO RECEIVED REPRODUCTIVE
ENDOCRINOLOGY TREATMENT FOR INFERTILITY**

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of Doctor of Philosophy
in Clinical Psychology
Specialty in Prenatal and Perinatal Psychology

by
Ann Diamond Weinstein

Santa Barbara Graduate Institute
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This is to certify that the dissertation entitled:

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Approved by:


Bobbi Jo Lyman, PhD, Chairperson

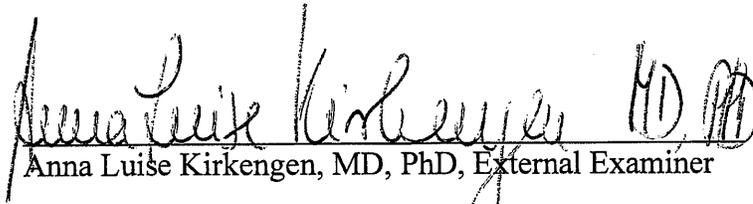
7/29/10
Date


Valerie Malhotra Bentz, PhD, Committee Member

8-29-10
Date


Michael Shea, PhD, Committee Member

8/3/10
Date


Anna Luise Kirkengen, MD, PhD, External Examiner

8/9/10
Date

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Abstract

The Experiences of Women Who Received Reproductive Endocrinology Treatment for Infertility

Ann Diamond Weinstein

2010

This study examined the experiences of women, with and without traumatic stress and/or dissociative symptoms, who received reproductive endocrinology treatment for infertility. Research in traumatology, psychology and medicine demonstrates the psychobiological impact of posttraumatic stress symptoms on bodily systems (Bremner, 2005; Scaer, 2007; van der Kolk, McFarlane, & Weisaeth, 1996; Vermetten & Bremner, 2002; Yehuda, 2002). The impact of posttraumatic stress symptoms on psychoneuroendocrine, immune system and vasomotor functions may also impact reproductive processes including conception, which are dependent upon complex processes within, and interactions between, these same bodily systems (Cwikel, Gidron, & Sheiner, 2004; Ferin, 1999; Gallinelli et al., 2001; Norwitz, Schust, & Fisher, 2001; Porges, 1998; Staun-Ram & Shalev, 2005; Wadhwa, 2005). Insight into the lived experience of, and relationship between, infertility, its treatment and traumatic stress was gained through a phenomenological study of the question, “What are the experiences of women, with and without self-reported trauma symptoms, who have received reproductive endocrinology treatment for infertility?”

Six participants in the Greater New York area between the ages of thirty-two and fifty-three explored the multidimensional aspects of their reproductive endocrinology treatment experiences for infertility in face-to-face interviews. Participants who received treatment from reproductive endocrinologists were screened for current or recent symptoms of traumatic stress consistent with DSM-IV-TR (American Psychiatric Association, 2000) criteria for posttraumatic stress disorder and dissociative symptoms.

Participants were not required to identify a specific traumatic event to allow for the inclusion of those whose symptoms may have originated in experiences of which they may have had no explicit memory. Of the six volunteers who participated in the study, four reported traumatic stress and/or dissociative symptoms on the self-report screening tools.

A thematic analysis (Moustakas, 1994) of the interview transcripts revealed six themes that describe the participants' lived experiences of reproductive endocrinology treatment and the impacts of these experiences on their lives. The discussion includes an interpretative phenomenological analysis (Larkin, Watts, & Clifton, 2006) of the results and their implications for clinical practice.

The insights gained from this study provide a basis for further research on the quality of health care provider-patient interactions and additional support services that may positively impact the psychophysiological responses of women to reproductive endocrinology treatment for infertility. The application of this knowledge to clinical practice may enhance treatment outcomes.

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Chapter 1: Introduction

It is estimated that 12% of women in the United States (U.S.), ages 15-44, have difficulty getting pregnant and/or carrying babies to term according to the 2002 National Survey of Family Growth (Chandra, Martinez, Mosher, Abma, & Jones, 2005, p. 2). The use of reproductive endocrinology treatment involving assisted reproductive technology (ART) procedures to treat infertility has increased steadily since 1978, when the first live human birth following in vitro fertilization (IVF) treatment was reported in England (Step toe & Edwards, 1978). The U.S. Centers for Disease Control and Prevention's 2006 Assisted Reproductive Technology (ART) Report, Section 5 (published in 2008) documents the increase in the performance of assisted reproductive technology procedures, as well as treatment outcomes for the years 1996 through 2006:

The number of ART cycles performed in the United States has more than doubled, from 64,681 cycles in 1996 to 138,198 cycles in 2006. The number of infants born who were conceived using ART also increased steadily between 1996 and 2006. In 2006, 54,656 infants were born, which was more than two and a half times the 20,840 born in 1996. (CDC, 2008, p. 61)

The International Committee for Monitoring Assisted Reproductive Technology's 7th World Report demonstrates the prevalence of ART procedures worldwide. The report analyzed data from 49 countries around the world that provided information on over 460,157 ART cycles performed in the year 2000. Based on the information received by the committee, the report states, "the total number of babies conceived through ART in the year 2000 may be estimated to be between 197,000 to 220,000" (Adamson, de Mouzon, Lancaster, Nygren, and Sullivan, 2006, p. 1607).

Due to the fact that reporting requirements vary from country to country, these statistics may provide an incomplete representation of the total number of women and children worldwide whose lives have been directly impacted by these treatment experiences.

There is a growing concern about the psychological impacts of infertility and its treatment on women (Benyamini, Gozlan, & Kokia, 2005; Demyttenaere et al., 1998; Edelmann & Connolly, 1998; Eugster & Vingerhoets, 1999; Fassino, Piero, Boggio, Piccioni, & Garzaro, 2002; Greil, 1997; Kee, Jung & Lee, 2000; Lee, Sun, & Chao, 2001; Merari, Feldberg, Elizur, Goldman, & Modan, 1992; Smeenk et al., 2001; Verhaak, Smeenk, van Minnen, Kremer, & Kraaimaat, 2005), and the increasing health costs of reproductive endocrinology treatment (Katz, Nachtigall, & Showstack, 2002). Research in reproductive endocrinology has begun to reveal the negative impact of stress on fertility, including stress resulting from the infertility treatment process itself (Boivin & Schmidt, 2005; Cwikel, Gidron & Sheiner, 2004; Eugster & Vingerhoets, 1999; Eugster, Vingerhoets, van Heck, & Merkus, 2004; Ferin, 1999; Gallinelli et al., 2001; Kloneff-Cohen, Chu, Natarajan, & Sieber, 2001). Recent studies have indicated that stress and negative psychological states impact infertility treatment outcomes (Boivin & Schmidt, 2005; Cwikel et al., 2004; Eugster & Vingerhoets, 1999; Eugster et al., 2004; Facchinetti, Mateo, Artini, Volpe, & Genazzani, 1997; Kloneff-Cohen et al., 2001; Smeenk et al., 2005).

Research in the field of psycho-neuro-immuno-endocrinology provides insight into the biological mechanisms—specifically the neuro-immuno-endocrinological pathways—that link psychological factors and conditions with infertility (Cwikel et al., 2004; Ferin, 1999; Gallinelli et al., 2001; Norwitz et al., 2001; Porges, 1998; Scaer, 2001,

2007; Staun-Ram & Shalev, 2005; Uvnas-Moberg, 2003). Studies in reproductive endocrinology have not differentiated between the effects of stress and traumatic stress on fertility. Traumatic stress, which results from a single or several traumatic events, can lead to the development of the chronic symptoms of posttraumatic stress disorder (PTSD) (Bremner, 2005; Scaer, 2001, 2005; van der Kolk et al., 1996; Vermetten & Bremner, 2002; Yehuda, 1999, 2002; Yehuda, Giller, Levengood, Trestman, & Siever, 1995). Yehuda and Davidson (2000) state that the distinction between chronic stress and traumatic stress is that removal of chronic stress alleviates stress symptoms, but they point out that PTSD symptoms “associated with exposure to trauma continue even decades after the event has passed” (p. 15).

Bremner (2005) acknowledges the distinction between the impacts of stress, posttraumatic stress disorder, the neurological effects of trauma, and the recent research suggesting that the specific deleterious effects of PTSD on bodily systems increases a person’s risk for various diseases related to the cardiovascular, endocrine, gastrointestinal, pulmonary and immune systems (p. 272). The recent evidence of the relationship of PTSD to conditions connected with a wide range of bodily systems suggests the possibility that other conditions not yet studied, including infertility, may be impacted by the unique psychophysiological disturbances associated with PTSD symptoms, as differentiated from those psychophysiological disturbances associated with stress.

Statement of the Problem

Research demonstrates that a substantial number of women experience trauma in their lifetime (Breslau et al., 1998; Resnick, Kilpatrick, Dansky, Saunders, & Best, 1993) and most often, before or during the childbearing years (Kilpatrick, Edmonds &

Seymour, 1992; Seng et al., 2001; Tjaden & Thoennes, 1998). There is a significant rate of reported PTSD in this population (Breslau et al., 1998; Resnick et al., 1993; Kilpatrick et al., 1992)—despite the fact that some women are unwilling to disclose their trauma histories to providers (Plichta & Falik, 2001; Seng, Sparbel, Low & Killion, 2002; Grimstad & Shei, 1999). This suggests that a significant cohort of women who are being treated for infertility may also suffer from the effects of past trauma as manifested in traumatic stress symptoms.

A review of the literature has revealed a lack of English language studies that offered the opportunity to women to provide in-depth explorations of their multifaceted mind-body experiences of infertility treatment. There is a particular dearth of studies addressing the issues of women who have experienced traumatic stress symptoms. Research by Allard, Sejourne, and Chabrol (2007) focuses on women's experiences of IVF procedures, but their work, published in French, is not available in English at this time. A study conducted by Benjamin and Ha'Elyon (2002) focused on women's experiences of pain during IVF treatment. Other researchers have focused on women's experiences during unsuccessful infertility treatment (Bergart, 2000) and in the years following unsuccessful treatment (Johansson & Berg 2005; McCarthy, 2008; Wirtberg, Möller, Högstrom, Tronstad, & Lalos, 2007). Comerford, Devine, and Semelsberger (2003) explored women's experiences of miscarriage after infertility treatment.

There is a gap in the literature on the infertility treatment experiences of women who report traumatic stress symptoms, which limits the opportunity for health care providers and partners to learn how best to meet the unique needs of these women before, during, and after reproductive endocrinology treatment. There is also a scarcity of

literature on the infertility treatment experiences and pregnancy and postpartum experiences of women who have successful treatment outcomes.

Research and Theory Guiding This Study

Reproductive Processes and the Psychobiology of Trauma

Medicine, traumatology, and prenatal and perinatal psychology each contribute to our current understanding of the complex psychophysiology of both posttraumatic stress and infertility and provide insight into the possible link between these two conditions. Current understanding in reproductive endocrinology of the biological mechanisms that link stress and infertility provides a foundation for the consideration of the unique psychobiological mechanisms underlying posttraumatic stress symptoms and the possible link between these specific mechanisms and infertility.

Posttraumatic stress symptoms are associated with psychobiological effects on systems in the body that play crucial roles in the regulation of stress and trauma, particularly the autonomic nervous system (ANS). Our current understanding of the deleterious long-term impact of posttraumatic stress on the mind and body includes evidence of changes in the psychoneuroendocrine, immune, and vasomotor systems (Bremner, 2005; Scaer, 2001, 2005; van der Kolk et al., 1996; Vermetten & Bremner, 2002; Yehuda, 1999, 2002; Yehuda et al., 1995; Yehuda, Teicher, Trestman, Levengood, & Siever, 1996). These same systems also play crucial roles in conception and the ability to sustain a pregnancy (Cwikel et al., 2004; Ferin, 1999; Gallinelli et al., 2001; Norwitz et al., 2001; Staun-Ram & Shalev, 2005; Uvnas-Moberg, 2003). Therefore, reproductive system functions, including the ability to conceive, may be affected by the psychobiological disturbances associated with posttraumatic stress symptoms. Our current understanding of the stressful impact on many women of the infertility treatment

process itself (Benyamini et al., 2005; Boivin & Schmidt, 2005; Cwikel et al., 2004; Eugster & Vingerhoets, 1999; Eugster et al., 2004; Kloneff-Cohen et al., 2001; Smeenk et al., 2005) suggests that this process may exacerbate posttraumatic stress symptoms in some women thereby impacting treatment outcomes.

The Importance and Impact of the Experiences of Women and Their Offspring Around the Time of Conception

In addition to theory and research that link the biological mechanisms involved in stress, trauma, and reproductive processes, this study is also based on theory, research, and practice in prenatal and perinatal psychology. Researchers, theorists, and clinicians in prenatal and perinatal psychology stress the importance of our earliest experiences and relationships and their potential long-term impacts, including our experiences around the time of conception (Castellino, 2000; Chamberlain, 1998; Emerson, 1997, 2000; McCarty, 2002, 2004; Peterson, 1994; Verny & Weintraub, 2002). The focus of prenatal and perinatal psychology encompasses a woman's experience of attempting to conceive a child through reproductive endocrinology treatment. Researchers and clinicians in the field (Castellino, 2000; Chamberlain, 1998; Emerson, 1997, 2000; Lipton, 2005; McCarty, 2002, 2004; Simkin & Klaus, 2004; Verny & Weintraub, 2002; Petersen, 1994) recognize that a woman's experience of attempting to or actually conceiving may be impacted by her own prenatal experiences.

Recent research in behavioral perinatology supports theory and research in prenatal and perinatal psychology by providing insights into the relationship between maternal psychophysiological states during pregnancy and the physiology, development, health, and behavior of the fetus, neonate, and infant (Field, Diego, Dieter et al., 2004; Field, Diego, Hernandez-Reif, Gil, & Vera, 2005; Field, Diego, Hernandez-Reif,

Schanberg et al., 2004; Wadhwa, 2001; Wadhwa et al., 2002; Wadhwa, 2005). Wadhwa (2005) emphasizes the particular significance of the early maternal-fetal psychophysiological relationship and provides insight into the impact of maternal psychoneuroendocrine processes, including those associated with stress in early pregnancy, on fetal development and health: “The effects of early experience have longer-lasting and more permanent consequences than those later in life” (p. 724). This research suggests that environmental impacts on a woman’s psychoneuroimmunoendocrinological processes during and after conception may influence her child’s long-term health and well-being. This highlights the importance of exploring women’s mind-body experiences around the time of conception and early pregnancy to enable us to gain a deep understanding of the impact of these experiences on women, as well as insight into how their psychophysiological states during and after conception may potentially influence the development, health and behavior of their offspring.

Wadhwa suggests a gap in the prenatal and perinatal psychophysiological research that this study begins to address:

We are not aware of any studies that have examined stress and stress biology processes in women before they became pregnant to track the physiological and psychosocial transitions from nonpregnant to pregnant state, and we suggest this is an important direction in order to better understand individual vulnerabilities for the adverse effects of prenatal and perinatal stress. (Wadhwa et al., 2002, p. 155)

Research by Khashan et al. (2009) also begins to address this gap in the literature. Their research demonstrates an association between experiences of stress/trauma before

conception and preterm birth: “Our population-based cohort study suggests that maternal exposure to severe life events, particularly in the 6 months before pregnancy, may increase the risk of preterm and very preterm birth” (2009, p. 1).

For each woman, what constitutes a “severe life event” is ultimately defined by her personal experience of that event. Exploring women’s experiences of reproductive endocrinology treatment for infertility provides us with an opportunity to understand the significance of these events in their lives, and thus the potential of these events to impact women’s attempts to conceive, the course of their pregnancies if they do conceive, and the health and development of their offspring if they sustain a pregnancy to term.

Recent research in the field of epigenetics further demonstrates the importance of understanding women’s psychophysiology around the time of conception and specifically conception through ART. Epigenetics is defined as “the study of heritable changes in gene expression that are not due to changes in DNA sequences (Eccleston, DeWitt, Gunter, Marte, & Nath, 2007; Feinberg, 2007).

Thompson, Kind, Roberts, Robertson, and Robinson (2002) expressed specific concerns about the epigenetic risks involved in ART. The authors propose that “environment-induced cellular stress” including a “less than optimal physiochemical environment in early life, acts to modify fetal and placental gene expression” (p. 2783). The authors raise the important question of “whether alterations in fetal development resulting from ART, could lead to an increased risk of adult disease” (Thompson et al., 2002, p. 2784). This also raises the issue of whether the external stress of undergoing ART treatment impacts the “physiochemical environment” in a woman, in a way that induces cellular stress for her egg cells and embryos.

Purpose of the Study

The purpose of this study was to explore women's experiences to gain a deep understanding of the multidimensional impacts of attempting to conceive through reproductive endocrinology treatment in light of its widespread and increasing utilization, and the potential for the experience of undergoing ART treatment to trigger or exacerbate psychophysiological symptoms that may continue for years after treatment ends. The potential for these symptoms to impact women's relationships with any children they may have was another factor that supported the exploration of these experiences.

Some women experience an exacerbation of their symptoms while coping with the stress of infertility and its treatment, including exams, medications, tests, and procedures. Some have had traumatic stress symptoms in the past that have abated, but experience a reoccurrence of those symptoms in anticipation of, during, and after treatment. Some develop traumatic stress symptoms for the first time as they become overwhelmed by the challenges they face trying to conceive and sustain a pregnancy through reproductive endocrinology treatment. The in-depth exploration of women's experiences considered in the context of research and theory in prenatal and perinatal psychology, traumatology, and medicine illuminates the multifaceted impacts of reproductive endocrinology treatment which, to date, have not been fully understood. In addition, insights gained from this study can inspire consideration of how adaptations can be made in the way care is provided to women to better meet their needs at this challenging time, reduce the negative impacts of these experiences, and potentially enhance positive outcomes for women and their families.

Research Question

Using a phenomenological approach, I conducted a qualitative study to answer the question, “What are the experiences of women, with and without self-reported trauma symptoms, who have received reproductive endocrinology treatment for infertility?” I was interested in understanding the nature of the participants’ experiences through the verbal and non-verbal communication of their thoughts, beliefs, emotions, sensations, experiences of their bodies in space in the treatment environment, and meanings they attached to these experiences before, during, and after treatment. I was interested in understanding how women’s beliefs and perceptions shape their experiences of infertility and its treatment and, in turn, how their experiences of infertility and its treatment shape their perceptions and beliefs about themselves.

I was also interested in understanding women’s perceptions of the interpersonal dynamics that may be present, spoken or unspoken, in the interaction between themselves and their health care providers while undergoing infertility treatment procedures. These procedures often require women to be in close physical proximity with health care providers in vulnerable body positions that in contexts outside of the medical setting could be associated with intimacy, but within the context of the medical environment, are usually not reflections of an intimate relationship. I was interested in understanding women’s experiences of this “intimacy that is not intimate” (V. M. Bentz, personal communication, April 1, 2005), particularly as it relates to the environment in which conception is attempted in infertility treatment.

My decision to use a phenomenological approach for this study was based on the understandings I gained from several perspectives: prenatal and perinatal psychology; traumatology; phenomenology—particularly feminist phenomenology—and the work of

practitioners and authors specifically concerned with the provision of health care to women. Each perspective has made an essential contribution to my conceptualization of this study, and no doubt, has shaped the descriptions shared with me by the study participants and my understanding of them.

Researchers, theorists and clinicians in prenatal and perinatal psychology (Castellino, 2000; Chamberlain, 1998; Emerson, 1997, 2000; Lipton, 2005; McCarty, 2002, 2004; Petersen, 1994; Schore, 2002, 2003a, 2003b; Verny & Weintraub, 2002) and traumatology (Bremner, 2005; Herman, 1992, 1997; Levine, 1997; Perry, 1999; Rothschild, 2000; Scaer, 2001, 2005; Schore, 2002, 2003a, 2003b; Simkin & Klaus, 2004; van der Kolk et al., 1996; Vermetten & Bremner, 2002; Yehuda, 1999, 2002; Yehuda et al., 1995; Yehuda et al., 1996) provided insight into the importance of understanding the impact of trauma and a person's earliest experiences on his or her life.

Researchers and theorists in phenomenology (Behnke, 2003; Belenky, Clinchy, Goldberger & Tarule, 1986; Bentz, 2003; Clark & Mishler, 1992; De Beauvoir, 1952; Fisher & Embree, 2000; Gilligan, 1991, 1993; Husserl, 1970; Irigaray, 1991; Kirkengen, 2001, 2008; Levesque-Lopman, 1988, 1993, 2000; Moustakas, 1994; Paget, 1990; Schutz, 1970; van Manen, 1990; Young, 2005; Zaner, 2003) and women's health care (Jordan, 1997; Kirkengen, 2001; Kitzinger, 1997; Malin, Hemminki, Räikkönen, Sihvo, & Perälä, 2001; Simkin & Klaus, 2004), acknowledge the multidimensional impacts of human experience on the lived-body and the importance of reflecting on these aspects of our experiences to gain a deeper understanding of them. A phenomenological methodology supported a multidimensional exploration of these experiences.

Marks and Yardley (2004), comment on the unique quality, appropriateness, and "key advantage" of using phenomenology in clinical and health psychology research:

Phenomenology foregrounds the experience of the individual, and thus provides a ‘space’ or a ‘voice’ for the lived experiences of different people, which are not adequately represented or analysed by methods which aggregate the statistics from large samples, such as randomized controlled trials or epidemiological surveys. (p. 71)

The work of Paget (1990), Toombs (1993), and Zaner (2003), addressing the doctor-patient clinical encounter, also supports the use of a phenomenological approach for this study, which focuses on the exploration of doctor-patient clinical encounters in the treatment of infertility.

Each of the perspectives mentioned above values the voice of the individual and in the case of feminist phenomenology, the unique voices and experiences of women (Belenky et al., 1986; Bentz, 2003; De Beauvoir, 1952; Gilligan, 1991, 1993; Irigaray, 1991; Levesque-Lopman, 1988, 1993, 2000; Paget, 1990; Young, 2005). The work of these authors and those concerned with women’s health care (Herman, 1992, 1997; Jordan, 1997; Kirkengen, 2001, 2008; Kitzinger, 1997; Malin et al., 2001; Simkin & Klaus, 2004) supports my view that women’s voices and words, when shared and respected as a source of authoritative knowledge of their lived experiences, may have a positive and potentially healing impact on the women who share them and be a unique source of insight and understanding that can inform and improve the care provided to women.

All of the participants in this study were involved in a process that is physiologically unique to women—the process of conceiving a child with the assistance of reproductive endocrinology treatment. In-depth descriptions offered and shared by the women participants in an atmosphere of acceptance and respect have provided us with a

deeper understanding of these experiences (Behnke, 2003; Bentz, 2003; Bentz & Shapiro, 1998; Clark & Mishler, 1992; De Beauvoir, 1952; Husserl, 1970; Kirkengen, 2001, 2008; Levesque-Lopman, 1988, 2000; Malin et al., 2001; Merlau-Ponty, 1958; Moustakas, 1994; Paget, 1990; Schutz, 1970; Young, 2005; van Manen, 1990; Zaner, 2003). These include descriptions of women's internal psychophysiological experiences that may have been influenced by traumatic stress symptoms as they interacted with the external physical environment of reproductive endocrinology treatment for infertility.

Working Definitions

The following definitions are provided to clarify the terminology used throughout this study.

Assisted Reproductive Technologies (ART): ART includes all reproductive endocrinology treatments that involve the handling of eggs and/or embryos, including in-vitro fertilization-embryo transfer (IVF-ET), gamete intrafallopian transfer (GIFT), zygote intrafallopian transfer (ZIFT), tubal embryo transfer (TET), and frozen embryo transfer (FET). ART also includes procedures used in oocyte donation and “gestational carriers”—instances where a woman volunteers to carry a pregnancy for another woman who is unable to conceive and/or carry a pregnancy to term (SART, 2008, Assisted Reproductive Technologies section, para. 1). “During IVF-ET, ZIFT, and TET, the oocytes and sperm are combined in a culture dish in the laboratory. Fertilization and very early embryo development occur outside the body, rather than in the fallopian tube. Once early embryo development is recognized, the embryos are transferred either into the uterus (IVF-ET) or the fallopian tube (ZIFT, TET). IVF-ET is the only procedure available for women with damaged fallopian tubes” (SART, 2008, Assisted Reproductive Technologies section, para. 2).

Behavioral Perinatology: As defined by Wadhwa et al., (2002), “an interdisciplinary area of research that involves conceptualization of theoretical models and conduct of empirical studies of the dynamic time-, place-, and context-dependent interplay between biological and behavioral processes in fetal, neonatal, and infant life using an epigenetic framework of development” (p. 150). This encompasses the study of the impacts of maternal psychophysiological states, including stress/trauma, prior to conception, during pregnancy, and after birth.

Infertility: The inability to conceive or carry a pregnancy to term after one year of unprotected intercourse and/or attempts to conceive through assisted reproductive technologies. This allows for the inclusion of women who choose to conceive using donor sperm and/or eggs and do not engage in intercourse to do so.

Phenomenological Research: The study of lived experience aimed at gaining a deep understanding of the nature and meaning of an experience (van Manen, 1990, p. 9), as expressed and communicated to the researcher by study participants.

Prenatal and Perinatal Psychology: The interdisciplinary study of the earliest periods in human development including conception, time in the womb, experiences during and after birth, including those with caregivers and the family system through the first year following birth. Theory and research in embryology, behavioral perinatology, neurobiology, attachment, trauma, psychology, and medicine provide the foundation for the exploration of how experiences during this developmental period impact an individual physically, cognitively, socially, emotionally, and spiritually and create enduring response patterns that impact development, behavior and health over the lifespan of the individual. This definition combines concepts from the Association for

Prenatal and Perinatal Psychology and Health (2009), McCarty (2000), Noble (1993) and Odent (2002).

Psychophysiology: The scientific study of “the interrelationships between the physiological and psychological aspects of behavior. Allied disciplines include psychology, physiology, neuroscience, medicine, and engineering” (Society for Psychophysiological Research, 2008).

Reproductive Endocrinology and Infertility: A surgical subspecialty of obstetrics and gynecology (OB/GYN) that addresses hormonal functioning as it pertains to reproduction. While a major focus of reproductive endocrinology is infertility, reproductive endocrinologists also evaluate and treat hormonal dysfunctions in females and males outside of infertility. Reproductive surgeons operate on anatomical disorders that affect fertility. To be certified by the state licensing board as an infertility specialist, a doctor must first complete a residency and obtain board certification in OB/GYN, then complete a Fellowship in Reproductive Endocrinology and pass the required licensing examinations in this subspecialty (Society for Assisted Reproductive Technologies, 2008).

Trauma: Contributions to the working definition of trauma for this study are taken from the American Psychiatric Association and researcher/clinicians in the field of traumatology. The DSM-IV-TR (American Psychiatric Association, 2000) defines trauma as “direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one’s physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate (Criterion A1). The person’s response to the

event must involve intense fear, helplessness, or horror (or in children the response must involve disorganized or agitated behavior) (Criterion A2)” (p. 463).

Yehuda (2002), and Foa, Rothbaum, and Zinbarg (1992) provide additional dimensions to the definition of trauma. Yehuda (2002) notes that in addition to events that evoke fear and threat responses, traumatic events may also include a major element of loss and may involve dehumanization, degradation, humiliation, forced separation, and relocation (p. 161). Foa et al. (1992) explain, “Both psychologically and biologically, the severity of traumatic events is related to their being intense, inescapable, uncontrollable, and unexpected” (p. 218).

Assumptions

One assumption I held before conducting this study was that women may experience a range of thoughts, emotions, and sensations during treatment that they may not express at the time, but which may have significant impact on their perceptions, feelings, and beliefs about themselves emotionally and physically and may affect their behavior. I also held the assumption that assisted reproductive technology procedures are similar across reproductive endocrinology practices and the experience of infertility and its treatment were likely to be life stressors for women. During and after the interviews, I held the assumption that the experiences the participants shared with me were true.

Situating the Researcher in the Study

The idea for this research emerged from my professional and academic interests and my experiences working with women as a childbirth educator, doula, and psychology intern in women’s reproductive health settings. Many of the women I encountered described or exhibited symptoms of traumatic stress while they were attempting to conceive, during pregnancy, following pregnancies that were lost through miscarriage,

stillbirth or abortion, or after they'd given birth. I became interested in the relationship between trauma, the psychophysiology of women's reproductive processes, women's experiences of reproductive health care, and women's early interactions with their children following these experiences. Understandings gained from my own lived experiences of traumatic stress symptoms also contributed to my initial conceptualization of this work.

The use of a phenomenological methodology helped me to approach the women and the data in a way that resonates with who I am as a person and a researcher. It was my heartfelt intention to approach the women gently and respectfully and provide a quality of presence that would allow them the space they needed to choose what aspects of their experiences they wanted to share and how they wanted to share them with me. It was also my intention to open myself to their voices and their words in a way that would allow me to gain a deeper understanding of their experiences. A phenomenological approach to this research provided a space within which the women could share their lived experiences and a medium through which their voices and my own can be heard. By placing myself at the intersection of current bodies of knowledge, I was able to facilitate the process of translating first, my lived experiences of being with the women and second, my immersion in their transcripts, into the understandings that emerged from this study.

Summary

There is an increasing utilization worldwide of ART procedures and reproductive endocrinology treatment for infertility. Some women may experience an initiation of traumatic stress symptoms during and after reproductive endocrinology treatment, an exacerbation of traumatic stress symptoms they had prior to undergoing treatment, or a

reoccurrence of symptoms that had abated in the past. The psychophysiological internal environment of the woman as she interacts with the external environment in which conception is attempted may have an impact on whether or not conception occurs, and may leave lasting psychological and physiological imprints on both mother and child if conception does occur.

There is a scarcity of research that offers an in-depth look at women's experiences of attempting to conceive through reproductive endocrinology treatment. The descriptions offered by the participants in this study include their internal psychophysiological experiences. For some women, their reproductive endocrinology treatment experiences may have been impacted by their traumatic stress symptoms as they faced the physical environment in which treatment was provided, and experienced physical and verbal interactions with health care providers.

A phenomenological approach provides us with the opportunity to understand how an individual experiences their world in their unique human embodiment with the imprints of their lived experiences and how their state of health and well being is an expression of these imprints. Most often, the relationship between trauma and health is studied through an epidemiological lens and research results are frequently expressed in statistical terms that do not capture the lived-body experience of the individual. The first person accounts of the participants in this study provide insight into rarely appreciated aspects of reproductive endocrinology treatment. It is through these accounts that we gain a deep understanding of the multi-faceted impacts of these experiences on these individuals in their wholeness as embodied humans. The participants' own words communicate their experiences and their narratives hold crucial knowledge that illuminates aspects of how reproductive endocrinology treatment is provided and how

these aspects of treatment may impact treatment outcomes. This knowledge may also contribute to the building of theory about the lived-body.

The information gained from this study may inspire women, their partners, and their health care providers to consider whether care provided with sensitivity to the individual needs of each woman at this challenging time, including those with traumatic stress symptoms, may accomplish the following: positively impact the quality of a woman's experience as she goes through the biopsychosocial challenges of infertility treatment; beneficially affect a woman's responses to treatment and possibly contribute to the efficacy of infertility treatment; and, if she conceives, favorably contribute to the pregnancy and long-term health and well-being of the woman and her child.

Chapter 2 will include an expanded discussion of research briefly identified earlier. Research on the psychophysiology of trauma and conception will be discussed to establish the possibility of the impact of trauma on reproductive processes. Research on the relationship between infertility, assisted reproductive technology treatment, its outcomes, and stress will be included. Research in prenatal and perinatal psychology, as a guiding theory, and studies in behavioral perinatology examining the importance and possible long-term imprints and impacts of early experiences on the health and well-being of a woman and the children she conceives will also be reviewed.

In Chapter 3, the methods chapter, I will review literature that explores the importance of using phenomenology and in particular, feminist phenomenology, as a tool for social change. I will also outline the design of this study in this chapter. The criteria for participant recruitment and participation will be provided. Finally, the process of data collection and identification and synthesis of themes from the interview data will be described.

Chapters 4 and 5 of this study explore the research findings and discuss these findings within the context of the scope and limitations of this study. Implications for future research conclude these chapters.

Chapter 2: Literature Review

Introduction

This literature review explores research and theory in the fields of medicine, traumatology, and prenatal and perinatal psychology to shed light on the psychophysiological relationship between female reproductive processes, infertility, and reproductive endocrinology treatment and stress/trauma. The literature review includes an exploration of the prevalence of reproductive endocrinology treatment for infertility and the prevalence and types of trauma women most frequently experience from childhood through their childbearing years, with a particular focus on trauma that involves the parts of women's bodies involved in reproduction. Also included is a discussion of research on the psychophysiological impacts of these experiences on women, specifically those associated with PTSD symptoms that may impact the organs, systems, and processes in women's bodies that are involved in reproduction.

In addition, the literature review includes research on the psychophysiological aspects of prenatal and perinatal psychology that illuminate the importance of our earliest experiences before, during, and after birth and the way these experiences may shape our development, behavior, and health over our lifetime. Contributions from research in behavioral perinatology are reviewed to illuminate the biobehavioral effects of stress and traumatic stress on the health of women before, during and after pregnancy, as well as the impacts of these maternal psychophysiological states on their offspring (Khashan et al., 2009; Wadhwa et al., 2002; Wadhwa, 2005).

This research provides support for the importance of understanding the psychophysiological states reported by women who face the challenges of infertility and its treatment in two ways. First, this data demonstrates the relationship between women's

psychophysiological states and the health and development of their offspring should they conceive. This includes their ability to carry a baby to term, a challenge women undergoing infertility treatment often face. Second, recent research in behavioral perinatology expands our understanding of the factors that may contribute to women's reproductive problems and infertility. Wadhwa et al. (2002) and Wadhwa (2005) note that fetal organ systems and physiological processes are programmed in utero, including neuroimmunoendocrinological and vasomotor processes involved in both stress/trauma reactions and reproductive processes. Prenatal programming impacts these systems and processes in ways that may be evident over an individual's lifespan. This research holds particular relevance for women undergoing treatment for infertility, as it raises the possibility that the physiological programming of women's reproductive and neuroimmunoendocrine systems and vasomotor processes during their own development as fetuses in their mothers' wombs may be related to the reproductive difficulties and infertility challenges they face when they as adults try to conceive.

Research and theory is presented on how women's psychophysiology, influenced by their past, may impact their experiences while undergoing reproductive endocrinology treatment for infertility and its outcomes. In addition, research is presented on how, regardless of the outcome, the experience of reproductive endocrinology treatment for infertility may impact women's psychophysiology during and after treatment, and thus, their lives and their relationships. A brief discussion of the literature that highlights important issues relevant to the provision of reproductive health care to trauma survivors is also included.

The issues, theory, and research discussed in the literature review support a deep understanding of the implications of the study described in the Discussion chapter.

Explanations of technical terms for assisted reproductive technology procedures are provided in Appendix A to clarify references to these procedures that occur throughout the dissertation.

Prevalence of Infertility, Utilization and Cost of Assisted Reproductive Technology Treatment

As described earlier, the results of the 2002 NSFG reported in the Center for Disease Control and Preventions' publication, *Vital and Health Statistics* (Chandra et al., 2005) indicate that 12% of women (7.3 million) in the U.S. ages 15-44 have "impaired fecundity" defined in the report as difficulty getting pregnant and/or carrying babies to term (most recent national statistics currently available). All of the women in this study had difficulty conceiving and/or sustaining a pregnancy to term. Throughout this study, I will use the terms "fertility problems" and "infertility" to refer to the participants' experiences.

A steady rise in the utilization of reproductive endocrinology treatment in the U.S. during the years 1996 through 2006 was reported in The Center for Disease Control (CDC) and Prevention's 2006 Assisted Reproductive Technology (ART) Report, Section 5. Based on the reports of ART procedure and outcome statistics by ART clinics, the report revealed that between 1996 and 2006, the number of ART cycles performed in the U.S. has more than doubled. The number of live-birth deliveries and the number of infants born following ART procedures was more than two and a half times the number born in 1996 (CDC, 2008, Figure 49).

The 2006 ART Report includes statistics on the incidence of multiple births in women undergoing ART procedures. These statistics reveal additional challenges women may face following this treatment, including the challenge of carrying a multiple

pregnancy to term and meeting the demands of parenting twins or triplets. The 2006 ART report presents the change in percentages between 1996 and 2006 of embryo transfers that resulted in live births (CDC, 2008, Section 5, Figure 56), as well as the percentages of “multiple-infant live births for ART cycles using fresh non-donor eggs or embryos” (Figure 64). These statistics are important, as noted in the report, because “twins, albeit to a lesser extent than triplets or more, are still at substantially greater risk for illness and death than singletons. These risks include low birth weight, preterm birth, and neurological impairments such as cerebral palsy. Both the percentages of twin and triplet-or-more births remain significantly higher for ART births than for births resulting from natural conception” (Figure 64). The report states, “The percentage of transfers that resulted in live births increased from 28% in 1996 to 35% in 2006. From 1996 through 2005, the percentage of singleton live births increased from 62% to 68%; the percentage of twin births remained stable, ranging from 29% to 32%; and the percentage of triplet-or-more births decreased from 7% in 1996 to 2% in 2006” (Figure 64).

Statistics reported in The American Society for Reproductive Medicine’s (ASRM) “Assisted Reproductive Technologies: A Guide for Patients” (2008) reveal another challenge women may face while undergoing ART treatment. The guide includes statistics on the incidence of miscarriage and ectopic pregnancy (a pregnancy in which the embryo implants in the fallopian tube which may rupture as the embryo grows and threaten the mother’s life) in women who conceive following ART. This reveals the increased incidence of pregnancy loss following treatment as women age, and the likelihood that a substantial number of women will suffer one or more reproductive losses while undergoing this treatment. The guide states:

Miscarriage may occur after ART, even after ultrasound identifies a pregnancy in the uterus. Miscarriage occurs after ultrasound in nearly 15% of women younger than 35, in 25% at age 40, and in 35% at age 42 after ART procedures. In addition, there is approximately a 5% chance of ectopic pregnancy with ART. (ASRM, 2008, p. 14)

As described earlier, reproductive endocrinology treatment and ART procedures are widely used in countries other than the U.S. The International Committee for Monitoring Assisted Reproductive Technology's 7th World Report (most recent available) analyzed data from 49 countries that provided information on over 460,157 ART cycles performed in the year 2000. Based on the information submitted, the report states, "The total number of babies conceived through ART in the year 2000 may be estimated to be between 197,000 to 220,000" (Adamson et al., 2006, p. 1607).

Concern about the financial cost of ART procedures (an average of \$9,226 per IVF cycle) was noted by Omurtag and Toth (2007, p. S122). All of the participants interviewed for this study lived in greater New York area at the time of the interviews and several commented that the cost of a single IVF cycle at the practices from which they received care at that time (2005 – 2006) was \$12,000, significantly more than the average reported by Omurtag and Toth (2007). This cost increased if they opted for additional procedures suggested by their health care providers that might increase their chances of a successful outcome in any given cycle. These procedures might include IVF using donor eggs, preimplantation genetic diagnosis, assisted hatching, and intracytoplasmic sperm injection (see Appendix A for explanation of terms). Women commonly undergo several IVF treatment cycles before they conceive or decide to discontinue treatment. The total cost of multiple cycles of treatment can place great

financial demands on women and their families depending on whether they have health insurance, and if so, the extent to which their policies cover these procedures.

Understanding the Psychophysiology of Human Reproduction: The Interface Between the Social Nervous System and the Reproductive System

Neuroendocrine Regulation Mediates the Link Between Social Environment and Health

Seeman and McEwen discuss their hypothesis that “neuroendocrine regulation” is a “mediating pathway between social environment and health” (1996, p. 460). McEwen and Stellar (1993) use the term “allostatic load” to describe the hypothesized link between neuroendocrine activity and health risks, defining allostatic load as the “cumulative strain on the body produced by repeated ups and downs of physiologic response, as well as by the elevated activity of systems under challenge...” (p. 2094).

Seeman and McEwen (1996) note that human physiologic activity is “precipitated largely by our interactions with the world around us” and observe:

With excessive or prolonged elevations in activity, the costs can begin to mount.

In this respect, both the HPA [hypothalamic-pituitary-adrenal] axis and SNS [sympathetic nervous system] would be expected to figure prominently in the accumulation of allostatic load as these two systems not only play central roles in mediating physiologic responses to nearly all types of stimuli, but also have far-reaching impacts on activity in nearly all of the body’s regulatory systems. (p. 460)

Subsequent psychophysiological research provides further evidence that an individual’s interactions with his or her environment impact complex mind-body systems, processes, and behaviors, including those involved in reproduction.

Porges' Concept of Neuroception, the Polyvagal Theory and Autonomic Nervous System Regulation

Porges (1998, 2001, 2004) provides an understanding of the relationship between the psychophysiology of female reproductive processes and the human social nervous system. Porges uses the term “neuroception” to describe the relationship between human perceptions and our social nervous system. When an individual’s neuroception evokes an experience of safety, their social engagement system may be activated and in turn may support manifestation of voluntary reproductive behaviors. Porges’ Polyvagal theory provides an evolutionary perspective on how our autonomic nervous system reacts to our social and physical environment and the role it plays in regulating our behavior.

Trauma That Breaches Body Boundaries: Prevalence in Women Prior to and During the Childbearing Years

The literature on women’s experiences of trauma demonstrates that a substantial number of women are survivors of violent experiences, in particular rape or sexual assault, child sexual and/or physical abuse, and partner violence. Many survivors of trauma suffer from posttraumatic stress disorder symptoms for years following these experiences. The following review of the literature reveals the fact that the majority of women who have been victims of violence were exposed to trauma well before or during their childbearing years, and many to trauma that breached their body boundaries and involved the parts of their bodies involved in reproductive processes.

Recent statistics on violence against women, provided below, support Briere and Jordan’s (2004) comments, “Interpersonal violence against women is virtually endemic in our society” and “the epidemiology of interpersonal violence against women is a pressing social issue” (p. 1252).

Plichta and Falik (2001) report on the Commonwealth Fund's 1998 Survey of Women's Health that estimates the prevalence of violent experiences and their relationship to health in women ages 18 to 64. The study projected that "over four out of ten women in the U.S. are likely to have experienced one or more forms of violence including child abuse (17.8%), physical assault (19.1%), rape (20.4%) and intimate partner violence (34.6%)" (p. 244).

In a report issued by the National Institute of Justice and Centers for Disease Control and Prevention, Tjaden and Thoennes (1998) discuss the findings of the National Violence Against Women Survey conducted between 1995 and 1996. The authors report that "18 percent of the 8,000 women surveyed said they had experienced a completed or attempted rape at some time in their life" (p. 2). Tjaden and Thoennes also report that of these women, "22 percent were under 12 years old and 32 percent were 12 to 17 years when they were first raped" (1998, p.2).

These are similar findings to those of Kilpatrick et al. (1992), reported in the The National Women's Study that collected data from 4008 adult American women. Results from this study indicate "one out of every eight adult women, or at least 12.1 million American women has been the victim of forcible rape sometime in her lifetime" (Kilpatrick et al., 1992, p.2). This study also found that age at the time of rape as reported by the women surveyed was less than 11 years old in 29.2%, 11-17 years old in 32.3%, 18-24 years old in 22.2%, and 25-29 years old in 7.1% (Kilpatrick et al., 1992, p. 3), indicating that 90.9% of forcible rapes reported by women in the survey occurred before age 30. Seng et al. (2001) report that "rates of exposure to traumas peak between 16 and 20 years of age and decrease precipitously thereafter" (p. 17).

The National Center for Injury Prevention and Control's 2006 report entitled, "10 Leading Causes of Nonfatal Violence-Related Injury, United States, 2006 All Races, Females, Disposition: All Cases" ranks sexual assault as the number one cause of injury in girls ages 1-4, and the number two cause of injury in girls in three other age categories: below the age of one, ages 5-9, and ages 10-14. For the category "All Ages", from birth to age 65+, sexual assault is ranked third among the 10 leading causes of nonfatal violence-related injury in the United States (Office of Statistics and Programming, National Center for Injury Prevention and Control, CDC, 2006). In addition, this report ranks "Other Assault Struck by/Again" as the number one cause of non-fatal violence-related injury for females in every age category from birth through age 65+, except for girls ages 1-4. This category includes, "all assaults that are not classified as sexual assault." In the report, "Self-harm, Poisoning" is the number two ranked cause of non-fatal violence-related injury starting at age 10 and continuing across all age categories through ages 65+.

In a study of the prevalence of adult sexual assault in a general population sample conducted by Elliot, Mok, and Briere (2004), 22% of the 472 female participants reported experiences of adult sexual assault. Fifty-nine percent of the women who reported experiences of adult sexual assault also reported experiences of childhood sexual abuse (p. 203). In a study of the prevalence of self-reported childhood physical and sexual abuse in a general population sample (Briere & Elliot, 2003), 32.3% of the women participants reported "childhood experiences that satisfied criteria for sexual abuse" and 19.5% of the women participants reported experiences that "met criteria for physical abuse" (p. 1205).

Tjaden and Thoennes (2000) report on the prevalence of male-to-female intimate partner violence as measured by the National Violence Against Women Survey. Survey data included the lifetime incidence of intimate partner violence. Among the women respondents, 4.5%:

reported being raped by a current or former marital/opposite sex cohabitating partner at some time in their lifetime...20.4% of the women reported being physically assaulted by a current or former marital/opposite-sex cohabitating partner at some time in their lifetime...4.1% of the women reported being stalked by a current or former marital/opposite-sex cohabitating partner at some time in their lifetime...[compared to male respondents] women were 22.5 times more likely to report being raped, 2.9 times more likely to report being physically assaulted, and 8.2 times more likely to report being stalked by a current or former marital/opposite sex cohabitating partner at some time in their lives. (p. 151)

Briere (2004) notes, "Because of the shame and secrecy typically associated with being a victim of rape or sexual assault in many cultures, it is likely that some victims do not identify themselves as such in research studies" (p. 17). This raises the possibility that the statistics on violence against women and children may not accurately represent the actual prevalence of these acts.

The statistics that are currently available demonstrate that a large number of women are victims of violence, that the majority of them are exposed to trauma well before or during their childbearing years, and that the specific types of trauma they experience often involve the parts of their bodies involved in reproduction. These statistics also suggest the likelihood that a substantial number of women attempting to conceive and sustain a pregnancy may have experienced repeated events of one or more

types of violent trauma. These experiences have been shown to have long-term impacts on women's health.

The Long-Term Impacts of Early Adverse Experiences on Women's Health

The relationship of early adverse experiences, including childhood emotional, physical or sexual abuse, and household dysfunction to health risk behavior and disease in adulthood has been demonstrated in retrospective studies (Felitti et al., 1998; Hillis, Anda, Felitti, Nordenberg, & Marchbanks, 2000; Hillis, Anda, Felitti, & Marchbanks, 2001). Felitti et al. (1998) report that of the 9,508 adults who responded to their questionnaire about adverse childhood experiences after completing a standardized medical evaluation at a large HMO, more than half reported at least one category of adverse childhood exposure and one fourth reported two or more categories of adverse experience. The authors found, "the number of categories of adverse childhood exposures showed a graded relationship to the presence of adult diseases, including ischemic heart diseases, cancer, chronic lung disease, skeletal fractures, and liver disease" (p. 245). In addition, the authors report that the seven categories of adverse childhood experiences (psychological, physical, or sexual abuse; violence against mother; or living with household members who were substance abusers, mentally ill or suicidal, or ever imprisoned) were "strongly interrelated and persons with multiple categories of childhood exposure were likely to have multiple health risk factors later in life" (p. 245). Felitti et al. (1998) chose ten health risk factors for the purposes of their study, including smoking, severe obesity, physical inactivity, depressed mood, suicide attempts, alcoholism, any drug abuse, parenteral drug abuse, a high lifetime number of sexual partners (≥ 50), and a history of having a sexually transmitted disease (p. 248).

Felitti et al. (1998) explain that the mechanisms that link adverse childhood experiences and health risk behaviors and adult disease,

Appear to center on behaviors such as smoking, alcohol or drug abuse, overeating, or sexual behaviors that may be consciously or unconsciously used because they have immediate pharmacological or psychological benefit as coping devices in the face of the stress of abuse, domestic violence, or other forms of family and household dysfunction. (Felitti et al., 1998, p. 253)

Health risk behaviors that are viewed as problematic by the medical community may be viewed by the individual with a history of early adverse experience as an “effective immediate solution” which they may continue to engage in on a chronic basis (p. 254).

Felitti et al. (1998) note that a two- to four-fold increase in sexually transmitted disease was reported in individuals who had experienced four or more categories of childhood exposure, compared to those who had experienced none (p. 245). Sexually transmitted diseases are associated with infertility, ectopic pregnancy, spontaneous abortion, and stillbirth (Hillis et al., 2001, p. 206). Hillis et al. (2000) discuss the relationship between adverse childhood experiences and subsequent sexually transmitted diseases in men and women. Analysis of survey data from 5,060 women who participated in their study found that 59% (2,986) reported one or more categories of adverse experiences during childhood. The study compared the risk of reporting an STD in women with and women without reported adverse childhood experience. The data revealed the following:

For women, each category of ACE [adverse childhood experience] was significantly and independently associated with an increased risk of reporting an STD. Compared with women who denied having experienced the specific

category of either abuse or household dysfunction, we observed the following increases in STD after adjustment for race and age at interview: 100% for those, who as children, had incarcerated family members, 90% for those who experienced childhood sexual abuse, 70%, for those reporting childhood emotional abuse, 60% for those reporting physical abuse, 50% for those reporting household substance abuse, 50% for those who lived with a mentally ill family member during childhood, and 40% for those who lived with a battered mother. (Hillis et al., 2000, p. e11, 3)

In addition, the authors found that the “prevalence of reporting an STD increased as the number of categories of exposure to adverse experiences during childhood increased” (Hillis et al., 2000, p. e11, 3).

While these studies are part of a growing body of literature that sheds light on the prevalence of multiple experiences of early trauma and the impact of those experiences on women’s health, including reproductive health, these studies assess the relationship between early adverse events and health risk behaviors and disease through participant recall of these events. They are limited by their dependence on the participants’ ability to recall adverse childhood events. The very fact that these experiences are adverse or traumatic may increase their likelihood of being inaccessible to conscious recall, as dissociation may be employed as a defensive coping measure during these experiences, especially in children (Perry, 1999). Unrecalled adverse childhood experiences may also impact health risk behaviors and the incidence of disease. This suggests that the statistics reported in these studies may be an underrepresentation of the relationship between and impact of adverse childhood experiences and adult health risk behaviors and disease. Studies that measure traumatic stress symptoms without requiring the participants to

recall specific traumatic events allow for the inclusion of individuals who may be suffering the affects of those experiences, but do not have conscious awareness of the experiences that may have triggered their symptoms. This may include adverse/traumatic experiences that occurred during the prenatal and perinatal period. Traumatic stress symptoms that result from recalled and/or unrecalled traumatic experiences and their psychophysiological underpinnings have been investigated in research on posttraumatic stress disorder.

Posttraumatic Stress Disorder Symptoms: Prevalence in Women

A cohort of women who have experienced trauma may also experience, or have experienced in the past, symptoms of posttraumatic stress. Knowledge of the prevalence of violence against women and the psychophysiological impacts associated with it enhances our understanding of a substantial number of women's experiences of the examinations and procedures involved in reproductive endocrinology treatment. Research on the pelvic exam experiences of survivors of sexual violence will be discussed later in this chapter.

Estimates of the prevalence of lifetime PTSD among women of all ages range from 10.4% to 12.3%, with rates of 25-50% among women exposed to abuse or assault trauma (Seng et al., 2001). Kilpatrick et al. (1992) note that "Almost one-third (31%) of all rape victims developed PTSD sometime during their lifetimes" and more than one in ten rape victims (11%) still had PTSD when the study was conducted (p. 7). In another study, Kilpatrick et al. (1989) noted that of women who experienced completed rape, perceived life threat and injury, almost 80% developed PTSD (as cited in Resnick et al., 1993, p. 984).

The National Comorbidity Survey found that females are twice as likely as males to develop PTSD (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). Yehuda (2002) suggests the “difference in susceptibility to PTSD” may be linked to “biological, psychological and social differences” (p. 26). She also notes that:

Alternatively, it may be a direct function of the types of events to which men and women are differentially exposed. For example, women are more than 10 times as likely to be raped and men are twice as likely to have experienced a dangerous accident. The capacity of different events to induce PTSD at different rates is only now being explored systematically. (Yehuda, 2002, p. 26)

Assaultive violence, which includes rape, is associated with the highest rate of PTSD (20.9%) of all traumatic events (Breslau et al., 1998, p. 626). In a recent study, Breslau, Peterson, and Schultz (2008) investigated the relationship of prior trauma to the incidence of PTSD after a subsequent trauma. The results of this study indicate that “prior trauma increases the risk of PTSD after subsequent trauma only among persons who developed PTSD in response to the prior trauma” (p. 431). These findings suggest that women with histories of PTSD are at increased risk of experiencing a reoccurrence of symptoms during and following reproductive endocrinology treatment, if aspects of the treatment remind them of, or are similar in some way to previous trauma.

These statistics only partially capture the prevalence of PTSD in women of childbearing age. The prevalence of PTSD in all women may be underestimated due to the fact that the DSM-IV-TR criteria for diagnosis of PTSD include identification of a specific traumatic event or events (American Psychiatric Association, 2000). Many women may not be able to identify a specific traumatic event as the source of their PTSD symptoms due to the prevalence of dissociation during and after trauma. Scaer (2001)

has observed, “Whereas many traumatized patients experience recurring and intrusive memories of the trauma, a significant number have partial or complete amnesia for the experience” (p. 100).

Briere and Conte report, in their study which assessed self-reported amnesia for abuse in adults molested as children (1993), “59% of abused subjects in the present study reported some time period before age 18 when they could not recall their first molestation experience” (p. 26). The authors suggest that the inability to recall abuse-related events “may arise from cognitive mechanisms invoked in order to avoid the painful affects associated with recall of especially violent abuse episodes” (Briere & Conte, 1993, p. 29).

Simkin and Klaus (2004) note, “During severe trauma the victim’s ability to remember can shut down and the experience becomes set apart or dissociated from ordinary consciousness. It may remain hidden from memory for years or exist as fragments of memory at a semi-conscious level” (pp.12-13).

Some women may be unwilling to disclose information about remembered traumatic events to care providers due to feelings of shame, self-blame (Grimstad & Shei, 1999, p. 88), fear of repercussion from the perpetrator, and insensitive or punitive responses to their disclosure from the care providers themselves (Bohn & Holz, 1996, p. 442). Kilpatrick et al. (1992), reports, “84% of rape victims do not report to the police” (p. 6). Plichta and Falik (2001) report that “only one-third of women who experience violence have discussed it with a physician” (p. 244). All of these factors contribute to the increased likelihood that PTSD is underreported in woman of all ages. In addition, it is likely that a substantial number of women with histories of trauma and PTSD symptoms receive medical care from providers with whom they have not shared this information. As a result, the providers are unlikely to have an awareness of the potential

impact of these past traumatic experiences on the healthcare needs of the women they are treating.

For some women, memory of the actual abuse may be inaccessible for many years, but recall can be triggered later (Simkin & Klaus, 2004, p. 12-13), often at “particular developmental stages, major life transitions or meaningful events” (p. 26). Scaer (2007) comments, “the potential for an event to be traumatizing depends in part on the meaning of the event to the person experiencing it” and notes that “a full-blown and prolonged traumatic physiological response may occur after a relatively minor stressful event if the victim has a past history of severe trauma, especially as a child” (p. 146). Scaer highlights the fact that “a threatening experience that replicates similar past trauma is far more likely to be traumatizing” (p. 146).

The observations of both Scaer and Simkin and Klaus support consideration of the possibility that the psychosocial and physical challenges of infertility and its treatment may trigger previously recalled or new memories of prior trauma, and initiate a reoccurrence, or exacerbation, of existing PTSD symptoms in women with trauma histories, whether or not they have conscious recall of prior trauma.

Issokson (2004) provides additional insight into the impact of the effects of childhood abuse on women who experience infertility and pregnancy loss:

For many women, the ability to conceive and carry a pregnancy to term is a milestone in terms of securing a sense of confidence in their bodies. Women who are abuse survivors may already have a conflictual relationship with their bodies and their sexuality. They may question the functioning and adequacy of their bodies. Difficulty either in conceiving or in carrying a pregnancy to term can trigger issues of body betrayal and failure as a woman and a sexual being.

Infertility diagnosis and treatment involves many invasive procedures over a prolonged period of time. It involves reliance on medical personnel who are often given great authority over a woman's reproductive fate. This is a challenge for any woman. Superimpose issues common to abuse survivors, and the process of conceiving a child through reproductive technology is not only stressful, but also ripe for triggering memories of abuse and symptoms of PTSD. (Issokson, 2004, p. 19)

Women's experiences of attempting to conceive and sustain a pregnancy often hold multiple layers of meaning for them, as do their experiences of reproductive endocrinology treatment for infertility. These are often seen as key events and turning points in their lives. The meaning these events hold in their lives may contribute to the potential for these experiences and their outcomes to be traumatizing.

Psychophysiological Responses to Traumatic Stress

The Autonomic Nervous System and Traumatic Stress

Differences in psychophysiological responses to stress and traumatic stress have been studied by researchers and practitioners in psychology and medicine (Bremner, 2005; Levine, 1997; Nijenhuis, 2004; Perry, 1999; Scaer, 2001, 2005, 2007; Siegel, 1999; van der Kolk et al., 1996; Vermetten & Bremner, 2002; Yehuda, 1999, 2002; Yehuda et al., 1995; Yehuda et al., 1996). Bremner (2005) notes,

In addition to there being a link between stress and a variety of physical disorders, there is new evidence that PTSD may increase the risk of physical disorders even more. This evidence suggests that PTSD, above and beyond the influence of stress per se, may increase the risk of several physical disorders, including heart disease, diabetes, ulcers, asthma and possibly cancer. (Bremner, 2005, p. 272)

The conditions mentioned above reflect the wide range of bodily systems that may be impacted by posttraumatic stress disorder, including the cardiovascular, neuroendocrine, gastrointestinal, pulmonary, and immune systems. Although Bremner (2005) does not specifically mention the effects of PTSD on the reproductive organs or system, the organs and systems that are mentioned are crucial to healthy reproductive functioning. This raises the question of the impact of PTSD symptoms on reproductive processes and suggests the need for further investigation.

Recent psychophysiological research demonstrates the mechanisms responsible for the long-term psychobiological impacts of traumatic stress in humans (Bremner, 2005; McEwen, 1998; Scaer, 2001, 2005, 2007; Seeman & McEwen, 1996; van der Kolk et al., 1996; Vermetten & Bremner, 2002; Yehuda et. al., 1995; Yehuda et al., 1996; Yehuda, 1999, 2002). This research supports current theories in the field of trauma and trauma treatment that acknowledge the psychophysiological foundation of PTSD behavioral symptoms and their manifestation as evidence of the changes that result in a traumatized individual's organ systems.

McEwen (1998) describes how stressful events (“major life events, trauma and abuse”) may impact physiologic processes and lead to illness: “The perception of stress is influenced by one's experiences, genetics and behavior...the overexposure to mediators of neural, endocrine, and immune stress can have adverse effects on various organ systems leading to disease” (p. 171). As van der Kolk (1996) notes, “Trauma seems to affect people on multiple levels of biological functioning” (p. 215), including regulatory functions controlled by the brainstem/hypothalamus, the limbic system, and the neocortex. Traumatic stress impacts regulatory processes in the autonomic nervous system, including the hypothalamic-pituitary-adrenal (HPA) axis (Bremner, 2005;

Levine, 1997; Perry, 1999; Rothschild, 2000; Scaer, 2001, 2005, 2007; van der Kolk, 1996; Vermetten & Bremner, 2002; Yehuda, 1999; Yehuda et al., 1995; Yehuda et al., 1996).

Although the impact on fertility of changes in HPA axis function in women with PTSD symptoms has not specifically been studied, the impact of PTSD, stress, anxiety, and depression on neuroendocrine, immunological, and vasomotor processes has been studied (Altemus, Cloitre, Dhabhar, 2003; Elzinga, Schmahl, Vermetten, van Dyck, & Bremner, 2003; Gill, Szanton & Page, 2005; McEwen, 1998; McEwen et al., 1997). Changes in these systems suggest the possibility that the altered physiology associated with these psychological states and/or traits may impair a woman's ability to conceive and sustain a pregnancy (Khashan et al., 2009; Wadhwa, 2005; Wadhwa et al., 2002; Weinstock, 2008).

Psychophysiological Changes Associated with Traumatic Stress May Affect Processes in the Reproductive System

Neuroendocrine, immunological, and vasomotor changes associated with traumatic stress symptoms are indicators of hypothalamic-pituitary-adrenal (HPA) axis functioning. Alterations in HPA axis functioning affect the hypothalamic-pituitary-gonadal (HPG) axis (Cwikel et al., 2004; Fachinetti et al., 1997; Ferin, 1999; Gallinelli et al., 2001; Scaer, 2001, 2005, 2007), which is vitally important to the regulation of reproductive cycles and fertility. Disturbances in this regulatory system can significantly hinder a woman's ability to conceive (Cwikel et al., 2004; Ferin, 1999; Gallinelli et al., 2001).

Dobson, Ghuman, Prabhakar, and Smith (2003) explain that "similar neurotransmitters and nuclei within the hypothalamus control stress and reproduction" (p.

152). The authors' review of recent animal research demonstrates the interrelationships between the "hypothalamus-pituitary-ovary axis" (HPO), which is involved in the regulation of the reproductive system, and the hypothalamic-pituitary-adrenal axis (HPA), which is involved in the regulation of systems that respond to stress (Dobson et al., 2003).

Scaer (2005) has observed an additional aspect of psychobiological dysregulation in PTSD, "somatic dissociation," which he defines as "abnormal physical changes that may occur in a region of the body that is dissociated, specifically when the perception of that region has been altered because the sensorimotor messages from it contained information regarding a life-threatening traumatic stress" (p. 242). Scaer describes changes in vasomotor regulation observed in individuals experiencing somatic dissociation of specific regions of the body or individual body parts and the relationship of these changes to the autonomic nervous system (ANS) cycling common in PTSD:

The regulation of circulation to that region of the body would appear to be altered, but in a variable fashion. Sometimes, a predominately sympathetic influence would be apparent, with coldness, pallor, and sweatiness; other times parasympathetic dominance would prevail, with redness, dryness, and increased warmth. In other words, the normal *vasomotor regulation* of that region would be abnormal in a cyclical fashion, associated with excessive constriction and dilatation of the small blood vessels. Impairment of blood flow in these regions would adversely affect the nerve supply of that region and the organs of the skin by depriving the regions of adequate blood supply and oxygen, leading to atrophy of the tissue. The dissociated region of the body would reflect the intrinsic

cyclical autonomic dysregulation that is a hallmark of the brain kindling seen in PTSD and the physiological spectrum of posttraumatic state. (2005, pp. 242-243)

Scaer's description of the physiological changes apparent in somatic dissociation supports the connection between somatic dissociation and PTSD and suggests that women who have experienced trauma, and particularly those who have experienced trauma that involved their pelvic area and the reproductive organs, may experience somatic dissociation during the process of infertility treatment that focuses on these areas. Somatic dissociation may occur in these women as a response to individual internal and external triggers experienced by the women during infertility treatment exams and procedures. As Scaer (2001, 2005, 2007) describes, somatic dissociation reflects physiological changes localized in the dissociated regions of the body at the organ, tissue, and cellular levels, changes that adversely affect the nerve, blood, and oxygen supply to these areas. If the areas that are impacted by somatic dissociation include the organs, tissues, and cells crucial to the process of conception, how might past trauma, and presently triggered somatic dissociative responses to reproductive endocrinology treatment, impact a woman's responses to the treatment process and, ultimately, her ability to conceive and sustain a pregnancy?

Porges' Polyvagal Theory, oxytocin, vasopressin and reproductive behavior.

Stephen Porges applies his Polyvagal Theory to love and reproductive processes in humans (1998) and provides a view of the mechanisms of autonomic nervous system (ANS) regulation as they relate to social engagement (2004) and reproductive behavior. Porges' theory explains the "neurophysiological and neuroanatomical distinction between the two branches of the tenth cranial nerve (i.e. vagus)" and proposes that "behaviors and psychological states associated with emotions of love, courting behaviors, and intimacy

are derivative of the evolutionary processes that produced changes in the structure and function of the cranial nerves especially in the regulation of cardiac function” (Porges, 1998, p. 838). Porges explains that “the mammalian autonomic nervous system retains components of three interactive but distinct, phylogenetically dependent neural systems” (p. 841), and the dorsal vagal complex (DVC [phylogenetically the oldest of these three neural systems]) “provides the primary neural control of subdiaphragmatic visceral organs” (p. 843). This includes women’s reproductive organs. He focuses on the regulatory function of the hypothalamus (in particular, the paraventricular nucleus of the hypothalamus) on the DVC (1998, pp. 847, 848). Both the hypothalamus and the DVC play a significant role in ANS regulation during and after the experience of trauma. Porges (1998) explains the relationship between the ANS, DVC, and endocrine responses:

The role of the paraventricular nucleus in the regulation of the DVC in modern vertebrates retains phylogenetically older functions and continues to respond to threatening situations by contributing to visceral and endocrine responses. However, this phylogenetic organization results in vulnerabilities, because perceived challenges to survival, whether or not truly life threatening, may elicit visceral and endocrine reactions that compromise normal physiological function. (p. 849)

Uvnas-Moberg (2003) notes that there are sensory nerves that follow the vagus branch from the uterus and mammary glands:

Similar to the vagal sensory nerves from the inner organs such as the stomach, these nerves do not convey messages through the spinal cord, but reach other low parts of the central nervous system directly. They probably do not convey precise

information about the location of touch, but more likely influence the deeper parts of the brain that deal with feelings and physiological reactions. (p. 44)

This suggests a clear link between the female reproductive organs and the limbic system, the part of the ANS system in the brain that plays an important role in the connection between feelings and physiological reactions, and in trauma. Uvnas-Moberg (2003) provides further explanation of the coordinated functions of the autonomic nervous system and the endocrine system, noting that the hypothalamus exerts significant control over functions of the autonomic nervous system, as well as the hormone control system in the pituitary gland. “In this way, the hypothalamus and the body communicate through autonomic nerve impulses and hormones secreted into the bloodstream” (p. 47). She also explains the important and varied regulatory functions of two related hormones, oxytocin and vasopressin, in both the autonomic nervous system and the reproductive system. Both oxytocin and vasopressin “behave like signaling substances in many places in the brain and spinal cord. They influence, for example, the areas of the brain that in turn direct the activity of the autonomic nervous system” (p. 47). As mentioned above, dysregulation of the autonomic nervous system resulting from traumatic stress is associated with many of the behavioral symptoms of PTSD.

Oxytocin and vasopressin, unlike many other hormones which are formed in, and secreted from, the pituitary gland, are formed in the supraoptic nucleus and paraventricular nucleus of the hypothalamus. They are released from the hypothalamus to the pituitary gland’s dorsal lobe and delivered to target organs in the blood, and “delivered directly from the hypothalamus to the nervous system through long nerve fibers” (p. 49). This dual system of transmitting oxytocin and vasopressin in the body increases the power of these hormones to exert both localized effects on specific

functions in target organs, and more generalized effects through their impact on the autonomic nervous system (p. 51). Uvnas-Moberg's description of the intricate relationship between oxytocin and vasopressin and their dual roles in both the reproductive and autonomic nervous systems raises additional questions regarding the following: events and processes that may impact the release of these hormones and optimal levels necessary for reproductive processes; the systems and processes that may, in turn, be impacted by non-optimal levels of these hormones in the body; and consideration of the role these hormones may specifically play in influencing the experiences and treatment outcomes of women with PTSD symptoms in treatment for infertility.

Uvnas-Moberg (2003) points out that oxytocin plays several roles in the reproductive system and fertility. It stimulates the release of eggs from the ovary and the production of sperm in the testicles, and appears to “increase the production of ‘growth factors,’ substances in the blood that facilitate cell enlargement and cell division” (p. 83). The fact that it appears that oxytocin increases the production of growth factors that facilitate cell enlargement and cell division may indicate another physiological process that could be impaired by the psychobiological impact of PTSD symptoms. Uvnas-Moberg contrasts the different behaviors associated with vasopressin and oxytocin: “vasopressin is involved in behavior marked by defensiveness, boundary setting, and aggression. Oxytocin instead produces behavior characterized by social interaction, friendliness and curiosity” (p. 84). The localized effects of vasopressin as a blood-borne hormone include contraction of the musculature in blood vessels, which contributes to high blood pressure (pp. 50, 51). This raises the question of what impact localized blood

vessel contraction in the reproductive organs may have on infertility treatment and conception.

In light of the varied roles played by oxytocin and vasopressin in intimate encounters (Porges, 1998; Uvnas-Moberg, 2003), and the importance of oxytocin in fertility (Uvnas-Moberg, 2003), another question arises regarding the impact of past trauma, PTSD symptoms, and women's perceptions of danger following trauma on the activity of these important hormones during reproductive endocrinology treatment. Does the context in which conception occurs, coupled with a woman's perceptions and beliefs shaped by past trauma, impact the physiology of reproduction?

The autonomic nervous system, the endocrine system, and perceptions of the context in which conception occurs. Uvnas-Moberg (2003, p. 118) notes that studies have investigated the effects of oxytocin on females and males during human sexual relations (Argiola and Gessa, 1991; Carmichael et al., 1987; and Carter, 1992; as cited in Uvnas-Moberg, 2003, p. 189). Uvnas-Moberg explains how the release of oxytocin may be impacted by the context in which sexual relations occur:

These effects of oxytocin are influenced...by the conditions under which the sexual encounter takes place. The more the encounter contains an element of tension and danger, the more it is influenced by oxytocin's sister substance, vasopressin, and so a stress reaction is produced. An extreme example, which deserves mention here, is sexual activity involving some sort of pain or violence.... This [stress] reaction then activates the aggression and defense mechanisms in the form of higher blood pressure, tightened muscles, and even reduced emotional responses and desensitization to touch. (Uvnas-Moberg, 2003, p. 119)

Uvnas-Moberg's observation provides further support for the possibility that the dysregulation of the autonomic nervous system that frequently contributes to PTSD symptoms may also impact reproductive system functions and women's experiences of infertility treatment.

The application of Porges' Polyvagal theory to reproductive behavior raises questions about women's autonomic nervous system responses to conception through ART, in which conception occurs not within an intimate act with one's partner, but in a medical setting, while women are receiving care from a medical practitioner. Porges (1998) points out that conception (when it occurs without ART) is the result of reproductive behavior for which complex body systems are intricately programmed. Porges explains the role of the ANS in human mating behavior as either supporting behaviors of engagement or "being physiologically mobilized via sympathetic excitation to escape" (1998, p. 854). By elaborating on the "physiological shutdown response profile [that] may characterize the female during rape, an unwelcomed and physiologically dangerous event" (p. 853), Porges provides additional understanding of the physiological processes that may become engaged in women with histories of sexually related trauma when they are faced with intimate interactions that remind them, consciously or unconsciously, of past trauma, from which they developed a classically conditioned physiological response (pp. 853-854).

The process and specific significance of conceiving a child in the context of a medical environment may impact trauma survivors' systems of reproduction and specifically the process of conception, on levels that Porges' work only begins to illuminate. The impact of ART on the intricate psychoneuroendocrine, immune, and vasomotor processes involved in conception as it replaces a consensual sexual act

between partners who have the intention to conceive a child is an unexplored area that bears further investigation.

The medical examinations and procedures and doctor-patient interactions involved in gynecological care and reproductive endocrinology treatment may activate the autonomic nervous systems of women. For women with trauma histories, settings and procedures that require them to remain immobile in vulnerable body positions can remind them of past trauma and elicit fight/flight/freeze responses (Hilden, Sidenius, Langhoff-Roos, Wijma, & Schei, 2003; Robohm & Bittenheim, 1996; Weitlauf et al., 2008). One such position is the position required during pelvic examinations, in which women lie on their backs with their feet in stirrups and knees separated while they are in close contact with medical providers.

Robohm and Bittenheim (1996) describe the results of their research on the gynecological care experience of adult survivors of childhood sexual abuse:

The gynecological care experience, one which evokes apprehension, fear and avoidance in many women, can be dramatically more upsetting or uncomfortable for survivors, even traumatizing. . . survivors of childhood sexual abuse rated the gynecological care experience more negatively than controls, experienced more intensely negative feelings, and reported being more uncomfortable during almost every stage of the gynecological examination. Further, survivors reported significantly more trauma-like responses during the gynecological examination than did the controls. These distressing experiences included overwhelming emotions, disturbing and unwanted thoughts, body memories, flashbacks of sexual abuse, and dissociation. Finally, the vast majority of survivors in our sample had never been asked about a history of sexual abuse by a gynecological

care provider, although most of them felt that providers should ask about such a history. (Robohm & Buttenheim, 1996, p.70)

Research by Weitlauf et al. (2008) investigated the pelvic exam experiences of women with sexual violence exposure and current symptoms of PTSD. They found that these women are “most at risk for distress during the [pelvic] examination. Thus, although sexual violence alone is related to examination-related distress, clinicians need to be particularly attentive to the potential for distress among sexual trauma survivors with PTSD” (p. 1,349).

Ogden, Minton, and Pain (2006) comment on the impact of trauma on an individual’s “somatic sense of boundary”. They explain that this sense of boundary is experienced at the body level. The somatic sense of boundary is “founded on the *felt sense* of boundary in the experience of safety, protection, and the ability to defend” (Ogden et al., 2006, p. 226). The physical examinations and procedures involved in reproductive endocrinology treatment may breach a woman’s somatic sense of boundary and evoke a felt sense of danger, while they simultaneously require that she override any body impulse she may experience to protect or defend herself.

Women, particularly those who’ve experienced interpersonal trauma, may face a conflict while undergoing reproductive endocrinology treatment between two basic human instincts designed to evoke behaviors that support the survival of the species: the instinct to survive in the felt sense of danger, and the instinct to reproduce. These women may find doctor-patient interactions particularly difficult in light of the conflicting psychophysiological experiences associated with these two drives. The instinct to reproduce motivates women to seek help to conceive from a health caregiver, but, in the process of helping, this same caregiver also performs exams, tests, and procedures that

may evoke feelings of vulnerability and fear, and may involve experiences of physical pain. This creates an approach-avoidance conflict that has the potential to evoke body-brain-mind reactions, observable behaviors that reflect the impact of this conflict on a woman's psychophysiology. This may include dissociative behavior that has the potential to hinder the integration of women's experiences during treatment and thereby additionally contribute to the triggering of, or exacerbation of, traumatic stress symptoms.

Bromberg (1998) refers to competing instincts as competing "Darwinian algorithms" and provides examples of situations that may be particularly relevant to understanding the experiences of women who may have suffered early interpersonal trauma in relationships with caregivers or peers:

What of situations where there are competing algorithms at the same moment? What of a moment when your mother bounds toward you with fangs bared? Or a moment when your father approaches with penis bared? Or...where your peer group suddenly becomes a pack of hyenas, stripping *you* bare while you are still alive? The algorithm of fight, flight or hiding pertains only to escape from predators. What does someone (particularly a child) do when there is another strong algorithm operating, such as "obedience to a parent or an adult" or "love of one's caretaker" or "being accepted by one's peers"? This is the situation, I suggest, that, at least from an evolutionary standpoint, defines the meaning of trauma, and may explain why natural selection seems to have endowed the human mind with a Darwinian algorithm that helps us cope with trauma by providing what Putnam (1992) has called, "the escape when there is no escape" (p.104)—the mechanism of dissociation. (Bromberg, 1998, p. 243)

Bromberg further describes the circumstances that may cause an individual to

resort to dissociation as a defense mechanism and how that process denies the individual the opportunity to integrate their mind-body experience.

Where drastically incompatible emotions or perceptions are required to be cognitively processed within the same relationship and such processing is adaptationally beyond the capacity of the individual to contain this disjunction within a unitary self-experience, one of the competing algorithms is hypnoidally denied access to consciousness to preserve sanity and survival. When ordinary adaptational adjustment to the task at hand is not possible, dissociation comes into play. The experience that is causing the incompatible perception and emotion is “unhooked” from the cognitive processing system and remains raw data that is cognitively unsymbolized within that particular self-other representation except as a survival reaction. (Bromberg, 1998, p. 243)

The distinction between primary and secondary dissociation is described by van der Kolk, van der Hart, and Marmar (1996):

Many children and adults, when confronted with overwhelming threat, are unable to integrate the totality of what is happening into consciousness; the experience is split into its isolated somatosensory elements, without integration into a personal narrative (van der Kolk & Fislser, 1995). This fragmentation is accompanied by ego states that are distinct from the normal state of consciousness. This condition, ‘primary dissociation,’ is characteristic of PTSD, in which the most dramatic symptoms are expressions of dissociated traumatic memories – intensely upsetting intrusive recollections, nightmares, and flashbacks. (p. 307)

van der Kolk et al. (1996) explain the process and experience of secondary dissociation in individuals who have experienced trauma:

They report mentally leaving their bodies at the moment of the trauma and observing what happens from a distance. These distancing maneuvers of ‘secondary dissociation’ allow individuals to observe their traumatic experience as spectators and limit their pain or distress; they are protected from awareness of the full impact of the event. Whereas primary dissociation limits peoples’ cognitions regarding the reality of their traumatic experience, and enables them to go on temporarily as if nothing happened...secondary dissociation puts people out of touch with the feelings and emotions related to the trauma; it anesthetizes them. (van der Kolk, et al., 1996, p. 307, 308)

Traumatic stress symptoms are often characterized by dysregulated oscillation between states of hyperarousal and hypoarousal. In a hyperaroused state, an individual has a felt sense of “experiencing too much activation” and in a hypoaroused state they have the felt sense of “experiencing too little activation” (van der Kolk, et al., 1996). Nijenhuis and van der Hart (1999) explain that the alternating states that characterize posttraumatic stress responses involve more than the experience of consciousness, but also include “complex psychological, behavioral, physiological and neurobehavioral responses” (p. 40).

Ogden et al. (2006) elaborate on the experience of dysregulated arousal triggered by traumatic reminders:

When hyperaroused, clients experience too much arousal to process information effectively and are tormented by intrusive images, affects, and body sensations. But when hypoaroused, clients suffer another kind of torment stemming from a dearth of emotion and sensation—a numbing, a sense of deadness or emptiness, passivity, possibly paralysis (Bremner & Brett, 1997; Spiegel, 1997; Van der Hart

et al., 2004), and/or may be too distanced from the experience to be able to process information effectively. In both cases, top-down regulation is compromised and meaning making becomes biased by the perceived danger signals. Whereas these extremes of arousal may be adaptive in certain traumatic situations, they become maladaptive when they persist in non-threatening contexts. In order to put the past in the past, clients must process traumatic experiences in an ‘optimal arousal zone’ (Wilbarger & Wilbarger, 1997). (2006, p. 26-27)

This optimal arousal zone is referred to as the “window of tolerance” by Siegel (1999) and falls between the zones of hyperarousal and hypoarousal. When individuals are functioning within the window of tolerance, “information received from both internal and external environments can be integrated” (Ogden et al., 2006, p. 27).

van der Kolk et al. (1996) investigated the relationship between PTSD and symptoms of dissociation, affect dysregulation, and somatization. The authors found that all of these symptoms are often associated with trauma:

[These symptoms] can be different expressions of adaptation to trauma. While they often go together, traumatized individuals may suffer from different combinations of symptoms over time. When treating individuals with histories of psychic trauma, it is critical to attend to the dimensions of dissociation, somatization, and affect dysregulation, even when intrusive recollections of the trauma currently are not prominent symptoms. (p. 83)

Seeman and McEwen (1996) comment on data from animal and human research that indicate:

Characteristics of the social environment also influence neuroendocrine activity and patterns of neuroendocrine response to stimuli...the presence of supportive social relationships tends to attenuate patterns of HPA and SNS [sympathetic nervous system] activation. In addition, the converse also seems to be true as non-supportive social interactions can exacerbate neuroendocrine reactivity.... Thus, if individuals who experience greater social support enjoy relative protection against excess exposure to such neuroendocrine activation, their reduced exposure to the 'wear and tear' of HPA and SNS activation (i.e., their smaller 'allostatic load') may contribute importantly to their better health and longevity. (Seeman & McEwen, 1996, p. 466)

This research suggests that the quality of the health care provider-patient relationship may also impact women's neuroendocrine reactivity and patterns of neuroendocrine response in treatment interactions. Health care providers may be more familiar with or attuned to manifestations of hyperaroused states and their characteristic fight/flight behaviors, especially since these may interfere with exams and procedures, but may not be aware that seemingly compliant, but in fact dissociative/freeze responses characteristic of hypoaroused states, are also indicative of past trauma, and/or experiences in the present that are overwhelming the patient's capacity to cope. Health care providers that fail to recognize behaviors associated with autonomic nervous system hyperarousal and/or hypoarousal may not realize when their patients are experiencing a procedure or interaction that is pushing them beyond their window of tolerance. As a result, providers may fail to adjust or adapt the way they are providing care and thereby prevent their patients from returning to a more regulated psychophysiological state within their window of tolerance. This may increase the likelihood that integration of that

particular experience (the treatment procedure or doctor-patient interaction) will be inhibited and thus, may additionally contribute to the persistence of patients' traumatic stress reactions.

The Impact of Beliefs and Early Imprints on Biology

Recent research in cellular biology has revealed the impact of environmental influences, including an individual's beliefs, on cellular functions (Lipton, 2005). Conception and reproductive endocrinology treatment processes are dependent upon normal cellular functioning. Environmental factors that influence cellular functions may impact conception and reproductive endocrinology treatment processes. Lipton (2001) explains that the cell membrane "coordinates the adjustments and reactions of a cell to its internal and external environments" and represents "the cytoplasmic equivalent of the 'brain'" (p. 1).

The cell membrane contains integral membrane receptor-effector proteins (IMPs) that act as "'perception switches' that link reception of environmental stimuli to response-generating protein pathways" (2005, p. 128). These protein complexes respond to perceptions of whether various minerals, neuropeptides, hormones, toxins, and various forms of energy are present in their immediate environment. In communities of cells, such as body organs and systems, each cell must defer control to decisions made by the brain (2005, p. 131). Lipton (2005) makes the link between an individual's beliefs and cellular functions in their body by pointing out "Our responses to environmental stimuli are indeed controlled by perceptions, but not all of our learned perceptions are accurate" (p. 135). This is repeatedly the case in individuals with PTSD symptoms whose brains and bodies react to internal and external stimuli in the present, that remind them, consciously or unconsciously, of those that were present during past traumatic events,

even though no present threat exists (Bremner, 2005; Ogden et al., 2006; van der Kolk et al., 1996; Vermetten & Bremner, 2002; Scaer, 2001).

Lipton's explanation of how cells and cellular membranes function supports the premise that perceptions affect biology. He points out that our perceptions can be true or false and therefore proposes that it is really our beliefs that shape our perceptions that control biology (p. 135). This raises the question of how the cellular functions of infertile women may be influenced by past trauma and posttraumatic stress symptoms that may profoundly impact their beliefs about themselves and their perceptions of the world. While women are undergoing treatment for infertility, the medical settings in which reproductive endocrinology care and procedures are administered become part of the world of these women. Each woman therefore experiences all aspects of her infertility treatment through the lens of her own beliefs and perceptions.

Prenatal and Perinatal Psychology and Behavioral Perinatology

From the perspective of prenatal and perinatal psychology, an individual's earliest experiences from conception through the postpartum period play an especially significant role in the imprinting of core beliefs (Castellino, 2000, 1995; Chamberlain, 1998; Emerson, 1997, 2000; Lyman, 2007; McCarty, 2002, 2004). Recent research in developmental biology, epigenetics and behavioral perinatology provides insight into how genes and environment interact in the development and functioning of the embryo/fetus and how the psychophysiological programming that occurs at this time, as organs and systems are developing, may impact an individual throughout his or her lifetime (Field, Diego, Dieter et al., 2004; Gluckman & Hanson, 2004; Huizink, Mulder, & Buitelaar, 2004; Khashan et al., 2009; Martin & Dombrowski, 2008; Nathanielsz, 1999; Schore, 2002, 2003a, 2003b; Thomson, 2004, 2007; Thompson et al., 2002;

Thompson et al., 2001; Van den Bergh, Mulder, Mennes & Glover, 2005; Verny & Weintraub, 2002; Wadhwa, 2005; Wadhwa et al., 2002; Weinstock, 2008).

Wadhwa (2005) notes,

Development is viewed not as a gradual elaboration of an architectural plan pre-configured in the genes, but rather as a dynamic interdependency of genes and environment, characterized by a continuous process of interactions in a place- and time-specific dependent manner. These interactions involve short- and long-term information storage, whereby genetic and epigenetic processes, at every step of development, become represented in the evolving structural and functional design of the organism (Institute of Medicine, 1992; Smotherman and Robinson, 1995).

(Wadhwa, 2005, p. 725)

This research also supports the possibility that the impact of women's psychophysiological experiences of their time in their own mothers' wombs, and the psychophysiological programming and core beliefs that emerged from those experiences, may in turn have impacted women's own reproductive processes, including their ability to conceive and sustain a pregnancy, and influence how they experience reproductive endocrinology treatment for infertility.

A growing body of recent research explores the short and long-term impacts of maternal prenatal psychophysiological states, including stress, traumatic stress, anxiety, and depression on fetal development and behavior (Austin, Leader, & Reilly, 2005; Diego et al., 2006; DiPietro, Costigan, & Gurewitsch, 2003; DiPietro, Hawkins, Hilton, Constigan, & Pressman, 2002; Field, Diego, Hernandez-Reif, Gil, & Vera et al., 2005; Field et al., 2004); the risk for fetal intrauterine growth retardation, premature birth, and the development of preeclampsia in women during pregnancy (Khashan et al., 2009;

Kurki, Hilesmaa, Ritalalo, Mattila, & Ylikorkala, 2000; Rondo, Ferreira, Nogueira, Ribeiro, Lobert et al., 2003); infant temperament (Austin, Hadzi-Pavlovic, Leader, Saint, & Parker, 2005; Davis et al., 2005, 2007); infant cortisol levels (Yehuda et al., 2005); negative behavioral reactivity in infancy (Davis et al., 2004; DiPietro, Ghera, & Costigan, 2008); intellectual and language functioning in toddlers (LaPlante et al., 2004); and emotional and cognitive problems in childhood (Bergman, Sarkar, O'Connor, Modi, & Glover, 2007; de Weerth, van Hees, & Buitelaar, 2003; Talge, Neal, Glover et al., 2007; Van den Bergh & Marcoen, 2004).

This research also brings to light the issue of how the psychophysiology of women before, during, and following reproductive endocrinology treatment may impact the psychophysiological programming and development of their offspring in the womb and after birth, if they conceive. Recent research suggests there may be two processes through which maternal affective states and the physiology associated with them may impact the physiology and development of the human fetus. Gitau, Fisk, Teixeira, Cameron, and Glover (2001) have demonstrated that maternal stress hormones—in particular, glucocorticoids—are transmitted across the placenta, which may help explain how maternal prenatal stress impacts the physiology and development of the fetus.

In addition, research has demonstrated an association between maternal anxiety and uterine artery blood flow in pregnant women (Sjostrom, Valentin, Thelin, & Marsal, 1997; Teixeira, Fisk, & Glover, 1999). Maternal anxiety was associated with an increased uterine artery resistance index, suggesting another mechanism by which the psychological state of the mother may affect fetal development. Teixeira et al. (1999) comment, “Further work is needed to determine whether overall anxiety during

pregnancy or even before or at conception might affect uterine artery blood flow, or instead whether the association is only with the current emotional state” (p. 156).

Research conducted by Khashan et al. (2009) demonstrates an association between maternal exposure to severe life events before conception and during the first trimester of pregnancy, and the risk of preterm birth, including some instances when the exposure occurred in the six months prior to conception:

We found that maternal exposure to severe life events in close relatives during the 6 months before conception slightly increased the risk of preterm birth but not of very or extremely preterm birth...An especially high risk of very preterm birth was found in women who experienced severe life events in older children in the first trimester.... Among mothers whose previous baby was preterm, severe life events in the 6 months before conception were significantly linked with preterm, very and extremely preterm birth. (Khashan et al., 2009, p. 6)

The authors suggest that increased levels of epinephrine resulting from stress, which, in turn, reduces blood flow to the fetus, may contribute to the relationship between preterm labor and severe life events experienced by a woman during the six months prior to conception or during the first trimester of pregnancy. This research further emphasizes the importance of exploring the impact of stress/traumatic stress on women before, during, and after conception.

As Wadhwa et al. (2002) point out,

There are no direct neural, vascular, or other connections between the mother and her developing fetus.... All communication between the maternal and fetal compartments is mediated via the placenta through one or both of two mechanisms: the actions of maternal and fetal factors on placental activity, or

transplacental passage of blood-borne substances...It now appears that the placenta may also take on some functions that are usually ascribed to the central nervous system, i.e. the capability of receiving, processing, and acting upon certain classes of stimuli. Indeed, we propose that one of the important roles of the placenta is to act on behalf of the fetus as both a sensory and effector organ to facilitate the transduction and incorporation of environmental information into the developmental process. (Wadhwa et al., 2002, p. 150)

Wadhwa et al. (2002) describe the impact of maternal stress during pregnancy on the embryo, fetus, and infant. The authors note that in human pregnancy, psychosocial/behavioral stress has been associated with “outcomes at various points along the developmental continuum, including fertilization and conception, early pregnancy loss (spontaneous abortion), fetal structural and functional developmental outcomes (malformations, physiological activity, neurobehavioral maturation, growth), length of gestation, infant birth weight [etc.]” (Wadhwa et al., 2002, p. 151).

The authors point out another significant observation relating to the measures of stress that were the most strongly associated with adverse outcomes: “Subjective measures of stress perceptions and appraisals are more strongly associated with adverse outcomes than measures of exposure to potentially stressful events or conditions” (Wadhwa et al., 2002, p. 151). This illustrates the importance of gaining a deep understanding of women’s subjective experiences at this critical time in the prenatal and perinatal development of their offspring and thereby supports the use of a phenomenological approach that provides participants with an opportunity to communicate and share these experiences with researchers.

A Phenomenological Approach to Human Fertilization

Jaap van der Wal (2002) uses dynamic morphology, an approach rooted in the scientific phenomenological tradition, to gain a deeper understanding of the human egg and sperm cells and the process of human fertilization. van der Wal explains that the dynamic morphologist is focused on the shapes and forms of living organisms and perceiving the language or gestural behavior expressed by or through that organism's shape and form. Using this approach, van der Wal observes that one of the characteristics of the egg cell is its openness, its intensive interaction and communication with its environment. He also notes that soon after fertilization, the egg cell produces substances that affect its direct environment, which is most often the mucous coat of the ovarian tube. The egg cell's openness and capacity to directly effect its immediate environment is related to its sensitivity and vulnerability to toxic influences in the environment (van der Wal, 2002, Introduction, para. 3).

If one views the environment immediately surrounding the egg cell (and by extension, the environment of the rest of the woman's lived-body, as well as the external environment in which the woman finds herself) as having the potential to directly and indirectly impact the egg, and the egg as having the capability to directly or indirectly affect its immediate environment, including the sperm that find their way to the egg, then van der Wal's dynamic morphological observations of the egg and sperm cells and the fertilization process, which includes a sensitive period of egg and sperm cell interaction prior to conception known as the pre-conception attraction complex (PCAP), can give us further insight into the possible connection between women's experiences of trauma symptoms and their reproductive processes at the cellular level. The impact of the environment at all levels, on the cells and the process of fertilization, again highlights the

need for consideration of how to identify and respond to the individual needs of women with traumatic stress symptoms who receive reproductive endocrinology treatment for infertility.

Research on the Relationship Between Women's Psychophysiological States and Reproductive Endocrinology Treatment and Its Outcomes

Recent research has revealed the range of emotional reactions women experience before, during, and after reproductive endocrinology treatment. Some studies have explored the incidence of anxiety and depression in women undergoing treatment and the relationship between these psychophysiological states and infertility treatment outcomes (Smeenck et al., 2001; Verhaak et al., 2005). Several studies have reported an association between stress, infertility treatment, and its outcomes (Boivin & Schmidt, 2005; Facchinetti et al., 1997; Kloneff-Cohen et al., 2001; Smeenck et al., 2005).

Two recent studies (Anderheim, Holter, Berg, & Moller, 2005; Cooper, Gerber, McGettrick, & Johnson, 2007) did not find a relationship between psychological stress and IVF outcome. The hypothesis of the study by Anderheim et al. (2005) was “psychological stress may have a negative influence on the results of IVF” (p. 2,970). Anderheim et al. (2005) defined psychological stress as “a low level of general psychological well-being” (p. 2,970). The study group consisted of 166 women in Goteborg, Sweden, undergoing their first IVF treatment cycle. The women completed two questionnaires—the first, following the information meeting one month before the beginning of their first IVF treatment cycle, and the second, one hour before oocyte retrieval in that cycle.

The first assessment included the Psychological General Well-Being (PGWB) index, which measures “anxiety, depressed mood, positive well-being, self-control,

general health and vitality” (Anderheim, et al., 2005, p. 2,971). The authors focused on participants’ total scores and their anxiety and depressed mood sub-scores. In addition, the psychological effects of infertility were assessed with a 14-item questionnaire that was developed specifically for the study, which measured feelings of “guilt, success, anger, contentment, frustration, happiness, isolation, confidence, anxiety, satisfaction, depression, powerlessness, competence and control” (p. 2971). Before oocyte retrieval, only the 14-item questionnaire of the psychological effects of infertility was administered. The authors report that this assessment had not been psychometrically evaluated prior to use and note, “One cannot exclude...that the failure to find an association between psychological stress and outcome of IVF is due to a lack of sensitivity of the instruments used” (p. 2973). This study did not include any physiological assessment of stress indicators in the participants.

An analysis of psychological variables in the study by Anderheim et al. (2005) demonstrated no differences between pregnant and non-pregnant women following their first IVF treatment cycle. The authors concluded, “We found no evidence that psychological stress had any influence on the outcome of IVF treatment” (p. 2969).

One weakness in this study is that the data only reflect women’s experiences during their first IVF treatment cycle at points prior to their knowledge of the outcome of the cycle. The fact that the study did not measure stress levels at additional points later in the treatment cycle—after embryo transfer while women wait to learn whether the treatment succeeded or failed, and at the end of the cycle when women receive this information and are impacted by it if they undergo a subsequent IVF cycle—limits the study’s conclusions about stress and IVF cycles specifically to the beginning of the first IVF treatment cycle. In addition, the findings of the the study are limited by the fact that

the study did not include women who had undergone multiple IVF cycles, a common circumstance in IVF treatment and one which may result in increased levels of stress. The psychological well-being and attitude of women undergoing their first IVF cycle may be different than those undergoing subsequent cycles. As the authors comment, “When IVF treatment is imminent, women have great hope for success.... If this study had been performed after failed IVF treatments, the results might have been different” (Anderheim et al., 2005, p. 2974).

This same limitation applies to the research of Cooper et al. (2007). This study’s goal was “to determine the effect of perceived infertility-related stress on IVF outcome” (p. 714). The Fertility Problem Inventory (FPI), a questionnaire that measures five parameters of perceived infertility-related stress, including social concern, sexual concern, relationship concern, negative view of child-free life style, and need for parenthood, was administered to couples in Vermont undergoing their first IVF treatment cycle.

The study group consisted of 129 couples in which both partners completed the FPI questionnaire. The age range of the participants was not provided. The FPI screening was part of the psychological evaluation of the standard IVF testing offered at this institution to all patients undergoing IVF treatment. Patients are “evaluated by a psychologist and treated as deemed appropriate with cognitive therapy, pharmacotherapy, or both” (Cooper et al., 2007, p. 716). This fact raises a question about the findings of this study. How did these psychological interventions impact couples’ perceived infertility-related stress and if so, can these findings be generalized to couples who don’t receive these psychological interventions before and during their IVF cycles?

Cooper et al. (2007) summarized the results of the study:

Couples who achieved pregnancy during their first IVF cycle had higher scores of perceived infertility-related stress on the sexual concern and need for parenthood scales of the FPI. Couples who achieved ongoing pregnancies had higher scores on the negative view of a child-free lifestyle, need for parenthood, and global stress scales...When female partners were analyzed separately, women who had ongoing pregnancies scored significantly higher in the negative view of a child-free lifestyle scale. (pp. 715, 716)

The authors reported that a “multivariate analysis of all variables revealed that only the percentage of mature oocytes fertilized predicted pregnancy ($p=.006$)” (p. 715).

Based on the study’s results, Cooper et al. (2007) suggest that “moderate stress is required for optimal performance” (p. 716). The authors also acknowledge the fact that only four couples in their study scored in the highest quartile of the FPI, a score that would indicate severe levels of infertility-related stress and therefore their data was insufficient to evaluate the relationship between severe levels of infertility-related stress to IVF treatment outcomes (p. 716).

The study did not include couples who had been through more than one or multiple treatment cycles, which might have affected their levels of perceived infertility-related stress and IVF treatment outcomes. In addition, additional key areas that might contribute to perceived infertility-related stress were not part of the FPI questionnaire, including concerns about the stress of the physical aspects of treatment, the health risks associated with the treatment, financial costs of treatment, and health risks and stress associated with multiple pregnancies that might result from successful treatment. Assessment of stress resulting from concerns about these important issues may have impacted the study’s findings had they been included.

The study's data limits the author's conclusions about the relationship between stress and IVF treatment outcomes to the lower levels of stress reported by the majority of participants in the study. Severe infertility-related stress, which may include traumatic stress, could be defined by the widely accepted PTSD symptom criteria in the DSM-IV-TR (American Psychiatric Association, 2000). Assessment tools (e.g., Trauma Symptom Inventory, Briere, 1995; Multiscale Dissociation Inventory, Briere, 2002) have been specifically designed to evaluate these symptoms and could be used in investigations of the impact of severe stress/traumatic stress on infertility treatment outcomes.

An inconsistency in these studies is the definition of a successful outcome. If a successful outcome is only measured by a confirmed clinical pregnancy, it leaves open the possibility that a woman will miscarry at a later time and will still be counted in the successful outcome cohort. The definition of successful outcome varies, from confirmation of clinical pregnancy through blood and urine hormone levels and ultrasound examination in the first weeks after embryo transfer, to live birth. A limitation of the study by Anderheim et al. (2005) is the fact that successful outcome of in vitro fertilization treatment was defined as pregnancy confirmed by a positive HCG urine test on day 19 after embryo transfer and ultrasound verified pregnancy 5 weeks after embryo transfer. The study did not report the number of live births following IVF treatment. In the study by Cooper et al. (2007), pregnancy was defined by a positive serum pregnancy test two weeks after embryo transfer. Ongoing pregnancy was defined as a live birth at or after 20 weeks (p. 714).

Research by Kloneff-Cohen et al. (2001) examined whether "baseline (which included acute and chronic) and procedural (acute) stress in infertile women undergoing in vitro fertilization (IVF) and gamete intrafallopian transfer (GIFT) negatively affected

achieving a pregnancy or live birth delivery” (p. 676). A secondary hypothesis investigated the “effect of stress on additional end points of IVF and GIFT: the number of oocytes retrieved, fertilization rates, number of embryos transferred, and pregnancy outcomes (e.g., low birth weight and multiple gestations)” (p.676). The study group consisted of 151 women ranging in age from 29 to 49 years old who were undergoing IVF and GIFT procedures at seven infertility clinics in Southern California. The types of psychological stress examined in the study included “the baseline stress of infertility, the stresses associated with undergoing a surgical procedure, and the social support and coping mechanisms used to deal with stress” (p. 676).

The study’s definition of clinical pregnancy required “successive measurements of serum hCG exceeded 5 MIU/mL every 3 to 5 days” and ultrasound detection of at least one gestational sac. A term pregnancy was defined as more than 37 weeks and less than 42 weeks. Low birth weight was defined as less than 2,500 grams at birth (Kloneff-Cohen et al., 2001, p. 680).

Assessments of baseline stress were taken at the time of the initial clinic visit. Assessments of procedural stress were taken when the treatment procedures were performed. The authors explained baseline and procedural stress as “the process of experiencing, perceiving and responding to a stressor...on reproductive endpoints of IVF and GIFT” (p. 676).

This study is unique in that it examined outcomes beyond achievement of fertilization and pregnancy and included data on live-birth delivery. It also examined data on infant characteristics that could be impacted by stress (p. 685), specifically infant birth weight (Wadhwa et al., 2002). The study used seven measures to evaluate “stress, affective response or mood throughout the reproductive process” (p. 679). These

included: Positive and Negative Affect Scale (PANAS), Bipolar Profile of Mood States (POMS), Infertility Reaction Scale, Expected Likelihood of Achieving a Pregnancy Scale, Network Resource Scale, Perceived Stress Scale, and the Ways of Coping Scale (Kloneff-Cohen et al., 2001, 679, 680). Multivariate analyses revealed “evidence that baseline stress predisposes women to negative reproductive outcomes during IVF and GIFT” (p. 685).

The authors report that “Acute baseline stress measures had surprisingly negative effects on the outcomes of successful pregnancy and live birth delivery (Kloneff-Cohen et al., 2001, p. 685). The study’s findings demonstrate that “the more ‘negative’ a woman’s outlook on life and, in particular, on the issues surrounding infertility, the worse her chances are of successful ART” (p. 686). In addition, the authors report an association between stress measures at baseline and birth weight of the babies born to participants in the study. A decrease in birth weight was associated with women who reported “feeling guilty” on the Infertility Reaction Scale and an increase in birth weight was associated with maternal positive affect score.

The authors comment that the inconsistency of their results with other studies may be attributed, in part, to the different assessment instruments used to measure stress (2001, p. 685). As evidenced by the studies of Anderheim et al. (2005), Cooper et al. (2007), and Kloneff-Cohen et al. (2001) there is no consistent definition of stress and different assessment tools are used in each study to evaluate that study’s definition of stress. As described above, none of the instruments used in the Anderheim et al. (2005), Cooper et al. (2007), or Kloneff-Cohen et al. (2001) studies incorporated physiological measurements of stress (e.g., cardiovascular measurements or measurements of stress hormones), which would have provided more comprehensive data, a more consistent way

to measure levels of stress in participants, and would have indicated an appreciation for the fact that stress/traumatic stress is a psychophysiological condition. Psychological assessments are not able to capture aspects of stress that are evidenced physiologically, and individuals who are physiologically impacted by stress, but do not report psychological symptoms, may be overlooked in studies assessing the relationship of stress to IVF outcomes.

The results of the Kloneff-Cohen et al. (2001) study suggest the particular importance of recognizing women's psychophysiological states as they enter reproductive endocrinology treatment. The research on stress and reproductive endocrinology treatment and its outcomes (Boivin & Schmidt, 2005; Facchinetti et al., 1997; Kloneff-Cohen et al., 2001; Smeenk et al., 2005), as well as the work of Khashan et al. (2009), demonstrating the association between maternal exposure to severe life events in the six months prior to conception and preterm birth in pregnancies that followed, provide support for the need to gain information about past stressful/traumatic experiences and related psychophysiological states in women before they conceive.

A review of the literature, including a search of the Cochrane Collaboration databases, PubMed and PsycINFO, yielded no meta-analyses of the effects of traumatic stress on ART treatment outcomes. In addition, a review of the literature did not reveal any studies that specifically explored the experiences of reproductive endocrinology treatment in women who reported or manifested traumatic stress symptoms prior to treatment. This study begins to address this gap in the literature.

*Recommendations for the Provision of Health Care to Trauma Survivors:
Considerations for How Care is Provided to Women Undergoing Reproductive
Endocrinology Treatment*

Simkin and Klaus (2004) describe adaptations in care that can be made by health care practitioners during pregnancy, labor, and birth that can support women with histories of childhood sexual abuse and reduce activation of trauma memories and their associated psychobiological responses. Their recommendations are gathered from their experiences listening to, observing, and supporting women during pregnancy, labor, birth, and in the postpartum period. Monahan and Forgash (2000), Schachter, Stalker, and Teram (2001), and Stalker, Schachter, Teram, and Lasiuk (2009) also provide guidelines for the provision of sensitive health care to survivors of childhood sexual abuse. Research demonstrating the positive impact of doula support on outcomes of labor, birth, and mother-infant interaction in the early postpartum period (Klaus, Kennell, & Klaus, 2002; Martin, Landry, Steelman, Kennell, & McGrath, 1998) highlights the need for investigation into the possible beneficial effects of physical and emotional support on the physiology of other reproductive processes, including conception through ART, particularly in women experiencing posttraumatic stress symptoms.

The work of Monahan and Forgash (2000), Schachter et al. (2001), Simkin and Klaus (2004), and Stalker et al. (2009) provides a foundation upon which we can build our understanding of women with posttraumatic stress symptoms who are in treatment for infertility. Affording women the opportunity to share their experiences going through this process may generate new knowledge about how to support them, and these support measures could have important positive psychobiological effects. In describing their experiences, women may have an opportunity to acknowledge and articulate their needs, identifying those that have been met and those that have not. These descriptions can be

shared with their partners and health care practitioners, providing them with insight into the importance to women of having their individual needs considered while facing the biopsychosocial challenges of infertility, including their specific needs within the medical environment while undergoing treatment and procedures to conceive.

Changes made in the provision of care that positively impact the quality of women's experiences of infertility treatment may also impact women's responses to treatment, contributing to treatment efficacy. Care that is more attuned to the individual needs of trauma survivors may assist in reducing posttraumatic stress symptoms in these women, which would reflect psychobiological changes in the stress regulation and the conception/pregnancy related functions of their neuroendocrine, immune, and vasomotor systems, including changes in somatically dissociated areas of their bodies. Most importantly, both the woman and, if she conceives, her child will benefit from the positive psychophysiological changes and imprinting that may result from adaptations in how care is provided through the contribution these changes will make to the woman's and baby's long-term health and well-being.

The Significance of the Quality of Touch to Women Receiving Reproductive Health Care

An important part of health care provider-patient interaction and communication is the quality of touch experienced by the patient. Understanding the types and significance of touch in the context of women's reproductive health care provides insight into the impact of experiences of touch in reproductive endocrinology treatment. One aspect of touch in reproductive health settings is the experience of authoritative touch. This has particular importance for women who are experiencing posttraumatic stress symptoms and who may have experienced physical trauma. Kitzinger (1997) describes several types of touch experienced by women during childbirth, another reproductive

health care experience during which authoritative touch may evoke varied responses in women with posttraumatic stress symptoms. Kitzinger explains:

Touch in childbirth can be classified in terms of its social function and its implicit value to the actors concerned. It may be instrumental, to perform a task, or expressive, to give affective contact, or both at once. It is often multifunctional and conveys meanings at different levels to the various participants, some of which may be acknowledged, or interpreted in conflicting ways. (Kitzinger, 1997, p. 215)

Kitzinger suggests several categories of touch experienced by women in childbirth, including blessing touch, comfort touch, physically supportive touch, diagnostic touch, manipulative touch, restraining touch, and punitive touch (1997, pp. 215-229). Women with posttraumatic stress symptoms and past experiences of physical trauma may experience and respond to the touch they receive in reproductive health care settings in positive and negative ways, depending on whether the touch they receive reminds them of past trauma. Kitzinger points out that,

Touch is never neutral. It is emotionally supportive or disabling. It is empowering or disempowering. Authoritative touch by caregivers in pregnancy and childbirth conveys strong messages to the woman concerning her status vis-à-vis her attendants, the reproductive efficiency of her body, the normality or abnormality of this birth, and about her value as a woman. (1997, p. 229)

The phenomenological exploration of the women's experiences of the quality of touch received during reproductive endocrinology treatment gives insight into women's psychophysiological reactions during exams, tests, and procedures. Kitzinger (1997) notes that women's experiences of the quality of touch they receive in the reproductive

health care setting of childbirth may evoke physiological responses associated with either anxiety or safety. The impact on them of the touch they receive is also contingent upon the interpersonal skills of the caregiver and shared values of caregiver and patient:

Though touch is considered the most intimate way of making human contact, when it is restraining or punitive it is an expression of the power that caregivers may exercise over a birthing woman. When it gives comfort, offers physical support, embodies cultural values shared between the giver and the recipient, however, it bridges the social space between them. Diagnostic and manipulative touch—elements of care in traditional as in technocratic cultures—may give contrasting messages, depending on the empathy and skills of the caregiver. It can cause pain, make a woman feel trapped, increase anxiety, and destroy confidence. Or it can help to maintain the spontaneous physiological process, reduce anxiety, and be a means of giving information and emotional support. (Kitzinger, 1997, p. 229)

Kitzinger's observations may also apply to infertility treatment. Women's experiences of diagnostic and manipulative touch—the type of authoritative touch most often experienced by women during the gynecological examinations and procedures common in infertility treatment—may be impacted by the empathy of the health care provider, and the shared or different cultural values of the health care provider and the woman. This suggests that the degree to which women with posttraumatic stress symptoms may experience authoritative touch in the medical setting as anxiety-producing or supportive may be influenced, in part, by the provider's capacity to observe, understand, and adapt the way they provide care in response to women's reactions to diagnostic and manipulative touch. Through a phenomenological study, we gain insight

into what women need to help prevent them from experiencing the touch they receive in the medical setting as a trigger that exacerbates their traumatic stress symptoms.

Research on the Quality of Patient-Doctor Communication During Women's Experiences of Reproductive Endocrinology Treatment for Infertility

Studies that include women's experiences of doctor-patient communication during infertility treatment shed light on the qualities that impact their satisfaction vs. dissatisfaction with the treatment they received. Research by Becker and Natchtigall (1991), Bergart (2000), and Malin et al. (2001) highlights the importance of the quality of patient-doctor communication during infertility treatment. In a study of Finnish women's satisfaction and dissatisfaction with infertility treatment, Malin et al. (2001) report, "the most positive treatment experience meant a good relationship with the infertility doctor, in which the doctor was humane, a good person, had time to listen, communicated well and was seriously committed to the woman's problem" (p. 131). The authors note that women reported their "most negative treatment experiences concerned poor relationships particularly with the doctors who did not take the patient seriously, and were impolite" (p. 131).

Results from a study conducted by Bergart (2000) indicate that the quality of doctor-patient communication described by women after unsuccessful infertility treatment was an important element of their experience of satisfaction or dissatisfaction with the care they received. Bergart reports that women were "pleased" that:

- (1) the doctor gave a realistic picture of the chances of treatment success;
- (2) the doctor and nurses were warm and concerned;
- (3) the doctor was not willing to treat indefinitely;
- (4) as the end of treatment the doctor stated (s)he was sorry that the treatment had not worked. (p. 62)

Women who expressed their “considerable dissatisfaction” with the care they received said their health care providers:

(1) were emotionally detached; (2) gave too little information about the treatments; (3) gave them ‘false hope’; (4) did not help them consider stopping treatment; (5) did not call back when they left word that they were stopping treatment. (Bergart, 2000, p. 62)

Becker and Nachtigall (1991) explored the role that “ambiguous responsibility” plays in doctor-patient interactions during infertility treatment, another aspect of interaction that may contribute to patients’ experiences of the quality of care they receive. The authors explain they examined,

the process by which ambiguous responsibility between patient and physician is negotiated in medical treatment for infertility.... Negotiation between doctor and patient subsequently revolves around the question, ‘Who is responsible for a pregnancy?’. (Becker & Nachtigall, 1991, p. 875)

How this negotiation is played out in verbal and non-verbal interactions between women and the doctors who treat them is likely to affect women’s experiences of treatment.

Although these studies did not specifically look at the experiences of women with traumatic stress symptoms, they highlight the importance to women of the quality of care received during the infertility treatment process and provide a glimpse into some of the elements of doctor-patient interaction that impact women’s experiences. This understanding creates curiosity about whether women with traumatic stress symptoms, who enter reproductive endocrinology treatment with unique needs may benefit from enhanced awareness and sensitivity on the part of health practitioners, and specific

adaptations in the way care is provided, which may result in increased satisfaction with the care they receive.

This research question, “What are the experiences of women with and without traumatic stress symptoms, who’ve received reproductive endocrinology treatment for infertility?” is grounded in the theory and research discussed in this chapter. This literature review also provides insight into the importance of the exploration of these experiences. A feminist-informed phenomenological methodology was chosen for its potential to provide a deep understanding of the specific experiences of women who’ve undergone this treatment.

Chapter 3: Methodology

Methodological Orientation

Phenomenology and Feminist Phenomenological Research

My choice to conduct a phenomenological study arises from my intention to understand and share women's lived experiences. It is rooted in the writings of theorists and researchers in feminist phenomenology. I believe a feminist phenomenological methodology, as demonstrated in the work of Levesque-Lopman (1988, 1993, 2000), Young (2005), Irigaray (1991), and Paget (1990), is best suited to providing insight into women's lived experiences and is the methodological base upon which I am building my research.

Feminist Phenomenology and the Voices of Women

I share the view of the feminist phenomenological researchers mentioned above that we can gain an understanding of a woman's experience and create a "discourse that cares" (Paget, 1990, p. 155) by providing an opportunity for a woman's direct communication with the researcher in which she uses her own voice and words. The title of Paget's work, "Unlearning to not speak" (1990), which she borrowed from a poem by Marge Piercy (as cited in Paget, 1990, p. 147), suggests that many women face a particular challenge in using their own voices, a challenge that is different from that of simply learning *how* to speak. It is the struggle to use one's voice after one has learned not to. As Paget points out, "unlearning to not speak" implies knowing how to speak, as well as "a prior silence and relinquishing the governing principles of that silence" (p. 147). Paget uses this concept to introduce her ideas on the limitations imposed by positivistic discourse in human sciences research; the issues involved in "creating a discourse for women's experience" (p. 148); and the essential importance of the direct

communication of women's words and ways of speaking in understanding their lived experiences. Paget observes:

A discourse that cares cannot be impersonal and remote. A discourse that cares needs to preserve connection with the world it portrays and interprets. Such a discourse necessarily invokes its subject matter for readers and permits (or tries to permit) readers to experience the subject matter as well. Such a discourse is concrete and generative: It shows a process lived through. (p. 155)

In discussing her work and a feminist approach to sociological inquiry, Levesque-Lopman (1988) states, "It acknowledges the study of women that places women's own experiences in the center of the process, and it examines the social world and women who inhabit it with new questions, analyses and theories built directly on women's experience" (p. 12). Levesque-Lopman's further elaboration on her objectives in conducting feminist phenomenological research to explore women's pregnancy and childbirth experiences resonates with my objectives for this study: those of providing an opportunity for women with and without traumatic stress symptoms to tell their stories of reproductive endocrinology treatment and to express what previously may not have been expressed. Levesque-Lopman states:

I wanted to provide each woman the opportunity to tell her own story in her own words; to provide a methodological framework for the expression of her pregnancy and childbirth experiences that was unique to her and that had often been muted, particularly in situations where her perceptions and the sense she made of "what was going on"- as well as her own interests, concerns, needs, and desires were at variance with those of the physicians, other medical professionals and attendants, and other women. (Levesque-Lopman, 2000, p. 111)

The work of Gilligan (1982, 1993), Brown and Gilligan, (1992), Gilligan, Rogers, and Tolman, (1991), and Belenky et al. (1986) illuminates the challenges girls and women face in trusting their perceptions and developing and sustaining their voices in our society. Gilligan (1991) focuses on adolescence as the stage during which girls often begin to lose their voices:

“Cover up,” girls are told as they reach adolescence, daily, in innumerable ways. Cover your body, cover your feelings, cover your relationships, cover your knowing, cover your voice, and perhaps above all, cover your desire.... And the wall that keeps memory from seeping through these covers may be the wall with the sign which labels body, feelings, relationships, knowing, voice and desire as bad. (pp. 22, 23)

The “cover up” often extends into adulthood. For many women, being able to find and use their voice can be especially challenging in the context of the doctor-patient relationship (Zaner, 2003), and particularly in the physical surroundings of the reproductive health care setting in which women are asked to assume vulnerable physical positions while undergoing gynecological examinations. For women who have experienced trauma, being able to find and use their voices in these settings can be an even greater challenge (Simkin & Klaus, 2004).

Phenomenology and Knowledge in the Doctor-Patient Encounter

Phenomenology has been used to gain an understanding of authority and knowledge in the doctor-patient encounter. Zaner (2003) comments on the displacement of the patient’s discourse in the doctor-patient encounter:

At the root of this displacement of the patient’s discourse within the clinical encounter is...a *displacement* of the patient’s lived relationship to his or her own

body in all its intimacy and everydayness and at the same time a *replacement* of it by the physician's diagnostic relationship to that body, now conceived as an objective and scientific body for clinical understanding and treatment. (p. 104)

Zaner's observation of the replacement of the patient's lived relationship to her own body by the physician's diagnostic relationship to and clinical understanding of her body is related to Brigitte Jordan's description of authoritative knowledge (1997). Jordan studied the role of authoritative knowledge in American hospital birth and observed that women's knowledge of the state of their bodies is superseded and delegitimized in the medical setting of American hospital birth (p. 61). The manner in which conception is attempted in a medical setting is also impacted by the beliefs held by both doctor and patient about what is and who holds authoritative knowledge in that setting. This conception of what constitutes authoritative knowledge in a medical setting may be limited to diagnostic and clinical findings and exclude a woman's own knowledge of the state of her body in that environment at that time. Jordan comments:

There are...situations in which multiple kinds of knowledge do not come together, in which one kind of knowledge wins out and carries the day...in which medical knowledge supersedes and delegitimizes other potentially relevant sources of knowledge such as the woman's prior experience and the knowledge she has of the state of her body. Nonmedical knowledge is devalued by the participants, usually including the woman herself, who comes to believe that the course charted on the basis of professional medical knowledge is the best for her. (Jordan, 1997, p. 61)

Clark and Mishler (1992) describe the results of their qualitative research on doctor-patient interactions that analyzed discourse in the clinical encounter. Their work

illustrates the different quality and type of information revealed in doctor-patient clinical interviews resulting from interview styles that either support or hamper patient narrative descriptions of their experiences of their illness. Their research demonstrates how “the patient’s experience is either recognized or reduced as social alignments are enacted” (p. 368) in the clinical encounter. In the case of trauma survivors, the willingness or unwillingness of providers to listen to the narrative descriptions of their experiences of their illness may have a particular and perhaps greater impact.

Phenomenology, Embodied Experience, and Trauma

Understanding women’s experiences of their bodies during reproductive endocrinology treatment may also be a key to understanding whether and how any traumatic stress symptoms they have may impact their treatment and its outcomes. Researchers Young (2005), Behnke (2003), Kirkengen (2001, 2008), and Kirkengen, Getz, & Hetlevik (2008) use phenomenology to explore embodied experience. Young (2005) explores female experience through a feminist phenomenological lens in her collection of essays entitled, “On Female Body Experience.” Young refers to the existential phenomenological writers whose theories on embodied consciousness (Merleau-Ponty, 1958) and the impact of sexual difference (De Beauvoir, 1952) on “situated being-in-the-world” (Young, 2005, p. 7) provided a basis for some of her explorations into female body experience. Young comments, “None of these essays take bodies as objects or things to observe, study or explain. Rather, the essays aim to describe subjectivity and women’s experience as lived and felt in the flesh” (pp. 6, 7). Young also describes the kinds of questions with which she approaches the subject of female experience, questions that can be explored through a phenomenological approach:

How do girls and women constitute their experienced world through movement and orientation in places? What are some of the feelings of ambivalence, pleasure, power, shame, objectification, and solidarity that girls and women have about bodies, their shape, flows, and capacities? How do the things and people we touch and are touched by become a material support for or extension of ourselves? To the extent that women occupy relatively disadvantaged positions in gendered power and role structures, how, if at all, is our subordination embodied? (Young, 2005, p. 9)

Behnke (2003) and Kirkengen (2001, 2008) use the lens of phenomenology to provide a deeper understanding of “the embodiment of violation and the violation of embodiment” experienced by trauma survivors (Behnke, 2003, p. 3). Behnke notes that Kirkengen’s study (2001) of the experiences of survivors of childhood sexual abuse, which used phenomenological and hermeneutical methods, facilitated access to the participants’ experiences of “shaken embodiment” (2003, p. 3) in the aftermath of abuse. Behnke points out that Kirkengen’s (2001) phenomenological study “Inscribed Bodies: Health Impact of Childhood Sexual Abuse,” also served to “stand in solidarity with the shaken: the survivors’ lived experiences were taken seriously—they were heard and believed, and a theoretical space that could do justice to this experience was opened up” (Behnke, 2003, p. 3, 4). Behnke comments further on Kirkengen’s research:

Kirkengen’s (2001) study demonstrates the value of phenomenology as a means to gain understanding of an individual’s experience of trauma and its subsequent impact on their health and their experiences of their body. Kirkengen (2001), notes, “It is thus our task as phenomenologists to learn to *hear* the silent sounds of the body passed over in silence, to listen instead of shouting it down—particularly

when this body is ‘mutely testifying’ to unspeakable violations that have been ‘socially silenced’.” (as cited in Behnke, 2003, p. 8)

The work of Kirkengen (2001, 2008) and Kirkengen et al. (2008) demonstrates how phenomenological research expands our understanding of embodied human experience. It provides knowledge about trauma, violation, health, disease, and health care not captured by the methodologies commonly used in biomedicine, which divide and reduce the totality of lived human experience into a mind-body dichotomy. Kirkengen (2008) notes that Merleau-Ponty’s work contradicts “the traditional distinction between thinking and perceiving” (p. 100) and “emphasizes that humans know about and perceive the world *by means* of their bodies” (p. 100). Kirkengen explains that subjectivity is grounded in the body and “consequently, the subjective body is primary to the object body and qualitatively different from the ‘mindless,’ purely physico-material body of the Cartesian legacy as it is integrated into biomedical theory (Thornquist, 2006)” (Kirkengen, 2008, p. 100). Kirkengen comments on how the concepts of “lived body” and “lived meaning” vs. the dichotomous concept of “mind and matter” are important to our understanding of health and trauma,

Applied on the diseased body, the traditional distinction between mind and matter as a basic concept is transcended. This position renders human experience and [particularly] sources of valid knowledge, relevant for an understanding of the impact of lived life on health. The view of the body as history and memory allows an integration of perception and experience into cognition and meaning. Thereby, an approach to the *lived meaning* of what a person has experienced *and* embodied, is provided. Since lived meanings are central to all incorporation of experiences, they are salient for any exploration of trauma impact. (p. 101)

Kirkengen's work is an example of how phenomenological research can provide a unique source of valuable knowledge about the experience of violation and trauma, "how it is imprinted into the lived body" (Kirkengen et al., 2008, p. 2,181), its impact on an individual's experiences receiving health care, and, in turn, an individual's embodiment of the health care they've received (Kirkengen, 2001). She elaborates on the theoretical shift that is necessary to deepen our understanding of violation trauma and its impacts on health:

The path from violation to sickness in a particular person is informed by personal appraisal of experience within a socio-cultural, historical and biographical context. Thus a theory of the lived body and of incarnate experience is a more adequate means to gain insight into the process of the transformation from violation to disease. A theoretical shift from the body of biomedicine to the lived body implies a shift of perspective: from "that" to "how". (Kirkengen, 2008, p. 101)

In addition, Kirkengen's work (2001) sheds light on how phenomenological research may provide a healing opportunity for study participants through the process of speaking in their own voices and sharing their experiences with a receptive other. It is my hope that this phenomenological research has provided a similar opportunity for its participants.

Phenomenology as a Means to Explore Women's Ways of Knowing Their Experience

Levesque-Lopman (1988, 1993, 2000) stresses the role phenomenological research can play in enabling us to better understand the unique experiences of women receiving reproductive health care by offering them the opportunity to use their voices outside of the doctor-patient relationship and the medical setting. Participating in semi-structured, open-ended, in-depth interviews with another woman may enable a woman to

reflect on and explore the nature of these experiences and to access her “way of knowing” (Belenky et al., 1986) her body, feelings, and relationships in an environment that acknowledges this information as authoritative knowledge. Levesque-Lopman (2000) states that one of the purposes of phenomenological research is “to select experiences which, through recollection and reflection, are given a change in attention, a new attention à la vie, that thus make ‘problematic’ what had previously been taken-for-granted, or seen-but-not-noticed” (p. 110).

Philosophical Foundations and the Use of Lifeworld Phenomenology

The work of Bentz (2003), Bentz and Shapiro (1998), Husserl (1970), Moustakas (1994), and van Manen (1990) guided the design and conduct of this study. The philosophical foundations of phenomenology ground the study in lived experience (Schutz, 1970), embodied consciousness (Merleau-Ponty, 1958), and the unique experiences of women (De Beauvoir, 1952).

van Manen explains the concept of the lifeworld: “Our lived experiences and the structures of meanings (themes) in terms of which these lived experiences can be described and interpreted constitute the immense complexity of the lifeworld” (1990, p. 101). van Manen notes that we may each inhabit several different lifeworlds each day, for example those of home, work or school, or for the purposes of this research, the lifeworld of the infertility treatment setting. The author also identifies four fundamental lifeworld themes or “existentials” that he suggests “pervade the lifeworlds of all human beings, regardless of their historical, cultural or social situatedness”, which may serve as guides in the research process: “lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)” (van Manen, 1990, p. 101).

Schutz's focus on human action and interaction in the lifeworld sheds light on another aspect of this phenomenological study:

The world of everyday life is the scene and also the object of our actions and interactions. We have to dominate it and we have to change it in order to realize the purposes which we pursue within it among our fellow-men. Thus we work and operate not only within but upon the world. Our bodily movements—kinaesthetic, locomotive, operative—gear, so to speak into the world, modifying or changing its objects and their mutual relationships. On the other hand, these objects offer resistance to our acts which we have either to overcome or to which we have to yield. (p. 73)

Schutz's (1970) observations may have special significance when applied to the health care of women with PTSD symptoms. Women who experience the medical setting as threatening and as a result whose PTSD symptoms may be exacerbated in that setting may find themselves having either to overcome or yield to the experiences through a range of fight/flight/freeze responses. This in turn may elicit a variety of responses from the providers engaged in their care.

Merleau-Ponty's work (1958) on the phenomenology of perception acknowledges the inseparability of the body and mind in human lived experience. He describes phenomenology as offering "an account of space, time and the world as we 'live' them" without consideration of the "psychological origins and the causal explanation" (p. vii). Merleau-Ponty's description provides further support for a phenomenological approach to this research, which seeks to share women's accounts of their lived-body experiences of treatment for conditions (stress/traumatic stress and infertility) that exemplify the inseparability of mind and body.

While De Beauvoir did her work on differentiating women's roles and experiences in society decades ago (1952), it is nevertheless applicable to women's experience today and, as such, provides a basis for this research. This study seeks to understand and give voice to the uniqueness of women's experiences of one aspect of reproductive health care today, care that is received within a health care system that is still largely male-dominated. De Beauvoir comments:

To begin with, there will always be certain differences between man and woman; her eroticism, and therefore her sexual world, have a special form of their own and therefore cannot fail to engender a sensuality, a sensitivity, of a special nature. This means that her relations to her body, to that of the male, to the child, will never be identical with those the male bears to his own body, that of the female, and to the child. (De Beauvoir, 1952, p. 731)

The work of the phenomenological researchers and theorists mentioned above supports my belief that this methodological choice allowed for the emergence of multiple kinds of relevant knowledge. This knowledge increases our understanding of stress/traumatic stress, infertility, and its treatment and provides insight into how the negative impacts of these psychophysiological sensitive conditions may be reduced through adaptations in the way care is provided.

Phenomenological Research to Inform Change in Women's Health Care

The phenomenological analysis of the qualitative data collected in this study may help inform change in the physical and interpersonal environments in which women receive reproductive health care. I have used lifeworld phenomenology to gain an understanding of the specific qualities and significance of participants' lived experiences, both of which provide keys to adaptations in care that may impact treatment outcomes. I

share van Manen's (1990) view that, "The essence or nature of an experience has been adequately described in language if the description reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner" (p. 10).

Levesque-Lopman's (2000) comments on the requirements for the possibility of the expansion of the boundaries of scientific knowledge in medicine that emerged from the Women's Health Movement and the Reproductive Rights Movement reflect my views and hope that this phenomenological study may contribute to that process:

This was to require changes in understanding of what is "real," possibly also requiring a shift in previously rigid boundaries between objective and subjective phenomena. Also, it was to require a more serious examination of the relationship between mind and body. Such shifts and changes were not intended as a negation of medical science or a denial of everything that had been achieved by the previous paradigm. Rather, they were to offer the possibility of moving towards an expanded and more complete form of knowledge. (Levesque-Lopman, 2000, p. 109)

By gaining an understanding of women's lived-body experiences in the reproductive endocrinology treatment environment, women, their partners, and their health care providers may begin to explore the impact of women's traumatic stress symptoms and other negative psychophysiological states on their experiences. In addition, this understanding may initiate consideration of how psychophysiological screening for these states may provide information that can inform how care is provided to women in reproductive endocrinology treatment. Women, their partners, and their health care providers may discover an opportunity to work together to identify ways to meet the unique needs of a substantial number of women who may face the dual and

possibly related challenges of negative psychophysiological states and infertility— sharing and hearing the knowledge each holds to facilitate a more comprehensive and more effective approach to treatment.

Research Methods

Participants and Sampling

The original focus of my research was to explore the experiences of women with traumatic stress (PTSD) and/or dissociative symptoms receiving reproductive endocrinology treatment for infertility. “Criterion sampling” (Rudestam & Newton, 2001, p.92) was used to select women who were undergoing reproductive endocrinology treatment and reported traumatic stress and/or dissociative symptoms on two self-report screening tools administered prior to participation. As I began to screen and interview participants, I felt important knowledge would be gained from the inclusion of the perspectives and experiences of women who had undergone reproductive endocrinology treatment, but had discontinued treatment with either successful or unsuccessful treatment outcomes some time before the screening process for the study. I also considered the importance of understanding the perspectives and experiences of women who went through reproductive endocrinology treatment and did not report current or recent traumatic stress or dissociative symptoms on the self-report measures. As a result, I broadened the research question to, “What are the experiences of women, with and without traumatic stress symptoms, who received reproductive endocrinology treatment for infertility?”

Nine volunteers were screened and six that met the criteria for the study were offered the opportunity to participate. The study’s six participants were between the ages of thirty-two and fifty-three. The participants included four women who were still

pursuing reproductive endocrinology treatment at the time of the interviews and reported current and/or recent traumatic stress/dissociative symptoms, and two women who had discontinued treatment prior to the interviews, neither of whom reported current or recent traumatic stress/dissociative symptoms. Of these two women, one had conceived following IVF treatment and given birth two months prior to the first interview, the second had discontinued treatment five years prior to the interviews following eight years of repeated treatment cycles which had not resulted in a term pregnancy or birth of a child.

Potential participants were made aware of the study through the posting of paper flyers, distribution of flyers through reproductive endocrinology practices, a posting about the study on the website of an organization that provides support for those facing fertility challenges, a posting on an internet forum for doulas in the New York area, and word of mouth.

I chose to use a study group size that allowed me to focus my energies on a comprehensive phenomenological analysis of the data generated from each of the interviews. The large amount of data generated from the interviews after I had conducted two in-depth interviews with five of the six women, and one in-depth interview with one of the women, influenced my decision to limit the study group size. A phenomenological study, as noted by Larkin, Watts, and Clifton, (2006), “typically involves a highly intensive and detailed analysis of the accounts produced by a comparatively small number of participants” (p. 103). In a literature review of interpretative phenomenological studies in health psychology conducted by Brocki and Wearden (2006), fourteen of the fifty-two studies considered in the review had seven or fewer participants.

The study group size was also limited by the number of women who contacted me expressing interest in participating in the study. Initially, an incentive was not offered for participation in the study. In an effort to increase potential participant interest, an incentive was offered for participation in each of the three phases of the study. The three steps included completion of the screening tools, participation in the first interview, and participation in the second interview. The total incentive offered for participation in all three phases was \$75.00 in the form of amazon.com gift certificates. The small study group size has yielded a depth of understanding that supports one of my research goals—to gain insightful information gleaned directly from participants’ descriptions of their experiences that may be used to inform the way health care is provided to women.

After completing one validated self-report screening tool for traumatic stress (PTSD) symptoms (Trauma Symptom Inventory, Briere, 1995), and one validated self-report screening tool for dissociative symptoms (Multiscale Dissociation Inventory, Briere, 2002), six women were chosen to participate in the study. Four of the women were identified as experiencing DSM-IV-TR (American Psychiatric Association, 2000) defined symptoms for PTSD (without recollection of a traumatic event), and/or related dissociative symptoms as described in the trauma literature (American Psychiatric Association, 2000; Bromberg, 2006; Scaer, 2007; van der Kolk, Pelcovitz, Roth et al., 1996; van der Kolk, van der Hart & Marmar, 1996).

The DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for PTSD include both identification of a traumatic event and presence of at least six symptoms from three symptom categories: persistent reexperiencing of a traumatic event, avoidance of stimuli associated with the trauma and numbing of general responsiveness, and persistent symptoms of increased arousal (pp. 467, 468). The DSM-IV-TR

(American Psychiatric Association, 2000) defines a traumatic event as one in which “the person has experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others” and that “the person’s response involved intense fear, helplessness, or horror” (p. 467). Yehuda (2002) points out that individuals may present with clinical symptoms of PTSD but may identify a stressor that does not meet the DSM-IV-TR criteria for a traumatic stressor. She notes that individuals may identify “subthreshold” traumatic events as particularly stressful because these events remind them of a previous traumatic event (Yehuda, 2000, p. 8).

As mentioned earlier, Scaer (2001) and Simkin and Klaus (2004) note that traumatic experiences may not be remembered at all, yet still may precipitate PTSD symptoms. Therefore, for the purposes of this study, participants were not required to identify a specific traumatic event. Participants were assessed for PTSD symptoms and their severity using PTSD self-report assessment measures.

The DSM-IV-TR (American Psychiatric Association, 2000) criteria for PTSD is limited to dissociative symptoms described as “dissociative flashback”, which is included in the reexperiencing criteria (p. 468). A broad range of dissociative symptoms are currently recognized by trauma researchers and clinicians as significant components of PTSD. Scaer (2001) explains:

Dissociation is one of the cardinal features of the late adaptive mechanisms of PTSD.... The persistence of dissociation in chronic PTSD may play a role in suppression of the HPA axis, and contribute to the loss of adaptation to the continued cyclical arousal in chronic PTSD. (pp. 66, 67)

For the purposes of this study, I examined the prevalence of dissociative symptoms, in addition to the symptoms described in the DSM-IV-TR (American Psychiatric Association, 2000) criteria, as part of the PTSD symptom cluster.

PTSD is differentiated from Acute Stress Disorder in the DSM-IV-TR (American Psychiatric Association, 2000) most significantly by the duration of the disturbance (symptoms lasting more than one month) and the timing of the onset of symptoms (delayed onset PTSD is diagnosed if symptoms occur at least six months after the stressor; p. 468). Acute Stress Disorder lasts for a minimum of two days and a maximum of four weeks and occurs within four weeks of the traumatic event (pp. 471, 472).

Screening Measures

The Trauma Symptom Inventory (Briere, 1995) and the Multiscale Dissociation Inventory (Briere, 2002) were identified as reliable and valid measures that will effectively screen potential study participants for DSM-IV TR (American Psychiatric Association, 2000) related PTSD and dissociative symptoms. The Trauma Symptom Inventory (TSI) (Briere, 1995), a 100-item self-report measure, was administered to study participants to assess the presence and severity of symptoms associated with PTSD and other psychological sequelae of traumatic events. The TSI was developed to evaluate acute and chronic traumatic symptomology, including the long-term effects of childhood abuse and other early traumatic events. The TSI is a standardized and normed measure that assesses ten categories of traumatic symptomology, including the following: anxious arousal, depression, anger/irritability, intrusive experiences, defensive avoidance, dissociation, sexual concerns, dysfunctional sexual behavior, impaired self-reference, and tension reduction behavior. The measure contains three validity scales, including: response level, atypical response, and inconsistent response, which allow for “the

detection of those who tend to deny even commonly endorsed symptoms, those who report an unusual number of statistically unlikely or bizarre responses, and those who respond to items of similar content in an inconsistent or random manner” (Briere, 1995, p. 3). The TSI was normed on 836 individuals from the general population and its scores can be converted to T-scores for comparison to the scores in the standardization sample. Subscales that provide separate data on the ten categories of symptoms could provide data for more detailed analysis of the prevalence of a particular subgroup of trauma symptoms in women receiving reproductive endocrinology treatment. Briere (1995) reports the TSI’s 10 clinical scales “were analyzed for internal consistency in the standardization sample using the alpha statistic. Reliability coefficients for the final version of the TSI clinical scales ranged from .74 to .91” (p. 34). Briere reports that the mean alpha level was .86 (p. 34). Alpha coefficients for the validity scales, response level (RL), atypical response (ATR), and inconsistent response (INC), were .80, .75, and .51 respectively (p. 34).

The Multiscale Dissociation Inventory (MDI; Briere, 2002), a 30-item self-report measure, was administered to study participants to assess the presence and severity of dissociative symptoms. The MDI is a standardized and normed measure that assesses six types of dissociative responses, including the following: disengagement, depersonalization, derealization, emotional constriction, memory disturbance, and identity dissociation. A dissociation profile is generated from the results of the six subscales, rather than a single score. Briere (2004) reports that the MDI is normed on 444 trauma-exposed individuals from the general population and its scores can be converted to T-scores that permit “empirically based clinical interpretation of clients’ level of dissociative disturbance” (p. 182). Briere (2002) reports that the six subscales

“were analyzed for internal consistency in the full general population sample (i.e., in both traumatized and nontraumatized individuals), as well as in the university student sample and the combined clinical-community sample” (p. 24). Mean alpha coefficients were .85 for the general population, .77 for the university population, and .92 for the clinical-community sample (p. 24).

Data Collection Procedures

Six participants were interviewed: four women whose self-report screening assessments indicated they were currently experiencing or had recently experienced clinically significant traumatic stress and/or dissociative symptoms and two women whose assessments indicated they were not currently or had not recently experienced clinically significant symptoms. Clinically significant symptoms on the TSI were indicated by a *T* score at or above 65 on any of the ten clinical scales (Briere, 1995, p. 11). Clinically significant symptoms on the MDI were indicated by a score at or above 80 on five of the six scales. Clinically significant symptoms were indicated by a *T* score at or above 95 on one of the MDI scales, (the Identity Dissociation scale; Briere, 2002, pp. 6-7).

The study participants were interviewed about the nature of their experiences receiving reproductive endocrinology treatment. Two 90-100 minute, semi-structured interviews were conducted with five of the participants. My decision to interview the women twice was based on my intention to establish a relationship and a level of comfort with them during the first interview that might support further and potentially deeper exploration of their experiences in the second interview. Only one 90-100 minute interview was conducted with one participant, due to the fact that she became pregnant in the period between interviews. The participant and I shared concerns about the how the

discussion and recall of stressful and deeply distressing experiences might impact her pregnancy. The pregnancy occurred without medical assistance, between IVF treatment cycles.

Each participant's second interview expanded upon the first. If the participant had focused on certain aspects of her experiences in the first interview and had not talked about others, I began the second interview by asking if she wanted to share her experiences about those, as yet, unexplored aspects. The women tended to delve more deeply into the meaning of these experiences in their lives and relationships, as well as their visions of their future during the second interview. At the end of the second interview, the women paused to express their intention that their participation in the study would potentially benefit other women, and took time to appreciate the commitment and investment they had made in sharing feelings and experiences that were often difficult for them to talk about.

All interviews were audio-recorded. Five of the women chose to be interviewed in their homes. One of the participants chose to be interviewed in a non-medical office space. I transcribed the two interviews conducted with the first participant. I reviewed the remaining nine interviews that were transcribed by a transcription service by listening to the audio recordings while checking for correctness and inclusion of non-verbal communications and expressions such as crying, sighs, laughter, pacing, and pauses in speech. As noted by Kvale (1996) the transcription of interviews involves "translating oral language, with its own set of rules, to a written language with another set of rules. Transcripts are not copies or representations of some original reality, they are interpretative constructions that are useful tools for given purposes" (p. 165). Kvale

highlights the fact that there is no “true, objective” way to transform oral communication to written language (p. 166).

Mishler elaborates on the qualities of speech that are difficult, if not impossible, to capture in transcriptions of oral language:

Each transcript includes some and excludes some other features of speech and rearranges the flow of speech into lines of text within the limits of a page. Some features of speech, such as rapid changes in pitch, stress, volume and rate, seem almost impossible to represent adequately while at the same time retaining the legibility of the text. Adding another complexity are the nonlinguistic features of any speech situation, such as gestures, facial expressions, body movements, that are not captured on audio tape recordings and are difficult to describe and record from observations or videotapes. Lastly, it must be born in mind that the initial record—audio—or videotape or running conversation—is itself only a partial representation of what ‘actually’ occurred. (Mishler, 1989, pp. 47-48)

Although the six participants interviewed spanned a range of ages and came from several different cultural backgrounds, it was not my intention to conduct a study that was large enough to support generalization of the data to other women of similar ages and cultural backgrounds. I did not conduct any statistical analysis of the data gathered from the administration of assessment tools during the screening process. My sole purpose in administering the assessment tools was to identify women who had received reproductive endocrinology treatment and had recently or were currently experiencing traumatic stress and/or dissociative symptoms.

Interview Questions

I gathered data about the women's experiences throughout their treatment. Demographic information and information about the length of time they had been trying to conceive and had been receiving treatment for infertility was obtained during the screening process. I used the following questions as a framework to assist the participant in focusing on and sharing a comprehensive account of her experiences in reproductive endocrinology treatment.

1. I am studying women's experiences of reproductive endocrinology treatment. Can you remember your first appointment and physical examination with the reproductive endocrinologist? Please describe in as much detail as possible what you remember about that experience. I'm curious about your feelings, thoughts, bodily sensations—just anything and everything you remember.

2. Can you tell me what you were thinking just before your first appointment?

3. Can you describe what took place during the first appointment?

4. How did your body feel during the appointment and physical/pelvic examination?

5. What emotions, if any do you remember feeling?

6. What thoughts were you having during and after the appointment?

7. Can you tell me feelings you had after the appointment and what meaning, if any, the experience has had for you?

8. I'm also interested in your other experiences receiving treatment. Can you remember other physical examinations or treatment procedures you experienced with the reproductive endocrinologist? I'm also curious about your feelings, thoughts, bodily sensations—just anything and everything you remember about these experiences.

9. Is there anything about your experiences receiving reproductive endocrinology treatment that you would have liked to be different?

10. How has the challenge of infertility and its treatment impacted your life?

Participant responses in each interview determined the questions asked. As described in Chapter 4, the Results chapter, the second participant asked if she could tell me her whole story first, without having to stop and answer the questions I had prepared. Her request helped me understand that the most effective way I could support women to explore the experiences they chose to share with me was to offer them the opportunity to tell their stories in their own way and in their own sequence. What they chose to include or exclude and where they chose to begin to weave their stories became aspects of their narrative that shaped my impressions and my understandings of their experiences. I realized that the more questions I asked, the more I was shaping their stories, rather than allowing them the space to freely sculpt their stories in the presence of an empathic witness. I sensed that by offering them the opportunity to do so, I was communicating my deep respect for them as women using their voices to share their experiences.

Some women expressed concern about whether they were giving me the information I was “looking for” and whether they were responding in the “right” way. Realizing I wanted to assist them in sharing *their* story, not the one they thought I wanted to hear, I began the interviews with the last four participants with a very open-ended statement and referred to the interview questions I had prepared only when/if I felt it was appropriate in the moment. As I participated in more interviews, my trust in knowing what was appropriate in the moment grew. The statement I began to start the interviews with was,

I am interested in hearing about and understanding your experiences of reproductive endocrinology treatment, including anything you feel comfortable sharing with me. I am interested in hearing about your thoughts, feelings, emotions, bodily sensations, before, during and after appointments, physical examinations and procedures, just anything and everything that may come to mind that you choose to share with me about your experiences. There is no one way to do this, no right or wrong way. You can tell me about your experiences in whatever way you feel you want to share them.

After interviewing the first two participants, I had an increasing sense that the quality of presence that I brought to the interviews was far more important than any questions I conceptualized to assist the women in exploring their experiences. The quality of presence combined with the open-ended format of the interviews supported the women's engagement in deep explorations of very personal experiences that I felt honored to witness.

Data Analysis Methods

Bentz and Shapiro's (1998) concept of mindful inquiry informed my approach to this phenomenological research. Bentz and Shapiro describe the mindful inquirer as making space and time for reflection before and after each move forward in the research endeavor as the researcher moves from his or her focus on the problem or concern, to personal reflections or interpretations of its meaning, to streams of research related to the topic, to methodological and theoretical literature (p. 43).

The actions I took during the data analysis process began with listening to and transcribing the audio-recorded interviews. The transition from audio recording to printed word through the transcription process inevitably impacts the data.

This was followed by immersion in the transcription of each woman's interviews. Initially, I assembled the narrative, holding all aspects as they emerged as equally important. Themes that captured the quality, impact, and significance of each woman's

experiences surfaced and were articulated after careful, repeated review of each narrative. From the themes that emerged from the individual narratives, I considered the aspects of the women's experiences that were both shared with other participants and unique within the study group. I developed a synthesis of themes that reflected their experiences as a group. This sparked an abundance of connections in my mind between the women's experiences, the research, and theory upon which this study is grounded and the implications of this research for practice and future research which will be discussed in Chapter 5, the Discussion chapter.

The phenomenological research processes described by Moustakas (1994), including Epoche, phenomenological reduction, imaginative variation and synthesis (pp. 84-101) informed the data analysis used in this study. The application of phenomenological research processes to the women's interview transcripts allowed me to, as van Manen (1990) explains, "uncover and describe the structures, the internal meaning structures of lived experience" (p. 10).

Moustakas (1994) explains the "Epoche" process, noting that the "Epoche" is the term Husserl used for "the freedom from suppositions" (p.85). Moustakas explains Epoche as:

A way of looking and being, an unfettered stance. Whatever or whoever appears in our consciousness is approached with an openness, seeing just what is there and allowing what is there to linger.... Thus the Epoche gives us an original vantage point, a clearing of mind, space and time, a holding in abeyance of whatever colors the experience or directs us. (Moustakas, 1994, p. 86)

In preparing for the process of Epoche while conducting this research (a crucial foundation of phenomenological research), I engaged in the writing of protocols—that is, rich descriptions of my own related experiences that impacted my choice to conduct this research. By engaging in a deep exploration of my own feelings and beliefs, I was able to gain an awareness and understanding of how they might impact the research study. Analysis of these protocols revealed my “way of knowing” and provided insight into the multidimensional aspects of my experiences, including aspects I tend to focus on and those I may ignore, meanings I’ve attributed to my experiences and the impact these meanings have had on the way I see and engage with the world, including the world of this research study. The depth of understanding I gained from this analysis assisted me in noticing what my limitations in perception might be and what expectations I bring to my experiences, revealing the lenses and filters through which I view and interpret the world. These lenses and filters have evolved out of my life experiences and impacted my conception of the design, implementation, and analysis of the research.

Through the process of analyzing the protocols, I developed a deeper level of self-awareness and a level of consciousness that I believe positively impacted my thinking and writing during this research. Awareness of my expectations and filters helped me to be open to seeing beyond them, and in so doing, enhanced my ability to learn from the interactions with, and experiences shared by the participants. Most importantly, I believe that through an increased awareness of myself, I was able to expand my capacity to be present with the participants and the fullness of the experiences they described during our interactions.

I initially utilized phenomenological reduction to work with the data transcribed from the interviews. Moustakas describes the process of phenomenological reduction:

The task is that of describing in textural language just what one sees, not only in terms of the external object but also the internal act of consciousness, the experience as such, the rhythm and relationship between phenomenon and self.

The qualities of the experience become the focus; the filling in or completion of the nature and meaning of the experience becomes the challenge. (1994, p. 90)

Moustakas (1994) suggests that the process of phenomenological reduction is dependent on a capacity to clearly reflect upon, attend to, recognize and describe the phenomena being studied and is enhanced or expanded with “continuing attention and perception, with continued looking, with the adding of new perspectives. Reflection becomes more exact through corrections that more completely and accurately present what appears before us” (Moustakas, 1994, p. 93). The steps of the process of phenomenological reduction are summarized by Moustakas:

The steps of Phenomenological Reduction include: *Bracketing*, in which the focus of the research is placed in brackets, everything else is set aside so that the entire research process is rooted solely on the topic and question; *horizontalization*, every statement initially is treated as having equal value. Later, statements irrelevant to the topic question as well as those that are repetitive or overlapping are deleted, leaving only the *Horizons* (the textural meanings and invariant constituents of the phenomenon); *Clustering the Horizons into Themes*; and *Organizing the Horizons and Themes Into a Coherent Textural Description* of the phenomenon. (Moustakas, 1994, p. 97)

This process was followed by the application of imaginative variation, the goal of which was to describe the essential structures of the phenomenon. This was sought through variation in frames of reference, use of imagination, consideration of the

phenomenon from divergent perspectives, and the employment of polarities. The steps of imaginative variation are clearly described by Moustakas (1994):

1. Systematic varying of the possible structural meanings that underlie the textural meanings;
2. Recognizing the underlying themes or contexts that account for the emergence of the phenomenon;
3. Considering the universal structures that precipitate feelings and thoughts with reference to the phenomenon, such as the structure of time, space, bodily concerns, materiality, causality, relation to self, or relation to others;
4. Searching for exemplification that vividly illustrate the invariant structural themes and facilitate the development of a structural description of the phenomenon. (Moustakas, 1994, p. 99)

The last step in the phenomenological analysis was to synthesize the meanings and essences of the experience of the phenomenon as a whole. As Moustakas (1994) points out, this textural-structural synthesis “represents the essences at a particular time and place from the vantage point of an individual researcher following an exhaustive imaginative and reflective study of the phenomenon” (p. 100). I have been inspired by the comments of Moustakas on the potential impact of phenomenological investigation into human experience: “One learns to see naively and freshly again, to value conscious experience, to respect the evidence of one’s senses, and to move toward an intersubjective knowing of things, people and everyday experiences” (Moustakas, 1994, p. 101). In my view, Moustakas’ comments resonate with the goals I had in conducting this research and the methodology I chose to employ in the process of the investigation.

The comments of Larkin et al. (2006) on the goals, limitations, and definition of the successful application of phenomenology reflect my experience of conducting this phenomenological study:

The central goal of phenomenology is to approach and deal with any object of our attention in just such a way that it is allowed maximal opportunity to show itself ‘as itself’. Another way of putting this is that the phenomenologist aims to reveal any subject-matter *on its own terms* (i.e., not according to the imposition of any *preconceived* set of assumptions and expectations). It is, nonetheless, inevitable that we will fall short of this target, for being a ‘person-in-context’ (and hence, an observer, indelibly situated within the meaningful world that we observe) we can never fully escape the ‘preconceptions’ that our world brings with it. But this should not discourage us from making the attempt... The important point is that our success as phenomenologists will not ultimately be dependent upon our revealing the ‘pure’ experience of a participant; it will be dependent upon our being prepared to do the most sensitive and responsive job we can, given our inherent epistemological and methodological limitations. (p. 108)

In an effort to do the most “sensitive and responsive job” possible, I tried to retain the integrity of each woman’s story while integrating it into the synthesis of themes that emerged from the experiences of the study group as a whole.

Additional comments by Larkin et al. (2006) support the interpretation of the data that will be explored in the Discussion chapter:

Interpretative analysis affords the researcher an opportunity to deal with the data in a more speculative fashion: to think about ‘what it means’ for the participants to have made these claims, and to have expressed these feelings and concerns *in*

this particular situation. Aspects of this interpretative work may also be informed by direct engagement with existing theoretical constructs. (p. 104)

Ethical Issues and Protection of Participants

Following careful description of research goals, methods, procedures, and use of data as approved by the Santa Barbara Graduate Institute Institutional Review Board, clear agreements regarding participation in the study were established with research participants. Due to the particular vulnerability of infertile women with traumatic stress symptoms, measures were in place to enable study participants to access additional counseling if necessary. Confidentiality and anonymity were maintained through coding of participants' identities, including coding of results of traumatic stress symptom screening scales, dissociative symptom screening scales, as well as interview data collected during the study.

It was estimated that participants would incur moderate physical and psychological risk by participating in this study. Awareness of the possibility that some participants might experience traumatic stress and/or dissociative symptoms during or following screening and interview measures brought to light an ethical question—how might participation in the research impact the infertility treatment process and a pregnancy, in the event that the participant conceived during the study? Measures were in place to refer women, at their request, to appropriate counseling if they experienced psychological distress, including increased traumatic stress and/or dissociative symptoms during or following the assessment and interview process.

Chapter 4: Results

This chapter will explore the results of the thematic analysis of the interview data. Six themes emerged from the analysis that shed light on the research question, “What are the experiences of women with and without traumatic stress symptoms receiving reproductive endocrinology treatment for infertility?” The themes provide a window into the participants’ mind-body experiences of reproductive endocrinology treatment and its impact on their lives.

If you would like to deeply understand the experiences of the women in this study, I ask that you take a moment to settle and open your heart to their voices. If I succeed in what I have set out to do, their voices may touch your heart, as they have touched mine.

Introduction to the Participants

Let me introduce you to the women in a more personal way now, by acquainting you with their names (pseudonyms) in the order that they came forward and offered to speak with me: Pearl, Lilah, Pam, Marina, Zoe, and Celia. Each woman came into reproductive endocrinology treatment with their unique reproductive health history and recent experiences trying to conceive in the context of their individual life circumstances at that time. The women were at different points along their fertility journeys when they spoke to me.

Pearl

Pearl, age 43 at the time of the interviews, was living in a committed relationship with her partner. She had a graduate degree and was working as a practitioner in alternative health care. Pearl had been trying to conceive for five years. She sought reproductive endocrinology treatment after one year of trying to conceive without

medical assistance. Pearl had been through 15 treatment cycles, including multiple rounds of intrauterine insemination (IUI) and in vitro fertilization (IVF) treatment. She had conceived in an early IUI treatment cycle, but lost the baby in the fifth month of the pregnancy. Pearl mentioned that the 9/11 attack on New York immediately preceded the period in which she was trying to conceive. She described experiencing posttraumatic stress symptoms that lasted for months after the attack and coincided with her attempts to become pregnant. At the time we spoke, she had taken an eight-month break from the reproductive endocrinology treatment cycles that followed the loss of the pregnancy, and was thinking about starting again.

Lilah

Lilah, age 37 at the time of the interviews, was married and had a son who was over two and a half years old. She was caring for her son full-time and had some college education. Lilah had been trying to conceive her second child for two years and had been in reproductive endocrinology treatment for 10 months. Her first child was conceived without medical assistance. She had been through several IUI cycles of treatment and had conceived twice, but the pregnancies were ectopic (the embryos implanted in the fallopian tube). Lilah terminated the first ectopic pregnancy and suffered a ruptured fallopian tube that required emergency surgery early in the second pregnancy. At the time she spoke to me, Lilah was waiting to be able to start an IVF treatment cycle.

Pam

Pam, age 37 at the time of the interviews, was married, had a college degree and was working in finance. Pam had been trying to conceive for two years. She had been receiving reproductive endocrinology treatment for 15 months. Pam had been through

several rounds of IUI and IVF treatment, but had not conceived. At the time we spoke, she was evaluating her treatment options for the next IVF cycle.

Marina

Marina, age 32 at the time of the interview, was married, had completed a graduate degree and worked in the business industry. Marina had been trying to conceive for two and a half years and had been receiving treatment from a reproductive endocrinologist for one year. She had been through several treatment cycles and conceived once during an IVF cycle, but miscarried very early in the pregnancy. Marina conceived again without medical treatment after our first interview, just before she was scheduled to start the next IVF cycle. We did not schedule a second interview out of concern about its potential to trigger difficult emotions while she was pregnant and the impact that might have on her baby.

Zoe

Zoe, age 42 at the time of the interviews, was married, had a college degree and was working in the film industry. Zoe had tried to conceive for two years. She had undergone one and a half years of reproductive endocrinology treatment and after a few IVF treatment cycles, had a successful pregnancy. Zoe contacted me in the last trimester of her pregnancy, but we agreed to meet after she gave birth out of concern about how the interviews might affect her and her baby during the pregnancy. She shared her experiences of treatment, pregnancy, and the early postpartum period with me, two months after she gave birth to her son.

Celia

Celia, age 53, at the time of the interviews, was single, had a graduate degree and worked as a practitioner in alternative health care. She shared her story with me five

years after she'd stopped reproductive endocrinology treatment. She had tried to conceive and been in reproductive endocrinology treatment for eight years. Celia had undergone multiple cycles of IUI and IVF treatment during which she conceived, but had miscarried early in the pregnancies following both types of treatment. Celia mentioned that the 9/11 attack on New York occurred during the period she was receiving reproductive endocrinology treatment. She described experiencing traumatic memories that were triggered after the attack. She looked back on her experiences of treatment and their impacts and also shared her mind-body experience of talking about them at the time of the interview.

As described above, the women had been in reproductive endocrinology treatment for different lengths of time. Each had undergone several diagnostic tests and repeated reproductive endocrinology treatment procedures. At the time of the interviews, all had undergone IUI and all, except Lilah, had undergone IVF treatment. Celia was the only woman who used donor sperm during some cycles of treatment. Zoe was the only woman who had carried a pregnancy to term and given birth following the treatment she received.

Learning to Listen

My interviews with each woman brought me face to face with the many ways they were impacted by their experiences trying to conceive. One by one, each woman picked up the thread and took a turn weaving this tapestry of experience with her voice, her silence, and sometimes her tears. Themes emerged from the six women's stories. Some themes emerged from the experiences of several women, and some were unique to specific women.

During my interview with the second participant, Lilah, I gained an increased awareness of the importance of offering each woman as much space as they might need to shape how they wanted to share their experiences. How they chose to tell me their stories contributed significantly to my understanding of their experiences and seemed to reflect how they continued to be affected, at the time we spoke, by what they'd been through. It was Lilah who made it clear to me that she had to tell her whole narrative her way first and requested that I withhold my questions until she'd had an opportunity to do so. I am grateful to her for bringing this to my awareness which helped me fully embrace my intention to be a witnessing other, and to hold presence for the participants. It allowed me to trust the women to find their own best way to communicate with me, thereby increasing my openness to hearing the aspects of their journey they felt were most important to share with me, in contrast to eliciting a story more directly shaped by my questions asked in a particular order.

I became sensitive to the potential significance of what they left out, as well as to what they chose to share and I honored their choice. I began each interview with an explicit acknowledgement that it was up to them to choose how and what they felt comfortable sharing with me, and there was no "right way" to do this. I was acutely concerned that the quality of interaction in the interviews, as much as possible, not feel similar to, or remind the women of previous traumatic experiences they may have endured and not contribute to their already high levels of stress. This gentle approach, at times left me with unanswered questions about the women's experiences. My intention not to contribute to the women's distress was more important to me than getting the answer to a specific question. I trusted my sense in the moment, of whether to ask or let go of my questions during my time with them. I was deeply moved sitting with each

woman as their verbal and non-verbal expressions communicated their experiences to me. I felt honored to have been entrusted with the richness of all they shared. I have felt from the beginning, their stories are, in some way, gifts they've given to me. It is in that spirit that I respectfully share them with you.

I want to explicitly acknowledge that inherent in the process of bringing these experiences to the reader, the participants were challenged with translating their lived experience into spoken words as they were face to face with me. I have been challenged to share my lived experiences of the women and their spoken words with you through the printed word and to do so within the limitations imposed by the structure of an academic dissertation. Each degree of separation from the original experience and the limitations imposed by the structure of a dissertation create the potential for certain aspects of the women's experiences to be lost in translation. I have tried my best to retain the essence of each woman's experience in the face of these challenges.

I've had to come to terms with the impossibility of being able to include in its entirety, each woman's narrative and to accept that what I present here to you, although representative of their experiences individually and as a group, cannot fully capture each woman's journey. The task of identifying themes also carries with it the necessity of separating the narratives of the women's experiences into parts and imposes in some way, artificial distinctions between the multidimensional aspects of their experiences. These distinctions or separations allow for a closer look or deeper understanding on one level, but the women's experiences might best be understood if you also consider that each theme is only part of the whole. If you stand back, I hope you will see that each theme is intricately interwoven in the fabric of the women's individual experiences, as well as the collective tapestry that emerged from the group. I ask you to hold that awareness as you

engage with the descriptions of the women's experiences. It is my hope that the participants' stories will communicate a felt sense of the impact of their experiences and inspire readers to consider the potential implications of these experiences for women, their families, and the health care providers who interact with them.

Theme 1: The Emotional Roller Coaster: Cycles of Treatment Evoke a Range of Intense and Shifting Emotions, Challenging the Women's Capacity to Cope

The women as a group described their experiences of a wide range of feelings throughout their fertility journeys and reproductive endocrinology treatment, including hope, anxiety, vulnerability, fear, excitement, joy, terror, disappointment, hopelessness, failure, inadequacy, sadness, grief, desperation, fragility, shame, guilt, irritability, anger, rage, depression, disconnection, shock, and numbness. All the women described having, at times, rapidly shifting and sometimes conflicting feelings during the process of trying to conceive. Several women also described experiences in which they felt powerless, helpless, exposed, invisible and betrayed. These feelings were evoked most often in interactions with health care providers and will be discussed in a later theme in the context of their experiences of the quality of care they received.

All the women described going through cycles of emotions that varied with the cycles of treatment and phases within each cycle, the outcome of each cycle, and the pauses between them. They experienced intense fluctuations between a wide range of emotions before, during, and after diagnostic tests and treatment procedures. Some of their feelings were expected, some were unexpected. For some of the women, the feelings they experienced were overwhelming. Others expressed a fear of being overwhelmed by their feelings if they let themselves experience them.

Pearl likened the experience of getting through the range of deeply painful feelings each day after she'd been through multiple treatment cycles and the loss of a pregnancy in the fifth month to the challenge of "balancing a pearl on a plate" and likened the elusiveness of trying to conceive and sustain a pregnancy to the experience of "trying to catch the butterfly all the time." Lilah explained that as a result of shutting off her feelings, she felt "like a volcano waiting to erupt.... All these pent up feelings, when you don't get to deal with them, they turn to anger." Pam's feelings had ranged from hope to devastation, depression, and an ongoing grief that felt endless. Marina described feeling hope then disappointment, after which she blocked out her emotions. Zoe tearfully explained that she experienced an "intense range" of feelings, "the gamut in terms of...feelings that I...kind of expected...feelings I certainly didn't expect." Celia explained that looking back on her reproductive endocrinology treatment experiences five years after she stopped, she felt a sense of "betrayal" resulting from the care she received from several of the medical providers from whom she sought treatment.

Acknowledging the Need for Help and Making the Call

All of the women except Celia described going through a period of time trying to conceive without medical assistance, the length of which varied among the women. Pearl, Lilah, Pam, Marina, and Zoe talked about feelings that arose as they came to terms with the fact that they were not conceiving on their own and felt they needed to seek medical assistance to do so. They explained how each month of trying to conceive on their own had begun with hope, but had ended with disappointment and increasing despair when the dreaded sight of blood signaled the beginning of their period and another unsuccessful attempt.

Calling to make an appointment with a reproductive endocrinologist meant accepting and acknowledging that there was a problem and outside help was needed. Since Celia had made the decision to try to conceive without a committed partner, she sought medical assistance to begin that process. Pam explained that she told herself she'd make an appointment with a reproductive endocrinologist after six months of trying to conceive, but as she came into the fourth or fifth month of trying, she started to resist the thought of going to the doctor. Pam commented that her hesitation came from her background in statistics and her understanding of statistical outcomes, in this case—those of reproductive endocrinology treatment. She stated it simply: a group of women got pregnant and a group didn't. Going to the appointment brought her closer to finding out whether she would fall into the reproductive endocrinology treatment group that conceived or the one that did not.

The women described coming to their first appointment with the reproductive endocrinologist with mixed feelings. Each woman came to the appointment with varying levels of concern about the fact that they had not conceived on their own during the time period leading up to the appointment, although Pearl, Lilah, and Celia had conceived at other times in their lives and Lilah had a child. Each woman who had been trying to conceive before their appointment with the reproductive endocrinologist carried feelings of disappointment following repeated cycles of unsuccessful attempts. The intensity of their disappointment increased with the length of time they had been trying. For Pearl, disappointment had turned to desperation. Before the first appointment with the reproductive endocrinologist, Pearl explained, "I was already to the point where I was like crying my eyes out every time I got my period," and had reached a "wretched state of desperation."

Expectations and Anticipatory Anxiety About Treatment

As they approached their first appointment with the reproductive endocrinologist, the women described feelings of failure, inadequacy, and fear about the treatment itself and the possibility that it would be unsuccessful. Some described the hope they held that the treatment would solve their problem and they would conceive. Pearl described feeling fragile, upset, and like a failure in anticipation of her first appointment with the doctor. She explained she was “scared to death” of the “horrible,” dreaded journey of infertility treatment on which she was about to embark, having already heard much about it from her friends who’d gone through it. Lilah commented that she felt “embarrassed” and “broken” and didn’t want to look at herself or think of herself as “infertile.” Pam described feeling “overwhelmed by a fear for the first time, that oh my God, I was never gonna have a baby.”

Several women expressed anxiety about what was going to happen during the appointment, not having been given information beforehand about what to expect. Three of the women, Lilah, Pam, and Marina, described feeling hopeful that the doctor would be able to “fix” what was wrong and they would conceive. Lilah expressed feeling apprehensive about the first appointment because she didn’t know what the first appointment would “entail,” but optimistic the treatment would “fix whatever is wrong with me.” Zoe explained that although she felt confident she could get through the physical aspects of the treatment, having heard much about it from friends who’d gone through it, initially she found it easier “not to expect and not to hope and not to believe” she was going to get pregnant to protect herself from disappointment.

Marina described feeling “casual,” not “over anxious” and hoped there wouldn’t be anything wrong. If there was a problem, she commented that she was thinking “we

can fix it quickly and start having kids,” it would be “something that can be corrected.” Celia, who was trying to conceive without a committed partner, described coming to the realization that if she wanted to have a child, she “didn’t have a choice” and had to seek medical assistance to do so. She came to her first appointment to explore that process.

The First Appointment

The women reflected on the range of feelings they experienced during their first appointments. Pearl described a realization she had in the waiting room at her first appointment, “I couldn’t do this [conceive] and now I’m here. I’m here in this horrible club that I don’t want to be a member of.” Celia described feeling confused about the sequence of what was going to happen at the first visit with the doctor. Lilah went to the first appointment alone. In the waiting room before the appointment, she described feeling awkward. The room was filled mostly with couples and she felt she “didn’t belong.” She also felt embarrassed that she had to be there and thought the other women must feel that way too. She explained,

We feel broken. You know, we feel broken. I feel like I’m inadequate. I feel like I’m an inadequate woman that I can’t do what I’m supposed to do, that my body is not functioning for whatever reason. I feel inadequate because my cycle is not normal, something was changing, something was happening within me and it was me...that was causing us to have problems.... Something inside of me was broke.

At the first visit, Pam described having the expectation that the doctor would “give me a couple of pills, put me on some Clomid [a drug used in infertility treatment to correct irregular ovulation and help increase egg production] send me home...30, 60 days, I’ll be pregnant. Not a big deal.”

Several women described their concerns about what the doctor and office staff would think of them. Some were anxious that they would be judged and blamed for their past and present choices. Pearl expressed concern about how the doctor would react to

her and her partner's ages and how long she'd waited to try to conceive. Some of the women had had abortions. Pearl imagined the doctor would tell her, "You know those two abortions you had? Well, you shouldn't have, because this is your punishment and you can go away now." Pearl commented that she also thought that her difficulty conceiving might be God's punishment for her past choices and behavior, which also contributed to the high level of anxiety she felt in anticipation of the first appointment.

Lilah noted that she felt that she was not meeting the doctor's and nursing staff's expectations when she came to the first appointment without her husband who couldn't be there that day. Celia expressed concern about how sharing the fact that she worked in alternative health care might affect the way the doctor treated her.

For each woman, the first appointment included a consultation with the doctor. Several of the women commented that their partners had not yet reached the point where they felt they needed medical help to conceive. Pearl and Lilah explained that this added to their stress leading up to the first appointment. Pearl described feeling ashamed talking out loud about her worries and recounting her reproductive and health history in front of the doctor and her partner, even though she had talked about them with her partner before. Pearl's worries included her concern that "there must be something that I've done wrong in my life" and maybe she had a sexually transmitted disease. She explained that feelings of shame surfaced during the first appointment because, "still, it's like you have to say it out loud and you know, it's like put the shame out there kind of thing and um, you're willing to do it because you want to get pregnant."

For some, the first appointment included a pelvic exam, but not for others. Not knowing what to expect increased the women's anticipatory anxiety and stress during the visit. All of the women expressed varying degrees of embarrassment or anxiety about

having a pelvic exam. Pearl, Pam and Zoe described previous experiences that contributed to their concerns about the exams. Pearl shared the fact that she had been sexually abused. Pam shared the fact that she had been the victim of two violent crimes. Zoe described having negative feelings about gynecology exams stemming from her first pelvic exams during which the doctors made insensitive and embarrassing comments in front of other medical staff. The women's experiences of the physical aspects of infertility treatment will be discussed more fully in a later theme describing their mind-body experiences undergoing exams, tests and procedures.

Despite the wide variance in the quality of care described by the women at their first reproductive endocrinology appointments (which will be discussed later), most of them left feeling hopeful that they could be helped to conceive. Pearl described feeling elated:

I definitely just remember a feeling of (laughs) elation. It was just like the clouds opened, the sun shined and we were laughing like (big exhale) we still could have a baby. He didn't tell us we were too old and to go away and you're terrible for even trying and get out of my office." Pearl also described her sense of relief after her first appointment, "I had another person on the team...and that was heavenly. Like I don't have to come up with all the answers myself. Somebody else actually does this. They can take the ball and run with it for a while because I'm tired of carrying this ball around...and having to check it constantly and see what it's doing and make sure I'm on the latest greatest ball."

Pam commented that she remembered the hope the doctor gave her when he told her, "I really think you're gonna get pregnant" at the first appointment.

Lilah and Celia left their first appointments feeling overwhelmed. Lilah recalled feeling unfamiliar with the terminology the doctor used during the first appointment and felt like he was losing her as he talked. After the appointment she felt overwhelmed and confused about what he said and unable to communicate what she'd been told to her husband. The doctor suggested moving ahead quickly with a diagnostic test, the purpose

of which she was also confused about. Lilah remembered feeling nervous, but also excited about proceeding at the fast pace suggested by the doctor.

Celia commented that it felt like everyone was “moving so fast” at the first appointment and her head started to get dizzy “like it is right now [during the interview]...I’m sure I was dissociated out of my mind. Um, and I have res [resources]—I have tools. So I just wonder how the rest of the world does it.” Celia described the experience of an unsuccessful pelvic exam the doctor attempted to do at the first appointment. Due to the doctor’s forceful attempts, but inability to insert the speculum properly in Celia’s vagina, Celia described her first appointment as “the worst experience.... It was terrible.” Celia’s painful experience left her feeling confused and surprised, “I didn’t get it...That this world that I had decided to walk into—I couldn’t believe that it was this cruel...I guess it felt like being raped kind of, you know?”

Menstrual and Reproductive Endocrinology Treatment Cycles Converge in a Sense of Urgency: Pushing to the Physical and Emotional Edge

The women expressed a sense of urgency about moving from one cycle to the next due to the knowledge that their treatment was limited to the total number of menstrual cycles they had each year. They had an acute awareness that statistically, their chances of conceiving declined with each passing year. They described how their emotional states shifted when they received information about test results and their significance from the doctors, before, during, and after treatment cycles. The doctors’ verbal and non-verbal communications were carefully observed and interpreted by the women as optimistic or pessimistic about the outcome of a particular procedure, as well as their overall chances of conceiving as time and treatment cycles progressed without success. The women described high levels of stress and anxiety while they waited for

diagnostic test results, for cycles of treatment to be synchronized with their menstrual cycles, to find out if they had conceived at the end of a treatment cycle, or, if they had conceived, to find out if the pregnancy was viable.

Pearl described the frustration and impatience she felt having to coordinate fertility treatment with menstrual cycles. She commented that going through the diagnostic evaluation process can take a long time and, in retrospect, can make the time spent waiting to make an appointment and then be seen by the reproductive endocrinologist feel like wasted time. “You have to wait another month for everything to happen...and...when you look at a year? A whole year you can only try to get pregnant twelve times.... Just twelve days in an entire year. That weighs on you so heavy.”

Pearl commented that hope would be rekindled with the prospect of each new cycle and each new treatment option or protocol. Each month she didn't get pregnant, she wondered what she could do differently the next cycle that might work and felt an urgency to know about the next and newest treatment options. “You get so excited when you get to try a different protocol, because you think this might be the one, this will be the one, this could be the one that works.”

Zoe described the tension between feeling a sense of urgency to move from cycle to cycle and the experience of having to wait for each step and watch for the outcome of each cycle. Looking back, Zoe described feeling like she was in a “time warp” while she was in reproductive endocrinology treatment: “You feel like the time it took you to conceive seemed forever, forever! And in our case it wasn't.” Zoe described being “so caught up in—in feeling and believing that every cycle matters, every cycle matters.” She explained how waiting and watching while she was trying to conceive contributed to the feeling of being in a time warp. “It just seems as if you're watching the minutes go

by [waiting to start a treatment cycle] and then...when you start it [the treatment cycle] you're just watching the minutes go by [laughs] you know, it's never ending."

The women's hope would be replaced by disappointment and grief if they failed to conceive or sustain a pregnancy, and the sequence would repeat itself with each unsuccessful treatment cycle. The time between treatment cycles did not allow them to fully process the array of intense, deep, and complex feelings that surfaced before, during, and after these physically and emotionally challenging experiences. All the women described having conflicting feelings about whether to take a break from treatment to give their bodies, minds, and hearts a chance to recover, or proceed as quickly as possible with the next treatment cycle and protocol. The conflict was fueled by their sense of urgency arising from their concerns about their chances of conceiving as they aged, the quality of their aging eggs, and the fact that they had a finite number of menstrual cycles in their childbearing years during which they could attempt to conceive. Some women were concerned that the doctors would refuse to treat them beyond a certain age. Some of the women pushed themselves through these cycles repeatedly until they felt they couldn't take it anymore and had become concerned about the toll it was taking on their physical and mental health.

Pam described the emotional roller coaster she experienced following her hopeful expectations in the first month in treatment. She explained that she was "so convinced" at the beginning that she would get pregnant from the treatment, she had told her husband, "Well, you know, obviously, I'm gonna get pregnant. I have a whole SWAT team of doctors working on me. They certainly know what to do. I'm on this magical medication, Clomid, which fixes whatever's wrong with my ovaries and causes my eggs to be fabulous." Pam commented that the "most traumatic moments" for her were

following the first unsuccessful treatment cycle and the last unsuccessful treatment cycle she completed just prior to the second interview. After the first treatment cycle, she experienced shock and disappointment. “I was convinced I was going to die.” She described the intensity of her desire to conceive and how far she was willing to push herself, “I would...cut off a limb...I would sell my soul to the devil to be pregnant at this point.”

Even though she had doubts that she would conceive during the first IVF cycle due to the amount of physical and emotional stress she’d experienced from the “overstimulation” reaction she had to the doses of hormones prescribed during this cycle, Pam explained that she regained hope for a positive outcome when the embryologist told her she had four “beautiful looking embryos.” She commented she was “very proud” when he gave her a picture of the embryos, which she put on her refrigerator.

You know, happy to death, hoping and praying, that even though my body was under an enormous amount of stress...that I would still get pregnant...I was thrilled that I hadn’t bled out [gotten her period] before—it was the first time I actually *made* it to a pregnancy test. I was so excited.

Pam received the call from the doctor with the negative pregnancy test result while she was at work. She described being unprepared for how “disastrous” it was for her to hear that she hadn’t conceived. “I kind of went into shock...I really, to this day, I say I went into shock. I remember I just stood in my office holding my cell phone and I just froze...I could feel the hysteria coming.” Pam explained the roller coaster of feelings she experienced in the hours and days following the phone call that included numbness, freeze, rage, hysteria, and grief. She went home and described how she felt while she waited to hear back from her husband so she could tell him the news:

I was frozen on the couch. I literally went numb and I was sitting frozen on the

couch and all I could think to myself was, 'Please strike me dead. Please let the lightning come down and strike me dead. I just want to die. I really, really want to die.'

When her husband arrived home several hours later and asked what had happened, she explained, "I sat frozen on the couch...I couldn't answer...and then the hysteria came in and I cried all night and I cried for the next couple of days.

Following another IVF cycle, Pam experienced what she thought were early pregnancy symptoms. When the pregnancy test was again negative, she described the impact of the unsuccessful cycle as "devastating" to both her and her husband. Pam described the range of symptoms she experienced that she attributed to the "psychological trauma" associated with infertility treatment. "I spent the first year thinking I was going insane, that I was losing my sanity." She noted that a therapist she had begun seeing explained that her feelings were "pretty normal" for what she'd been through. Pam was relieved. She listed the symptoms she had been experiencing, which included nightmares, panic attacks, sweats, and dissociative symptoms—not being able to figure out why you're standing where you are, wanting to set your own house on fire, kill yourself, or kill somebody else. She commented that the panic attacks at night were particularly terrible. "I don't even sleep. Even when I sleep, I just have nightmares now." She tearfully described a recurring nightmare she had been having every night for months: "I inevitably have some kind of dream where I have a baby that's dying, but I can't save him."

Pam elaborated on the depression she experienced and explained that she cried all the time and wanted to stop. She had been "working on not crying anymore" and commented that she felt angry with herself that the depression she felt hadn't lifted and

was “pissed” that she couldn’t “get over it.” She commented that she felt like she was living a nightmare in her waking life, from which, “sooner or later” she would wake up.

Pam explained that the fact that the doctor had not found any conclusive reason why she wasn’t getting pregnant made it difficult for her to make a decision to stop trying to conceive. She felt she couldn’t stop trying because her baby might be,

Just one more try away. It’s the next one. It could be this cycle. It could be the cycle after that. It’s out there. The baby’s there and I feel that to give up on trying for our own child is some kind of weakness on my part. I wasn’t strong enough to do it.

She commented that she had come to see her experience in reproductive endocrinology treatment as a trauma like other traumas in her life, one that she felt, was not recognized as such by her family, friends or the doctors who provided her medical care. She commented on the huge toll IVF treatment was taking on her life:

It takes control of your life. I fear losing my job. I fear losing my career. I fear losing my sanity. My sanity is a big one these days. I wonder how many times I’m gonna be able to do this before I really, honestly, seriously just crack, like somebody ends up putting me in a strait jacket and hauling me away. I do worry about it now.

Living with the Uncertainty of the Viability of a Pregnancy in the First Trimester

Marina, Lilah, and Celia described their experiences having positive pregnancy tests following treatment cycles and then losing the pregnancy in the first trimester. Lilah conceived twice following IUI procedures and Marina had a positive pregnancy test once following an IVF treatment cycle. Celia had conceived several times and miscarried each time.

Celia described the excitement she felt during the pregnancy that lasted the longest—into the sixth week. She commented that she “felt all these things” and learned about the signs of early pregnancy. If she didn’t feel them, she questioned whether she

was still pregnant, “I would go through all this stuff in my head. It was so annoying.... But I was pregnant, you know. And I, oh my God, it was so amazing.” At five or six weeks, she felt a change in her body, and a few days later, “It was gone. That was really unfortunate. Um, I wonder what else I felt besides sad and unfortunate. I feel like there’s another piece.”

Marina and Lilah described the stress and difficulty of waiting for hormone and sonogram test results over several weeks to confirm whether or not the pregnancy was viable. Each described their cautious optimism and distress over the uncertainty about whether the pregnancy would proceed. Neither was able to obtain a definitive answer for several weeks. Even though the medical staff cautioned them that there was cause for concern about the outcome of the pregnancy following each pregnancy hormone test result that was borderline normal, their hope would be bolstered. They tried not to get excited in order to protect themselves from disappointment if they lost the pregnancy, but with each passing day they didn’t miscarry, their excitement increased and they began to allow themselves to think the pregnancy could have a successful outcome.

Marina described her experience going for the first sonogram after the positive pregnancy test, during which the doctor was unable to see an embryo in her uterus and couldn’t give a definitive explanation for the discrepancy between the two test results. A doctor she consulted for a second opinion explained that sometimes a miscarriage happens so early, that if a woman had become pregnant naturally, she wouldn’t have even known she was pregnant. She would have gotten her period and not have realized she was having an early miscarriage. The practice of closely monitoring hormone levels every two days and conducting early sonograms following reproductive endocrinology treatment cycles brings the uncertainty of the viability of a pregnancy during this early

embryonic period into a woman's conscious awareness in a way that does not usually occur when a woman conceives without medical assistance.

Lilah went into reproductive endocrinology treatment after several months of unsuccessfully trying to conceive her second child. Lilah explained that she was adopted and it was very important to her that her son not be an only child. She conceived during a cycle in which she underwent IUI and described being excited and optimistic as her hormone levels initially increased. The blood hormone level test results, taken every two days, showed increasing hormone levels and provided a positive early indicator of the potential viability of the pregnancy. Six weeks into the pregnancy, Lilah started bleeding. Her emotions abruptly changed from hopefulness, cautious optimism, and excitement to fear at the first appearance of vaginal bleeding, and then to despair, loss, and grief when symptoms and diagnostic tests confirmed the pregnancy wasn't developing normally. Following a sonogram performed by a different doctor than the one she had been seeing regularly, Lilah described feeling "destroyed" as the doctor, while watching the computer monitor, repeated, "There's nothing there. There's nothing there. This isn't a viable pregnancy." Lilah remembered being in the exam room with her husband after the sonogram, lying on the exam table and crying hysterically, feeling that the doctor had "stomped on every single dream and hope" she had. Following the sonogram, Lilah waited to miscarry. She continued to have symptoms of early pregnancy, fatigue and nausea and commented,

That was the worst, to like technically be pregnant, but not be pregnant. It was just, that was horrible. Horrible. And it's like you're fighting it, cause like you're telling yourself mentally, like well, I'm not pregnant anymore, so I, I can't be tired and I can't be this nauseous.

Lilah's distress led her to ask the doctor if there were other options besides waiting to miscarry. "I needed to end it. I needed it to be over. I needed to do whatever I could to just make it stop now." Lilah opted for a D & C, but the pathology report following the surgery revealed that the pregnancy was not in her uterus, it was ectopic, which explained why she continued to be tired and nauseas. She was then faced with having to make a decision about how to end the ectopic pregnancy. She chose to take a chemotherapy drug used to dissolve ectopic pregnancies, after which it took three more weeks for her hormone levels to return to their non-pregnant level and during which time, she still had pregnancy symptoms. She had been pregnant and optimistic for six weeks. For six more weeks she lived with the sad awareness that she carried a non-viable pregnancy, had to make difficult treatment decisions, and waited to get her period.

Lilah conceived a second time after another IUI, but her hormone levels didn't increase in the pattern expected of a viable pregnancy. At increased risk for another ectopic pregnancy, having already had one, Lilah was monitored very closely by the doctor. She was told to go to the emergency room immediately if she experienced any pain due to the fact that pain could be an indication that her fallopian tube had ruptured, a serious life-threatening emergency associated with ectopic pregnancy. When she was five and a half weeks pregnant, her hormone levels dropped and went up again. A sonogram was scheduled to determine the course of treatment since the hormone levels indicated the pregnancy did not appear to be developing normally. Prior to the sonogram, Lilah fainted, began bleeding vaginally, was taken to the emergency room, began experiencing excruciating pain and was diagnosed with a second ectopic pregnancy that had ruptured her fallopian tube and caused internal bleeding. Lilah explained that extremely intense emotions surfaced as she began to realize the seriousness of her

condition and the fact that she could die. She remembered thinking, “Oh my God, I’m bleeding internally” and described becoming overwhelmed with the fear that she would never see her son again.

I’m sitting there and I’m like, oh my God, I’m never going to see my son again (crying as she spoke about this). Oh my God, the feelings were unbelievable. So I just like [said to my husband] ‘Promise me, (crying) just promise me you’ll take care of S [their son]...And... just make sure he knows I love him.

Lilah remembered thinking,

This is like the worst feeling I’ve ever felt in my life, the worst. I felt like that was it. Like everything was over, right then and there. Like my life had just ended and I was just, I had enough time to just say my goodbyes. And all I kept thinking (crying) is I’m never gonna see my son again. You know? It was the worst, the absolute worst.... But, I came out of it. I didn’t die (laughs). I got to see my son again. They sent me home the same day.... I don’t even know if I can really truly give justice to what I felt at the time.

The doctor removed the ruptured tube. Following the surgery, Lilah explained that she was depressed for several weeks:

I felt weak (emotionally) because I haven’t been able to handle this as well as I should have.... I didn’t leave my house and for days on end, I didn’t take a shower, and you know, my son stayed in his pajamas all day and you know...I didn’t really bother with him. I didn’t really play with him for probably a good three weeks after my surgery. I didn’t go out.

She described feeling embarrassed by her “weakness.” It was “unacceptable” to her and she felt she “shouldn’t be feeling like this.” She explained how these feeling turned to anger, which she directed at herself, “I was mad at myself for feeling what I was feeling, and mad at myself for questioning why I was feeling what I was feeling.”

She commented that thinking about her son helped her get through all she’d been through:

I just keep thinking, as hard as it is for me to go through all this, I have him.... He is the air I breathe. He really is. You know? He is the sun every day.... The tough part is when I think about him and think about my need to give him a sibling, and for him to have a sibling.

Lilah explained that she felt challenged to hold and contain the intensifying accumulation of emotions that had been evoked by each experience she'd been through and its outcome. Her feelings would build up inside and feel "overwhelming and inundating." She commented that they would "creep up" when she was sitting by herself quietly, watching a movie and "all of a sudden, something triggers and then all these emotions come flooding in and then all the things that you weren't allowed to feel and think about, and then, now, you're a basket case." She described not knowing how to deal with these waves of emotions, trying repeatedly to shut them off, and the anger that would "erupt" within her when she could no longer contain them:

And then, when it just gets to the point and you're like a volcano waiting to erupt, then, you know, you start screaming at people, and you start snapping at people and you have road rage, you're driving like 80 miles an hour.... All these pent up feelings, when you don't get to deal with them, they turn to anger.

Lilah described how much time she had to put her feelings away unresolved, she felt "more raw" than when they first came out because she had thought about them again and "rehashed" them, but couldn't deal with them. She elaborated on the conflict she experienced, the struggle between wanting to deal with the feelings, not being able to stop thinking about them, and feeling guilty if she took time to be with her feelings,

I feel guilty for...wanting to deal with my feelings and wanta think about my feelings and then I feel guilty for doing that.... And then you feel guilty because you didn't cook dinner because you were sitting on the couch crying...but then the phone rang, so you have to stop doing that, so then you were talking and you were trying to act like everything was ok...and be there for somebody. So you didn't cook dinner and now he's home [husband], and he's starving and your son didn't eat and...now you're guilty because you didn't do the things you were supposed to do...a never-ending cycle, it just doesn't end.

Recognizing the Edge and Making the Decision to Pause or Stop Treatment

Pearl commented that her willingness to do anything—as she called it, her "obsession" to conceive—included taking all the drugs, the hormones over a four-year

period, that were part of the reproductive endocrinology treatment process, even though breast cancer ran in her family. She reported that the hormones made her more emotional and negatively affected her mood to the point where she didn't recognize herself and wondered, "Who was I?" As she looked back to the time before she decided to take a break from treatment, she commented that she had lost perspective, was "out of my head" and in a desperate mode, in a desperate place. She described that over the course of four years of treatment, she had been brought to an emotional edge, and felt she couldn't handle it anymore. At that point, she described going back to the first doctor with whom she felt comfortable and cared for, who responded to her despair and prescribed antidepressants, "I was just like bawling my eyes out. I couldn't speak. I was just gone and saying things like, 'I can't take this anymore. I can't take it. I can't take it.'"

Celia commented on the process of pushing herself through the many complications she experienced during reproductive endocrinology treatment. She explained that she underwent "a couple of surgeries" that included a myomectomy to remove a fibroid tumor from her uterus which was only discovered after several treatment cycles. Following the initial surgery to remove the tumor, Celia experienced a high fever and had to undergo a second surgery to treat an infection that had developed. Prior to the surgeries and during the time she was receiving reproductive endocrinology treatment, Celia developed high blood pressure and had to begin taking medication for hypertension, to which she had "bad reactions." Even though she was on medication, she had been told that her blood pressure had been difficult to control during the surgery. She commented that her "determination" enabled her to push through these physically and emotionally challenging experiences.

A friend of Celia's finally helped her to reflect on how her determination was preventing her from seeing the impact her fertility journey was having on her health, as well as the serious complications resulting from her hypertension, that she and her baby might face if she successfully conceived and sustained a pregnancy. Celia described the internal conflict she faced following the conversation with her friend. She commented on the two aspects of the conflict and explained that one part of her was saying,

'Oh my God.' And then there was this little part of me, this little baby, little child that was going, 'But what about me?' You know.... And yet, there was this bigger part of me that said, 'Oh, I'm not an idiot. I need to stop this, or I'm going to die.'

She had come to the realization she had pushed herself to the point where she felt she was endangering her health and if she continued, would, perhaps, be endangering her life.

Celia looked back on her experience of coming to the decision to stop treatment:

So I've always had this determination, so this determination carried into my fertility—which is important because my determination (I hope I've learned my lesson), often overrides what's real or what's reality.... In terms of this overriding thing I do, it wasn't until maybe two years ago that I realized in my eight years of doing fertility stuff, how out there on a limb I was. And I so didn't see it.... I couldn't believe that I didn't see what was happening.

Celia noted that it wasn't until she was able to connect with another part of herself, a "little one inside of me that said, 'I can't do this,'" that she was able to stop overriding her experience and stop pushing herself through the treatment and the complications.

Celia described her last experience, before deciding to stop treatment, of trying to give herself injections of fertility drugs:

My body's screaming, 'Please don't.' Like I was trying to even still push through it. And my body's going 'Don't do it. Don't do it.' And I just like cried. I couldn't do it. It was just, like, I couldn't do it.

Connecting with the “little one inside of her” also helped her to let go of the belief “‘I could have pushed.’ For most of the time up until that point, I would have said or would have wondered, ‘Did I try hard enough? What did I do wrong? I’ve never failed at anything.’” Celia added that all her life, she had gotten the message, “If you were really strong, you could do it.” She commented, “You know, I don’t give up. Pull yourself up by your bootstraps. You gotta be strong and independent.... But it almost killed me.”

Celia commented that she believed that women who sought treatment when they were older felt shame or guilt, “Most of us, myself included, walk around with this shame or guilt like we—we should have done it sooner.” She described going back to the reproductive endocrinologist she liked who did not do IVF, and had agreed to continue seeing her for regular gynecological care:

I, you, walked around with...a little bit of shame.... I have to say that after awhile, I felt shame about the fact that I hadn’t gotten pregnant. That I kept having miscarriages, when I’d go to these places [doctors’ offices where other women were trying to conceive]. I think I was so, excuse my language, fucked up and dissociated and in shock.

Celia’s description of feelings of shame and being “dissociated and in shock” touches on other types of coping mechanisms several other women described in their efforts to deal with the physical and emotional challenges of treatment.

Theme 2: Protecting Oneself from Painful Emotions and Physical Challenges Through Compartmentalization, Disconnection, and Dissociation

Several women explained that they coped with the physical and emotional challenges and stresses involved in repeated cycles of treatment by compartmentalizing each experience and trying to distance themselves from their feelings about what they’d been through. Some of them described using dissociation during the treatment exams, tests, and procedures. These experiences will be discussed below, in the context of

another theme. Some women described blocking out their feelings, shutting them off, or pushing them down in order to get through one treatment cycle after another and still be able to function in their lives. Celia commented that she didn't remember how many cycles of treatment she had been through.

Lilah explained that in contrast to the times when she felt very angry, like “a bitch on wheels” and had “zero tolerance and zero patience,” she also experienced periods in which she felt withdrawn and completely closed off during the time she was receiving reproductive endocrinology treatment.

I'm just like a drone, sitting in the corner. I'm not a part of the conversation. I'm not a part of the room. I'm in my own little place. I just physically am there, but my mind's not.... Not really wanting to be there, but having to be there, and just, so going into myself. So, I'm here, you [referring to her husband] wanted me to be here, so I'm here.... So it's like one extreme to the other.

Lilah explained that she compartmentalized her experiences in order to be able to function and take care of her child. She commented that she had the feeling that if she opened all the “different compartmentalized boxes and emotions”, which she likened to Russian nesting dolls, each containing another smaller one inside, each of which contained some experience she had been through or emotion she put aside, she wouldn't be able to function, she'd have to be institutionalized and “somebody would have to come and take care of my child.”

She commented that she usually was able to “just shrug things off” and felt that if she allowed herself to really feel her feelings, she didn't think she would be able to continue with the treatment. “If you don't shut off your emotions and shut off your feelings that you're having, at least for the time being, you'll never get through it.”

Marina explained that each time she was told a treatment cycle didn't work, whether it was a cycle in which they tried insemination or IVF, “for one day, I'd be—got

very upset and stuff, but then, after, the next day I'd be fine.... I'd kind of block it out and think, 'I've got to move on.'" She explained that she didn't like to "break down in front of people" and described how sometimes her feelings surfaced when she was alone, but she felt she had to cover them up again before anyone could see her.

I think normally I try and block things out and then if it gets so, where you just...come out...last time...you just don't...happens...So then maybe when I'm alone, I'll kind of break down and do it then. You've got to get yourself stronger before anybody else comes into the house.

She described how she coped at work if she received a call with news that a treatment cycle was unsuccessful and she couldn't block her feelings, "So I'll just, like go into the bathroom and I have my tears and everything and then I'd go quiet.... So you know, I deal with it that way."

As Pam described above, she experienced "shock" and felt "numb" and "frozen" upon finding out that she hadn't conceived in the first IVF cycle. She described how her experience of the world had changed over time since she began trying to conceive and commented that her feelings of disconnection had increased. She no longer felt part of the "real world" and at the same time, the "real world" had come to seem less real and more like a dream to her.

I feel that I'm not living in the real world anymore. I'm not living in the tangible world that everybody else lives in. I'm living in my own world. I'm living in my little bubble world.... Few things in life seem real now. Life is more like a dream that I'm passing through these days. Nothing seems tangible or concrete to me anymore.... It's a dream what I'm going through at this point...somewhere in the back of my mind I keep thinking it will pass. It's a nightmare, this is a nightmare.

Pam described how the feeling of disconnection impacted her at her job:

I have a large staff and everybody's needy, everybody needs something, the phone's ringing, the email is beeping at me, and you can't...you barely even know where you are. Everything is strange to you. There's nothing that is normal

or right about what's going on and you lose all ability to focus or concentrate or come up with cohesive answers to any kind of problem or anything.

Pam elaborated on the quality of her feeling of disconnection by describing her experience upon awakening each morning. She explained that she woke up in the middle of the night one night following a dream in which she found out she was pregnant. When she realized it was a dream and she wasn't really pregnant, she experienced the shift from the relief she felt in the dream to the oppressive return of an "over-overwhelming sense of drowning in this deep pool of water, and all the world exists above you and you can kind of hear the sounds and you can kind of see the images, but everything is distorted through the water." She commented that that feeling returned and remained with her "everyday, every morning" since the dream.

Zoe described a period of time at the beginning of her pregnancy during which she experienced a sense of disconnection and disbelief. She also described having difficulty connecting with, or "bonding" with her baby after he was born. She explained that she wouldn't allow herself to believe that she would get pregnant. She described not being "convinced" she was pregnant, even at the end of her last IVF cycle when the pregnancy test was positive. "It's so funny, you know, the point where after we did the last cycle, I was convinced it didn't [crying] happen." She tearfully described her disbelief when she discovered she was pregnant:

I took a pregnancy test and it was negative [crying] and twenty-four hours later it was positive. And it wasn't like I took it early. It was like I waited till the last, the last possible second. So I just didn't believe it, and I don't think I did believe it for a while.

Zoe cried as she explained that she continued to not want to believe she was pregnant to protect herself from being "disappointed" for some time into the pregnancy.

Even after seeing the first image [sonogram] which you see it, like you know – it's ridiculous when you go through IVF, it's like you have way too much

information and you see this – you see this, you know, embryo at two weeks, you know and it's like, you know it's like a dot, and you're like 'Man, what is that?' And then even after the heartbeat, didn't want to believe it, you know? Cause you just don't want to be disappointed.

Zoe tearfully elaborated on her experience of crossing over from disbelief to acknowledgement and connection to her pregnancy when she first experienced unfamiliar sensations in her uterus:

Sensation...right, that crossed over to that point. And even then, it was so odd, like the sensations were so weird, so just not identifiable. It was just a different [sighs] you know...was it...I'm trying to think back...like a, you know, a gurgling almost that a, yeah, you know it felt...it was like a gurgling.

Zoe commented that the gurgling sensations became more consistent and were followed by “thumping” sensations, which initiated a shift in her awareness to the realization that she carried a “real person inside...a real person that you know will have...and know it will be, you know, unique. [Crying] And it's great, and it's great.”

Zoe commented on how she thought the experience of having difficulty conceiving impacted how connected she felt to her baby after he was born. She explained that the fact that it wasn't easy for her to conceive contributed to her feeling that her son was a “gift rather than an entitlement” and it raised a question for her.

I think when you feel like it's a gift, then you go to this place where you aren't sure if in fact you *are* entitled to it. And I think that that feeds the feeling that, you know, the overall feeling of being somewhat disconnected too, because if you don't quite feel entitled to this gift, then it's easy to [pauses and sighs] it's, it's in a way, it's easy to avoid bonding...and bonding is hard especially if you don't feel um, as if it's, it's something you deserve.

Zoe explained that there were times she found herself, “not feeling as if I had the right to pick him [her baby] up whenever I wanted.” She reflected on what she would tell herself at those times:

It was easy just to let the nurse pick him up, you know it was easy just to let her, um, when she was feeding him and holding him and stuff...it was easier to

rationalize because I could say to myself, ‘Well, she’s here. Allow yourself to do what you want to do and what you need to do so when you’re with him, you are—you can be with him and you’ll be available and not sit there worrying about the stuff I’m not getting done.’

Zoe commented that she came to understand that that was her way of rationalizing, “The reality is that you...part of it I’m sure was because I felt like I wasn’t necessarily entitled to um, to be that primary caregiver in a weird way. It’s hard to explain. It’s like there was just something there.”

Zoe consented to have an elective cesarean as advised by her doctor, since she didn’t go into labor by her due date. She described feeling disconnected during and after the surgery, during which she had spinal anesthesia. “When they take the sheet away [after the surgery is completed]...this torpedo at the front of you is gone, you know all of a sudden, you’re like—it’s like you’re literally—you couldn’t be anymore, um, disconnected—emotionally, physically, everything.” She explained that following the surgery she experienced pain from the incision, as well as a severe headache (possibly related to the spinal anesthesia) for several days that interfered with her being able to stand up and take care of her baby. The pain was hard to manage and contributed to the difficulty she had bonding with her son after birth.

Zoe described her thoughts on her initial feelings after the baby was born and her feelings at the time of the interviews when the baby was two months old. “It’s almost like before I didn’t feel like I had the right [to be the primary caregiver] because I didn’t know what to do and I didn’t have the confidence.” She considered that around the time of the interviews other feelings had surfaced:

It’s almost like I’ve been in a situation where I want to regain control, and yet, I don’t feel like I necessarily have the right to have that control and that’s probably more my own feeling of not being entitled to any gift.... I always found it difficult [growing up] to accept any gift.

Zoe elaborated on how going through IVF treatment resulted in her feeling she had “control” and may have impacted her anxiety and worries about the baby after it was born. She commented that going through IVF treatment gives a woman a “semblance of control” and if she successfully conceives as a result, that in turn, reinforces the idea that she has control. Zoe explained that after the baby was born, she came to the realization,

That’s [the idea you have control] not really true...you can say to yourself, ‘Well, nothing bad’s gonna happen,’ and you try to play in, play through your mind all possible scenarios so that you prepare for something bad happening and then, the next thing you know, you’re in this place where you’re constantly playing the scenarios out to give you a sense of control. And maybe, um, you know, whether or not it’s linked specifically to IVF, I’m sure it is on some levels.

Realizing she didn’t have control over everything that might happen to her child seemed to evoke feelings that may have impacted her early connection to her baby. Zoe considered that there might be a relationship between her feeling of wanting to protect herself against disappointment during IVF treatment if she didn’t conceive, her difficulty being “convinced” she was pregnant once she did, and the difficulty she had bonding with her baby after the birth.

As Celia reflected on her experiences trying to conceive during the interviews, she became aware of how “disconnected” she felt talking about them, which indicated to her, that she had been disconnected at the time of the treatment as well. She commented:

It’s interesting how disconnected we can become.... I thought I was different somehow [from other women receiving treatment who she observed as disconnected]. You know, I was trying to be resourced. The way I’m feeling right now, obviously I wasn’t so different. I mean I watch these women just go in and say, ‘Okay, cut off my right arm, I don’t care.’ But I didn’t feel that way.

In the first theme, Celia’s referred to her “determination” and her tendency to “override what’s real” when she described how she repeatedly pushed through the physical and emotional challenges she faced trying to conceive. She described the

internal conflict she experienced between different aspects of herself, different self-states that she became aware of when her friend brought her attention to the health risks she faced if she continued pushing herself through treatment. Celia described these aspects as if she hadn't been in touch with them up to that point, and as if they were disconnected, dissociated from each other. She gave voice to these different aspects that expressed her conflict. As described above, the "little girl" part surfaced and asked, "But what about me?" when she thought about stopping treatment, yet at the same time, a "bigger part" of Celia realized, "I need to stop this or I'm going to die." Her description of her internal experience illuminates the internal conflict and compartmentalization of feelings that had enabled her, up to that point, to "override" the intense emotional and physical challenges she had faced.

While talking about these experiences during the interview, Celia thought of insights she'd gained from her explorations of her own pre- and perinatal experiences and their imprints. She described a persistent sense of disconnection in her comment, "It also takes me, um, takes me back to, um, uh, how I've lived most of my life, which is not knowing whether I'm really here or not here."

The women's experiences before, during, and after treatment and the intense and, at times, intolerable emotional states associated with them, pushed many of the women to engage the coping mechanisms of compartmentalization, dissociation, and disconnection. As described above, the women used these protective coping mechanisms in response to specific difficult experiences throughout the treatment process, but, over time, some women also found themselves experiencing persistent feelings of disconnection that interfered with their relationships and their ability to focus on their lives in the present.

Theme 3: The Lived Body Experience of Treatment Evokes Feelings that Range from Trust and Safety to Fear and Threat

Each woman came into reproductive endocrinology treatment carrying the lived body experiences of her life and their imprints. Pre- and perinatal experiences, including the experience of having been adopted, early interactions with primary caregivers, prior experiences with medical providers and medical procedures, chronic and past health conditions, prior reproductive losses (elective or spontaneous), and previous traumas, including violent crime and sexual abuse, were all part of the women's somatic histories.

The mind-body-energy imprints of these experiences at all levels—cells, tissues, organs, and body systems—held the potential to evoke mind-body reactions, including sensations and emotions that ranged from a felt-sense of safety to that of life-threat. These reactions occurred at the interface between the women's somatic histories and their experiences in the medical-technological world of reproductive endocrinology treatment.

The women described a tension between wanting medical and technological help to conceive and the vulnerable feelings they experienced during the exams, tests, and procedures. They were faced with two competing biological drives and had to prioritize one over the other. The conflict was expressed in their descriptions of how their bodies felt during the physical interactions with their health care providers. In order to undergo the treatment, they had to override their biological drive to protect themselves and its expression in their mind-bodies, in deference to their biological drive to reproduce. They had to blanket or separate from the feelings evoked by the invasive nature of the treatment and the vulnerable posture the procedures required, in an effort to cooperate with their medical providers and allow them to perform the procedures that they and their doctors believed held the promise of procreation.

All the participants were living within proximity of New York at the time of the interviews. For Pearl and Celia, the 9/11 attack on New York City coincided with their efforts to try to conceive and imposed an unexpected and significant environmental stress that created an additional mind-body challenge during their fertility journeys. Pearl commented that she experienced posttraumatic stress symptoms for months following the attack. On self-report measures of posttraumatic stress and dissociative symptoms, completed by each participant before the first interview, Pearl, Lilah, Pam, and Marina reported they had recently experienced posttraumatic stress and/or dissociative symptoms. Pam explained that earlier in her life she had been the victim of two violent crimes, after which she experienced posttraumatic stress symptoms. The symptoms had subsided, but returned while she was undergoing reproductive endocrinology treatment.

Posttraumatic stress symptoms are the psychobiological expression of the impact that overwhelming experiences can have on all aspects of our being and, as such, illuminate the inseparability of our minds and bodies. Entering reproductive endocrinology treatment with posttraumatic stress symptoms, or developing symptoms while in treatment, added an additional mind-body challenge for some women, to a process that was inherently stressful.

The women's somatic histories shaped their feelings about their bodies, their self images, and their sense of body boundaries. They described how their feelings about their bodies were impacted by their experiences during reproductive endocrinology treatment and the quality of care they received from their health care providers. The women's relationships with their health care providers and the impact that had on their experiences will be discussed further in another theme. The women experienced numerous interactions with health care providers, including nurses, technicians, and

doctors. Some received care from one or more doctors within one reproductive endocrinology practice, some from one or more doctors in two, three, or four different reproductive endocrinology practices.

The Pelvic Exam: Lying on Your Back with Your Feet in Stirrups, Knees Spread Apart

The women described their experiences of close physical contact with health care providers who were seeing and touching their most intimate body parts, their external and internal reproductive organs, necessitated by the treatment. They all went into treatment with feelings about pelvic exams that were shaped, in part, by their somatic histories and each commented on their mind-body experience of lying on their back on the exam table with their feet up in stirrups, knees apart for the multiple exams, tests, and procedures that were required for treatment. Some commented on their feelings about the fact that many different people's hands had performed the exams and procedures and explained how these experiences challenged their sense of body ownership and their belief prior to treatment, that their body was special and private. Their comments revealed the body-mind dilemma they were repeatedly faced with: choosing close physical contact, for a purpose that necessitated exposure of their genitals and invasion of their body boundaries, during which they felt deeply vulnerable, in the context of a relationship that was not intimate, with a person they barely knew or were meeting for the first time, but who held the potential to be the catalyst in a process that might help them have the child they longed for.

A few of the women described receiving care that they felt was attuned to and respectful of their mind-body reactions during treatment, care that enabled them to feel more relaxed. They explained that in interactions with care providers, who acknowledged them as whole human beings and whose behavior demonstrated their

awareness of the fact that each woman was a unique mind-body with feelings, they felt sensitively cared for and experienced a deep sense of gratitude and relief. The technical skill, as well as the sensitivity of the doctors to the women's experiences of being examined, greatly affected how the women felt physically and emotionally during and after the exams.

Pearl explained how pelvic exams with a speculum made her anxious and tense, particularly in her vagina and legs. The speculum is a metal or plastic instrument that looks like a duck bill that is inserted into the vagina. When it's expanded, it spreads the vaginal walls and makes the cervix visible for examination. She realized that just knowing or anticipating that there was a possibility of having a pelvic exam with a speculum during an appointment made her tense even before she got to the doctor's office. She thought that past feelings of shame about her body, her physical sensitivity, and her "prudish" upbringing may have contributed to her tension.

The first reproductive endocrinologist she saw observed how tense she was during the part of the pelvic exam in which the speculum was inserted, and how she relaxed when he was about to do the manual part of the exam using only his hands. Pearl commented that she felt that having metal in her vagina was not normal, but fingers were part of normal human behavior and her body seemed to know the difference, even when she wasn't consciously thinking about it. The doctor expressed concern that he was hurting her. Pearl remembered thinking that the doctor's observation of her tension and his concern indicated to her that,

He was being extremely aware of...um...how my body was reacting...it's really clear that he can read these signs and not like facial tension, but pelvic tension. You know, he was like, 'You're not even on the table.' Like I was sort of standing in the stirrups (laughs) almost.

Pearl remembered explaining to the doctor, “I know I have a tough time in the stirrups. I know I’m a little tense with the speculum.” When the doctor asked her if she could relax her legs and she told him she didn’t know if she could, she remembered him saying, “Okay, well we’re just going to work with this.”

Pearl described how grateful she was for the doctor’s acceptance of her not being able to relax during that part of the exam, and his willingness to work with her reactions to the exam, no matter what they were. During the first exam she remembered the doctor saying,

“If anything is uncomfortable, please let me know. If it’s too hot or too cold or I’m pressing too hard, please direct me, let me know. I haven’t been here before, so I’m trying to work it out for you.” And that was like, “Thank you God.”

She commented that different doctors responded differently to her tension. In contrast to her experience with the first reproductive endocrinologist, Pearl described her experience of a pelvic exam with another reproductive endocrinologist who had difficulty inserting the speculum due to her tension and his lack of skill in dealing with it. He expressed frustration with his inability to insert the speculum, in a way that resulted in Pearl feeling blamed, as if the tension in her body was something she should be able to release on his command. Pearl felt it was “her fault” the exam wasn’t preceding well. She commented that she felt violated after the doctor’s repeated attempts to insert the speculum. “It’s like the rapist making the victim feel bad she’s not enjoying it or something.” After this experience, Pearl explained that she started sharing her history of sexual abuse with the doctors, in the hope that this would ensure that they would be gentle with her because she felt this information was a “medical situation that they could understand.”

Pearl noted that it was difficult being a patient in a large infertility practice in which she was cycled through eight doctors, often seeing a different doctor, one whom she never met before, for exams or procedures during the treatment cycle. The appointments were often very brief. The doctor would introduce himself, do the pelvic exam quickly, tell her when to come back, and leave the room. Pearl felt it was very impersonal each time she was examined this way, by a man she didn't know. Pearl remembered one pelvic exam during treatment where the doctor she was scheduled to see entered the room with an intern she did not know and had not anticipated would be present. The doctor did not ask her permission for the intern to remain in the room during the exam and did not introduce him. Pearl described her discomfort with this totally strange additional person in the room, looking at her with her legs up in stirrups, knees spread apart:

Doesn't introduce him. He doesn't introduce himself. And so it's like, 'Hi there, and this is my vagina.' ...Like...like at one point, I put the sheet down and I said, 'Hi. I am Pearl. And who are you?' Could we at least have an icebreaker before you're like looking in my vagina already?

She described the way she coped with her feelings, physical and emotional, during the exam. Pearl commented that she is a highly sensitive person and thought that she had always disconnected, made a choice to take her mind elsewhere during those exams:

I think maybe I've always done that when I've had to have an exam like that. And in fact, I know I've tried to do that. I've physically said like, 'I'm going to leave now' in my head, to go away to let something happen.... You know, I'd feel like how can I get out of here and I'd be trying to be somewhere else completely.

The first doctor's way of interacting with Pearl during the pelvic exam helped get her back into her body. Pearl remembered lying on the exam table and sort of looking all around, scanning the room, moving her head and eyes around from one side to the other.

She remembered wanting to dissociate herself from the process. The first doctor would engage her in conversation and look her in the eye when he spoke to her. Pearl commented that she particularly appreciated how he would push the drape down to cover her vagina, sometimes even stand up, and then make eye contact with her before talking to her during the pelvic exam. She explained that she felt the doctor was being respectful and sensitive to her feelings about the situation that were likely to have been different from his, since he may have been used to staring at vaginas all day. His intention to make eye contact in a respectful way, by covering her, given how exposed the most intimate parts of her body were in her position on the exam table with her legs in the stirrups and knees spread wide apart, kept her engaged with him in the present and connected to her body. Pearl noted, “I think at first it probably was difficult, but in retrospect, I know I really appreciated that because it was respecting that I was attached to my body.”

Lilah described feeling embarrassed having her vagina exposed and looked at while she was on the exam table with her legs up in stirrups and commented,

Well the biggest feeling is being completely demoralized when you're in the exam rooms.... You kind of have to not think about it. You have to almost like close yourself off, and not feel anything about it.... I try not to focus on the room at all. I'll pick like a speck on the ceiling tile...and I'll sit there and stare at that dark speck.... I'll almost feel like I can't feel myself from the neck down. I feel like I'm a head and there's a body that's completely separate...completely disconnected. Like I don't want to, I don't want to hear.

During the first interview, as Lilah reflected on how she coped with pelvic exams by distancing and disconnecting, she commented that she could feel herself doing it while she was describing the experiences to me, “I'm kind of doing the same now, like, I'm kind of feeling like I'm telling somebody else's story.... Like I'm the narrator for this story.”

Pam recalled the embarrassment and disbelief she experienced at her first pelvic exam at the beginning of her first IUI cycle. For treatment purposes, the appointment is intentionally scheduled on the second day of the menstrual cycle. She had not been told in advance that a pelvic exam would be performed that day. As Pam described, this was a particularly difficult day in her cycle, due to her endometriosis, “Endo patients have a certain type of menstruation. It’s not very nice. It’s not pretty and for the life of me, I couldn’t believe that these doctors were gonna come in here and examine me under these conditions.” Pam told the nurse she didn’t seem to understand she (Pam) was bleeding and she remembered the nurse responding, “Yeah, we don’t care. Hop up on the table.” Pam went through the exam and commented that three people were in the room at the time, two nurses and the doctor. She described her feeling of “overwhelming embarrassment” and disbelief that the doctor wanted to become “this intimately personal with my body.”

Celia described her first pelvic exam with the first reproductive endocrinologist she saw. She remembered trying to “come into relationship with the doctor,” especially since “she was going to be handling my body” and trying to engage the doctor, but got no response. Celia described her interaction with the doctor while she was on the exam table,

“She [the doctor] just kept jamming this thing into me, and I was just going, you know, grinning and bearing it, because I can do that.... She started telling me something was wrong with my pelvis, and I was shaped the wrong way and um, then she asked me what I did for a living...so I just said something about being in alternative healthcare and—and—she like took the speculum and went Wham. And I just like jumped off the table, just about, not really, but I was like...and then she just dropped everything there and she says, ‘Well, this obviously isn’t for you.’ And she walked out. It was terrible. It was terrible.”

Marina explained that she was “quite a private person” when it came to her body, “I would never even change [clothes] in front of my friends.” Before the treatment, she described herself as the kind of person who thought about and treated her body as “special to herself.” In order to deal with the pelvic exams, Marina explained,

You do have to kind of be separate to some extent to kind of deal with it. To let that someone on the table have an examination, then, back to myself kind of thing. You’ve got to think—I suppose acting you’re somebody else. And then you kind of—you know, by the time I get to work, you then, you throw yourself back into yourself, hopefully.

She explained that the feeling of being separate from her body didn’t last, but other feelings persisted:

So, it doesn’t last in the sense that you think you’re somebody else, but you do think, ‘God, so many people have seen me now.’ Things like that.... You think you’re just—your body’s just now like a slab of meat versus something that’s...yours kind of thing.

Over time she came to feel, “Well, it’s just a body...like it doesn’t feel special or yours kind of thing anymore,” and that her body was just there for the “prodding and poking.” Marina mentioned that she joked with her friends, “You know, now we drop our pants for anybody” and commented that joking was probably a way of not letting her mind think about or get into the actual feelings of what it really was like to have the exam and procedures and to have many people see her body. She commented that she hated that “everybody’s seen everything now.”

The women explained that they became desensitized to some extent, to the exams, tests, and procedures over time and expressed surprise that these experiences had become routine in the context of their lives while they were in treatment. The treatment cycles themselves became a routine part of the women’s daily lives, “a lifestyle” as Celia

described it, for those who had been through multiple cycles over the course of months and years.

Reproductive Endocrinology Treatment: Tests, Medications and Procedures Considered and Experienced by the Women

Diagnostic tests. The women's physical experiences in reproductive endocrinology treatment often began with diagnostic tests that included comprehensive blood tests to evaluate hormone levels and medical conditions that might impact fertility, pelvic ultrasound exams, and hysterosalpingograms. Pelvic ultrasound allows for evaluation of the pelvic structures, including the bladder, ovaries, uterus, cervix, and fallopian tubes. It is performed trans-abdominally—externally through the abdominal wall during which a small handheld device called a transducer is passed back and forth over the lower belly, or transvaginally—internally, where the transducer, shaped to fit into a woman's vagina is inserted into the vagina. In both types of ultrasound exams, the transducer sends the reflected sound waves to a computer, which makes them into a picture that is shown on a video screen and the pictures or videos may be saved as a permanent record.

The hysterosalpingogram is an x-ray test used to evaluate the uterus and fallopian tubes. A tube is inserted through the cervix into the uterus through which dye is inserted. X-rays are taken when the dye has filled the inside of the uterus and fallopian tubes. The test is used to help determine the cause of infertility and to evaluate patients who have had several miscarriages. The test can show areas of scarring inside a fallopian tube or changes in the uterine cavity that might be associated with growths in the uterus.

Treatment medications. Several medications are used during different phases of treatment, depending on whether the woman is undergoing an IUI or IVF cycle. The

medications include hormones and corticosteroids and are administered orally, through intramuscular or subcutaneous injection, vaginal capsule, or transdermal patch. Clomid, taken orally, is prescribed for ovulation induction. Bromocriptine, taken orally, is prescribed for elevated prolactin levels that can interfere with normal ovulation. Antagon/Cetrotide, administered by injection, is used during the stimulation phase of an IVF cycle to prevent ovulation. Follicle stimulating gonadotropins, administered by injection, are used to stimulate the ovaries to produce as many follicles as possible during the stimulation phase of an IVF cycle in which fresh eggs will be used, rather than eggs that were retrieved and frozen during a previous cycle. Human chorionic gonadotropin (HCG), administered by injection, is given when follicles are believed to be mature. This medication triggers the brain to start the ovulation process which can take up to forty hours to complete. Progesterone, administered by injection or vaginal capsule, is used to enhance or increase the uterine lining, preparing it for the potential implantation of an embryo. Estrace, administered orally or through a transdermal patch, is used to stimulate thickening of the uterine lining in preparation for pregnancy. Lupron, administered by injection, is used to suppress ovulation and stimulate the ovaries.

Dexamethason, taken orally, is a corticosteroid used to prevent early androgen and progesterone rises during egg maturation that may be detrimental to egg quality. Methylprednisilone, taken orally, is a corticosteroid prescribed prior to embryo transfer for women whose IVF treatment includes intracytoplasmic sperm injection (ICSI) (a process in which a pre-selected sperm is injected into the cytoplasm of the mature egg), or assisted hatching (a process in which the membrane around the embryo is pierced to facilitate hatching of the cells out of the membrane in preparation for implantation). The medication is used to prevent activation of a maternal immune response that theoretically

might be triggered if the mother's immune system detected changes in the egg or embryo resulting from the micromanipulation procedures.

Treatment procedures. Initially, the women underwent intrauterine insemination (IUI) with partner's sperm or donor sperm. The procedure is usually conducted on two days, coinciding with the woman's ovulation cycle. Medications may or may not be used to stimulate follicle maturity and induce ovulation. The sperm are injected directly into the woman's uterus through the cervix. This enables "washed sperm" (sperm that has been separated from the semen) to bypass the cervix, increasing the number of sperm reaching the uterine cavity and fallopian tubes. IUI may be indicated in cases when there is poor sperm/cervical mucus interaction, and the cervix actually acts as a barrier to conception. IUI may also be effective in cases of unexplained infertility. For women who did not conceive and sustain a pregnancy through these procedures, IVF using fresh eggs was the next step.

The IVF process includes the following procedures: ovulation enhancement, egg harvest or retrieval, and embryo transfer. In the ovulation enhancement phase, follicle stimulating gonadotropins and other medications are prescribed in an attempt to optimally stimulate the production of several eggs, rather than just a single egg which is usually produced each month. Ultrasound exams are used to carefully monitor the development of the egg follicles in order to schedule the egg retrieval procedure when the eggs are mature and ready to be fertilized. In the egg harvest or retrieval phase, the IVF team removes the eggs by ultrasound-guided aspiration while the patient is under anesthesia. A very fine needle is passed through the vaginal wall to remove the eggs by gentle aspiration. Abdominal incisions are not required and the procedure is done on an outpatient basis. Insemination of the harvested eggs takes place in the laboratory. A

sperm sample supplied by the male partner or a donor is processed, and a large number of sperm is placed with each egg in a separate dish, along with a culture medium.

Zoe's doctors suggested intracytoplasmic sperm injection (ICSI), instead of the usual procedure to facilitate fertilization. As mentioned above, ICSI involves injection of a single sperm into the cytoplasm of a mature egg with a glass needle to increase the likelihood of fertilization when there are abnormalities in the number, quality, or function of the sperm. In either procedure, the dishes containing the sperm and egg are then placed in an incubator calibrated to the same temperature as the woman's body. Fertilization takes place in about eighteen hours. Twelve hours later, the fertilized cell, or embryo, divides into two cells. Three or five days later, when the embryos have divided again and consist of four to eight cells each, they are ready to be transferred into the uterus.

Pam's doctor suggested preimplantation genetic screening (PGS) or diagnosis (PGD), which she was considering at the time of the second interview. This is a laboratory technique in which a cell from a developing embryo is removed and evaluated, prior to embryo transfer, for chromosomal analysis to diagnose genetic conditions. The presence of an extra or missing chromosome can result in lack of implantation, pregnancy loss, or other conditions such as Down's Syndrome.

Some women considered using donor eggs if they had been through repeated unsuccessful IVF treatment cycles and it was suspected that the quality of their eggs was not likely to result in a pregnancy.

The embryo transfer procedure usually takes place on an outpatient basis, without anesthesia. Women receive intramuscular injections of progesterone to enhance/increase the uterine lining in preparation for implantation of the embryo. The doctor exposes the cervix and cleanses it with a special culture medium. The embryos are then loaded into a

very thin catheter, passed through the cervix and deposited near the top of the uterus. None of the women reported that their embryos had undergone assisted hatching prior to the embryo transfer procedure. The assisted hatching procedure (as mentioned above) involves manipulation of the embryo under the microscope to chemically dissolve or weaken a portion of the zona pellucida, the shell-like membrane that surrounds the embryo prior to implantation, to facilitate the process of implantation. Repeated blood hormone level testing and sonograms follow the embryo transfer procedure to monitor whether the treatment has resulted in a viable pregnancy.

Additional embryos not being used at the time of an IVF cycle could be frozen for use at a later time through a process called cryopreservation. The embryos are transferred to a special solution and then cooled at a carefully controlled rate. When they are needed in future cycles, they are thawed in a machine designed to carefully control the warming rate. After thawing, they are washed free of the freezing solution and may be used for another transfer cycle. Any embryos that appear to be abnormal are not transferred.

Some women considered using donor eggs after they had been through repeated unsuccessful IVF treatment cycles and it was suspected that the quality of their eggs was not likely to result in a pregnancy. Using a donor egg requires the coordination of both the donor's and recipient's cycles so the retrieval of eggs from the donor is timed to coincide with the readiness of the recipient's uterus to receive the donated eggs through an embryo transfer procedure. The donor eggs are fertilized with the recipient's partner's sperm or with donor sperm. If the sperm is provided by the recipient's partner, the provision of semen by the partner must be coordinated with the timing of the donor's egg retrieval procedure.

Some women use donor sperm if there are problems with their partner's sperm or they do not have a partner, or have a partner who is not committed to the process. Celia chose to use donor sperm in most of the treatment cycles she underwent. A sperm donor is selected by the recipient from information provided by sperm banks. The donor sperm is sent by the sperm bank to the reproductive endocrinologist for use during the recipient's treatment cycles.

Some of the women underwent additional tests, treatment, and procedures depending on the outcome of each treatment cycle and their individual health issues that arose during the time they were in treatment. For Lilah, her experiences also included taking a cancer drug to dissolve an ectopic pregnancy conceived during a treatment cycle, followed by emergency laparoscopic surgery to remove a ruptured fallopian tube caused by a second ectopic pregnancy conceived during another treatment cycle.

For Pearl, her experiences included a stillbirth in the fifth month of a pregnancy that was conceived while she was undergoing reproductive endocrinology treatment. Marina experienced a very early miscarriage following a treatment cycle. Celia experienced multiple early miscarriages while in treatment and underwent a myomectomy, a surgical procedure to remove a large fibroid tumor that was discovered while she was receiving reproductive endocrinology treatment. Zoe's experiences included carrying a pregnancy conceived during an IVF cycle to term, a cesarean birth, a debilitating post-operative headache in the days following the surgery that interfered with her early interactions with her baby, and the postpartum experience of bonding with her baby at home.

Fear, Vulnerability, Powerlessness, Pain and Shame Accompany Many of the Women's Physical Experiences of Treatment

The women described feelings of fear, vulnerability, powerlessness, and shame as they went through the physical aspects of diagnostic tests and treatment cycles. They resigned themselves to coping with these feelings as they surfaced during the treatment exams, tests, and procedures and chose to make a sacrifice of self in the hope they would be able to manifest their dreams of having a child.

The hysterosalpingogram. Lilah described her experience of the diagnostic hysterosalpingogram test performed by a radiologist, not her reproductive endocrinologist. She explained that during the test, the nurse who was present in the room with the radiologist positioned herself opposite the bottom end of the exam table where she had a clear view of Lilah's vagina. Lilah explained that she felt very uncomfortable having two people looking at her in that position:

You kind of have that feeling like, 'Oh my God, I didn't shave, how a mess am I down there?' Like you know, you have to shower so that there's no odor or anything...all the things you have to prepare just to go for this test, that you really don't want to be going for in the first place.... It's an extremely embarrassing position to put yourself into, but you have no choice.

Lilah described how she prepared herself for and handled the experience. Having gone for the HSG test alone, she told herself,

So like, I'm just, I'm going to go lay on this metal table that's freezing cold and you know I want to have some doctor [radiologist] who has absolutely no gynecological experience whatsoever, inject dye into my uterus and then take pictures and it's not that big of a deal. Just focus on the pictures and just think about the outcome, don't think about the process. I'm usually pretty good at that, but it's like...doing it all by yourself just sucks.

Lilah explained that one HSG test [she'd had two at the time of the interviews] was particularly difficult to cope with both physically and emotionally, due to the fact that she experienced a great deal of pain when the radiologist inserted the speculum, had

painful cramping she didn't expect, both during and following the test. Her physical and emotional distress was compounded by the fact that she was alone and no one offered her help.

Lilah observed that, while she was relating this experience during the interview, even though it had occurred five months previously, she could bring up the physical sensation of it. "I'm telling you it felt like he shoved a shovel in there. It's just like miserable, horrible, horrible, horrible, horrible. Like I've had annual exams that were uncomfortable. This hurt! Like he actually hurt me." Lilah described it as a body memory that she could feel in the present and though it would affect how she felt in future exams:

I can tell you, I can remember the *feeling* of him putting the speculum in me. Like I can actually feel it, like it didn't go away, it didn't leave. I can't, I don't know how else to explain it, but my vagina remembers exactly how it felt when he was putting that speculum in me. And like it's gonna cringe if I ever have to go back to him and have it done again, because I'm anticipating what it's gonna feel like, because I remember exactly how it felt.

Lilah described how getting to the goal was her priority and this influenced how she handled this difficult experience:

What do you do? You say something? You know, again, you just, ok, it's just one more uncomfortable thing you have to go through to get to the goal, so you just suck it up. Focus on something else while he's like practically ripping your vagina out and don't worry about it. And just don't even think about it and just pretend that it's not happening. Think about something else. And it will be over in a minute and then ok, it's still not over, well ok, it will be over in just 30 seconds more. He's almost done. You know, but it's tough.

Lilah wasn't prepared for the amount of painful cramping she experienced during the test. She described being asked to lift herself onto one hip, then roll onto the other to help the dye flow from one side to the other. "And I was like in tears on the table. It was

just *so* uncomfortable. It was really really painful and it was just horrible. And he's like [the radiologist], "You're getting cramping? Yeah, that's to be expected."

Following the test, Lilah described trying to cope with cleaning up the dye that had leaked out all over the exam table and onto her body and her clothes:

I had a white shirt on that day and I'm like, ok, great. So I go in the bathroom and I got really bad cramping...and like I didn't know what was going on, but it was horrible. So I go and I sat on the toilet...so toilet was covered, so I'm like, oh my God, I've got to wash the toilet, so I'm like cleaning the bathroom. I'm like washing the floor...using paper towels.... I'm trying to wash my back and trying to wash my whole private area.

Lilah expressed her concern about leaving a mess in the bathroom and how embarrassed she would have felt about doing that. The medical staff didn't offer any help.

Lilah commented that another difficult aspect of the mind-body experience of infertility treatment was coping with unfavorable news and negative test results while lying on the exam table with her legs up in stirrups. She explained that it was particularly difficult to receive and handle bad news about what the doctor was observing during a test or exam while she was in that uncomfortable and "demoralizing" position and in pain.

Pam also described her feelings lying on the exam table just prior to undergoing the hysterosalpingogram and explained that she had a panic attack when she saw the equipment that was going to be used and anticipated the pain she thought she would experience during the test.

Treatment medications. Several of the women described their experiences taking the medications prescribed during the IVF cycles to stimulate egg production, regulate the timing of ovulation, and prepare the lining of the uterus for possible implantation of an embryo. Some of the women talked about the challenge of giving themselves the

necessary injections at the required times or having their partners administer the injections correctly. Celia administered her own injections, as did Marina when she traveled on business trips. Pam and Zoe described their concerns about making sure their partners administered the injections correctly. Zoe and Marina commented that they had little experience with medical conditions that required the level of medical self-care that was required in the IVF cycles.

The IUI cycles required a less demanding protocol of hormone medications.

Marina explained,

I think the inseminations were just—were a lot easier, because one, you don't have to go to the doctor so often; two, it doesn't mess around with your body as much. It's very kind of quick and it's over in a couple of weeks, so it's not dragging out.

She commented that she didn't take any medications during the first insemination cycle, but did during the second one and noted that the injections she had to take during the IVF cycle were more intrusive:

It got to the stage where at one point, you're having about four injections a day and coming from never having...I don't...used to go to the doctor's ever—and suddenly, I'm there every day. I'm having four injections a day.

Going to the doctor's office for blood tests also required “getting a needle.”

Marina shared her experiences taking the follicle stimulating hormones prior to the egg retrieval procedure during her first fresh IVF cycle:

I overstimulated.... So leading up to the retrieval I had, um, so practically looked as if I was two or three months pregnant because I was really out here and I put on weight and stuff. So it was very—like I couldn't even wear trousers and things. It was quite uncomfortable physically.

Marina recalled that she was uncomfortable sitting and bending down. Another woman who had been through the treatment explained to Marina that the feeling she experienced during that phase of treatment was like having “rocks in your belly.” Marina agreed,

“That is exactly how it feels.” She found it helpful to know that she wasn’t the only one to experience those feelings. Without that information, she “would’ve been more concerned.” She noted that the doctors mentioned the possible side effects of the medications, but didn’t describe what she might feel in her body.

Pam wondered whether previous surgery for endometriosis that involved her bladder may have contributed to the intensity of pain she experienced in her urinary tract and bladder during the follicle stimulating phase. During the early phase of the first IVF cycle, she described, “The pressure on my bladder was enormous and the pain was excruciating, the radiating pain that actually came through my back and out my hips and down my legs.” She commented that it was very difficult for her when she experienced sudden pressure on her bladder. It made her feel like she was going to cry.

After a few days of injections during the follicle stimulating part of the first IVF cycle, Pam became concerned about what she was feeling after the injections. She reported her sensation to the nurse at her next visit for routine blood tests to monitor her hormone levels, “Something’s wrong.... This cannot be right.... The last two nights when I do the stim injections, I can actually feel the medication hit my ovaries. I can actually feel my ovaries kick in and start to work.” The nurse assured her it was her imagination. Pam’s blood hormone levels were over four times the level they were expecting them to be, after five days of hormone stimulation. Pam commented that she “became like a rabbit apparently and my body went crazy and started to produce a gajillion follicles.” On the seventh day of hormone stimulation, she went into the office for an ultrasound and told the doctor that she felt her ovaries responding to the medication 15 or 20 minutes after the injection went in. Pam remembered the doctor’s answer to her, “Don’t say this to the other patients. And whatever you do, if your ovaries

start to talk to you, seek help.” Pam commented she felt this was the worst moment she had with the doctor. She felt very upset and “belittled” by his answer.

Pam described her experience of having her husband give her progesterone injections every day for part of the IVF cycle. She commented that she was very anxious about having her husband administer them and experienced panic about the possibility that they might incorrectly measure the medications, she would take the wrong dose, or the injection might be given in the wrong place. She explained that she wasn’t prepared for the pain she experienced from the injections which she partially attributed to the fact that the medication had to be injected into the muscle tissues in the glut muscle, in the upper outer side of the buttock. Pam noted that she was a very thin person and after the third injection, she couldn’t walk down the stairs, “both sides of my gluts had locked up on me and I actually couldn’t move.... Every time you bend a leg, you know, it’s excruciatingly uncomfortable, and I was so big and so fat.” She reported this to the nurse in the doctor’s office who prescribed a smaller needle which was helpful.

Celia described her experiences taking the various medications, and while doing so, she observed the sensations in her body in those moments during the interview. She commented that when she took Clomid,

[It] was the most sensual I’ve ever felt in my life. I could have had sex every day, several times a day. That’s how I felt. I felt really sensual, I felt really—it was like, you know, I became more feminine. I just felt like really happy.

She took several other drugs and felt differently. When she took Pergonal, she explained,

I was just, you know, someone had given me my PF Flyers or whatever, I mean I was rocking. I was like on my way, and then by nighttime, I was exhausted. But the next day, I knew I could just shoot up again...it was fascinating to me. Oh I loved it. I loved it.... It was expensive and it was great.

Celia explained that mixing the “concoctions” made her feel like she was “this little drug dealer.” After she gave herself the injections, “It was a rush, like boom, and I was like, “Okay, I know that in like half an hour, I’m going to feel fabulous.” As she was describing her experiences taking the fertility drugs, Celia noticed that she started to feel “a little racey” and wondered whether it might be from her body remembering, “feeling the fertility drugs” in her body. At the same time, Celia noticed she felt pressure on her chest. She explained that in the latter part of her fertility treatment, she became hypertensive. She commented that she thought she’d “better slow down, cause otherwise, I’m going to need to take drugs or something,” referring to the medication she was on at the time of the interview for hypertension. Celia was writing a book about her experiences of treatment around the time of the interviews and even though she had been off the medication after she stopped infertility treatment, she had to go back on the medication while she was writing about her experiences.

Egg retrieval procedure. Pam elaborated on her experiences leading up to the egg retrieval procedure during her first fresh IVF cycle. She described how her body was overstimulated by the follicle stimulating hormones she’d been given to increase the number of eggs she produced. She explained that she blew up like a balloon and gained a pound or two a day. She had to buy clothes since none of her clothes fit, not even her pajamas. She noted that she felt lucky not have been hospitalized at that point for the effects of being overstimulated. She commented on the amount of pain she was in, having produced thirty eggs, an unusually high number:

I was in so much pain. It was so uncomfortable.... I was so big and in so much pain, I couldn’t even walk across the street at that point. It was horrific for me.... [My husband] all but carried me into the building [for the egg retrieval procedure].

Pam explained that she thought she might have experienced so much pain because the production of thirty eggs left thirty “puncture wounds” in her ovaries, twenty of which were on her right ovary and felt that the ovary “thinks it’s going to ovulate one egg” and it’s “not really prepared for that kind of trauma.

Pam described being brought into the room in which the IVF egg retrieval procedure was done and waiting for the anesthesiologist to sedate her:

Nobody tells you what you’re gonna go through in retrieval. They move you from one room to the next...you know and then you get into this room and it’s, this...at least for me, I’m sure different clinics are different, but it’s this stark operating room with the big operating lights over it and a slab metal table and they tell you to take all your clothes off, get up there and put your feet in the stirrups. And you’re laying there and you’re geez, I’m stark naked laying on a metal slab here. There’s like fifteen men in the room and this is really very humiliating. This is really very scary.

Pam commented that she assumed the table had to be stainless steel because of the bleeding involved in the procedure and described the dehumanizing impact of her experience of the egg retrieval process:

You don’t really feel like a person when you go through these procedures. You can tell that, to the doctors in the room, you’re a number. You’re the next one up for retrieval. This is a statistical thing that they’re doing. How many can they get done in a day, or an hour, or whatever?

Pam explained that she had panic attacks when she laid down on the operating table in preparation for IVF egg retrieval procedures. Repeated experiences of intense physical pain during the treatment process increased her level of fear as she went through the IUI and IVF cycles. She explained how prior to the IVF egg retrieval and embryo transfer procedures, she tried to meditate and moderate her breathing on the operating table, which sometimes was effective and other times not, in controlling her panic attacks. During the second retrieval procedure, she experienced a “severe” panic attack on the table that was noticed by the anesthesiologist, after hearing a nurse, who thought

she was under anesthesia when actually she wasn't, say they were going to start the surgery. Pam described hyperventilating, feeling lightheaded, and like she was going to faint. She tried to relax and meditate, but when she felt nervous, she found that hard to do.

Pam was upset that her husband wasn't allowed in the room during the IVF retrieval or transfer procedures. His support felt like a "lifeline" to her, like, "oxygen" and she wasn't prepared for the fact that he would not be with her through the procedures. She described crying when she found out at the first IVF retrieval procedure that he wouldn't be allowed in the room. She kept asking the nurses for an explanation and if he could be present if he wore scrubs.

Pam described the humiliation she experienced when she found many more people in the room during the retrieval procedures than she expected, most of whom she didn't know. Only the "key people" introduced themselves by coming up to her to shake her hand as she laid naked on the metal slab table, feet up in stirrups, without a sheet to cover her. She commented the embryologists always introduced themselves to her in the surgery room. The retrieval doctors introduced themselves to her and her husband in the pre-op area, but didn't come into the operating room until after she was under anesthesia. "Trust me, there is nothing more frightening or humiliating than laying stark naked on a metal table in a hospital room...and you're cold and what are you really gonna do? I tend to crack jokes." Pam commented that she felt cracking jokes,

Diverts the attention. Otherwise, I feel like everybody's standing there looking at me naked. Really, that's how I feel. Either crack a joke to divert their attention or everybody's just staring at me laying there naked on this cold slab metal.

Pam explained that the doctor who did the first IVF egg retrieval "had a thing where, for sterile reasons, you have to be completely naked. And I was really not

prepared for that.... This was his thing. This was how he did it. I assumed it was necessary.” She explained that the doctor who did the second IVF egg retrieval “apparently was not as neurotic” and allowed her to keep the hospital gown over her chest:

I promise you, when I go in for my third retrieval, I don’t care who the doctor is, I will *insist* on a minimum of a sheet over my chest. I really think at a minimum, they could leave a blanket over you until you’re out for the surgery. Do they really have to throw it up off of you while you’re still laying there awake and you experience the humiliation of it? It’s terrible. It’s terrible.

Pam explained that another aspect that upset her was the fact that she felt lying naked in front of other men was disrespectful to her marriage:

I’m a married woman. It’s just not something that should be happening—that strange men should be staring at me like this while I lay there. This is not appropriate. It’s not respectful to my husband or my marriage.... They don’t seem to take that into consideration.

She wondered if patients undergoing heart surgery or cancer surgery also found it humiliating:

Do I feel more humiliated than I would if I was having heart surgery just because I feel that it’s a female problem? I mean, trust me, you do doubt your sense of being a woman and being female, and what’s wrong with my body?

Coming out of the retrieval procedure, Pam explained that she felt “entirely unprepared for the pain” that she was going to feel:

Now when you come out of retrieval, women are in pain. That’s a given. The question is how much pain. And I remember I woke up out of retrieval...my eyes opened up and just this, this flood hit me, this overwhelming feeling of pain. I felt like my body was on fire. It was just pain. That’s it. That’s all I sensed was pain. I thought I was gonna scream for a second.

When Pam was offered more narcotic for the pain, she remembered wanting to wait a couple of minutes to see if it would pass. She described curling up in a “fetal position” and starting to “shake with the pain. My husband came in to see me and by then I was

broken out in a sweat, and I couldn't talk, and I couldn't move." Pam's husband encouraged her to let the nurse give her more narcotic. Pam hesitated at first, due to her concerns about the impact of "foreign medication" on her body and whether it would inhibit her "pregnancy attempts," but finally accepted more pain medication which helped.

She commented that she had never experienced pain like that before, "I had never had it radiate through my body like that where it's basically the only perception you have...of what's going on around you." Following the retrieval procedure, Pam, unable to walk, was carried back to the car by her husband. She described the five days between the egg retrieval procedure and the transfer of the embryos back into her uterus. She remembered being so bloated from the hormones and in so much pain at that time, "I didn't even recognize myself anymore. I kept saying to [the doctor], 'It seems like an alien spaceship has come down and taken my body and given me this strange one instead.'"

In the second IVF cycle, Pam had to return to work the day after the retrieval procedure. She continued to experience the effects of the hormones. She had hot flashes and broke out in sweats and felt sick. She commented that she was "beet red" all the time: "It looked like I was horribly, horribly sunburned and you feel marked. You feel like a woman wearing a scarlet letter on your shirt." Although initially, she had tried to hide the fact that she was undergoing infertility treatment from other people at work, the symptoms she experienced during the IVF cycles were physically visible.

Concerns about the optimal number of eggs retrieved. Zoe commented on her feeling of wanting every step of the treatment cycle to have optimal results, wanting to produce the optimal number of eggs that would result in the best chance of yielding high

quality embryos. She described her experience waiting to be taken in for the retrieval procedure, in the same room in which women recovered after the procedure. Zoe overheard the doctor who performed the procedure telling the women who were recovering how many eggs had been retrieved. She commented that she found herself comparing herself to them, and felt like a “loser” because the number of eggs the doctor thought they might retrieve from her was less than the number that had been retrieved from the other women. It was only later that Zoe found out that having a very high number of eggs was not associated with the best outcome for the embryos.

Marina described feeling “anxious” while she was “waiting around” to hear how many eggs were retrieved, how many were fertilized and when the embryo transfer would be conducted, either day three or day five after fertilization. During the first IVF cycle, the doctor retrieved twenty-two eggs. Marina ended up with four embryos, two of which were transferred into her uterus and two of which were frozen. “That was all that was left.” She remembered being told that it actually wasn’t as good to have so many eggs ready to harvest. Without knowing that retrieving more than 18 eggs actually decreased the chances of the eggs surviving over time, Marina commented that she thought she would have had a negative outlook on the next cycle if they retrieved fewer eggs than the twenty-two they had retrieved during the first cycle.

Embryo transfer procedure. Following the egg retrieval procedure and the fertilization of the eggs, the embryos that are selected by the embryologist are transferred back into the uterus. Celia mentioned seeing a picture of her “four amazingly beautiful embryos...four beautiful perfect embryos with my donor.” She described her feelings following the embryo transfer procedures, conceiving and miscarrying several times:

I couldn't believe I was having—I saw these little embryos and they were put inside me and fascinating. And you know, I was—it lasted through a bunch of weeks. But I wonder why nobody, like, you know what? There had to be another test maybe. Cause I kept getting pregnant for a couple—a few weeks.

Following her first unsuccessful IVF in which she was overstimulated with hormones, Pam described her thoughts after the embryo transfer procedure:

The body's just so over flooded with hormones, it's under so much stress at that point, that it's probably inhibiting conception. I managed to convince myself and I thought well, it must have had an affect on the embryos and my body was under a lot of pressure and it will go better next time. [The doctor] understands how I work and how I 'stim' and if we have to do this again, it'll go better.

Following the first fresh IVF cycle, Pam was left with three frozen embryos. She decided to go ahead with a frozen IVF cycle in which they used the embryos frozen from the previous fresh cycle. Pam commented that during a frozen cycle, “you're not as hyped up on your hormones and it's less stressful.” The embryologist met with her and her husband prior to the embryo transfer procedure. He explained that they had thawed the three embryos, but one of them didn't survive the thaw, one partially survived the thaw and one embryo “looks really good, so we're optimistic for you.” The embryologist confirmed that they would transfer two embryos, the one that partially survived the thaw, and the one that looked good. Pam, once again, received a picture of her embryos and put it up on her refrigerator. She described how she felt during the two weeks before the pregnancy test that would indicate the outcome of the treatment cycle. “You do your progesterone injections, you hold your breath, you cross your fingers, you get very superstitious.” Once again, the pregnancy test was negative and as described earlier, Pam felt “devastated.”

At a follow-up consultation with the reproductive endocrinologist, Pam recalled being told, “Well now, don't be too disappointed that you're not pregnant because really

none of your embryos survived the thaw.” The doctor explained to her that one of her embryos survived the thaw at 20% and the other at 40% and they “typically need a 60% survival rate to know that the embryo is even viable.” Pam was confused and questioned the doctor about why they had performed the transfer procedure at all if the embryos hadn’t survived the thaw at a rate that would make them viable for implantation. He explained that at that point, she was already doing the injections and there’s always a possibility that one of the embryos would survive, so they transfer them and “hope for the best.” Pam explained that she would have appreciated it if someone would have told her on the day of the transfer, not to get her hopes up, not to get “all psyched up because they [the embryos] really don’t look that good, so let’s have a realistic picture. It’s a miracle if you get pregnant on this cycle.” Pam commented, “Nobody tells you that and you go through this two-week period thinking that you have these viable embryos inside you.”

Pam described her thoughts and feelings during the two-week period following the embryo transfer procedure. She explained that she went through a “psychological thing” where she felt she had to “take care of the babies, and I have to eat more, and you have to do this, and you have to...’cause possibly babies. You possibly are carrying babies at this point.” She commented that if she knew that her embryos were statistically unlikely to implant in her uterus because they had only partially survived the thaw, she would have viewed the cycle very differently, “I don’t think it would have been as hard for me.”

Mind-Body-Mind: Belief Affects Body Chemistry, Body Sensations Affect Belief

As described in an earlier theme, Zoe went into reproductive endocrinology treatment not wanting to believe that she could become pregnant to protect herself from the feelings she thought she might experience if she didn’t conceive. She explained that

there was a turning point in the treatment when she was able to believe that she could become pregnant, and in the next cycle, she conceived. She commented on the different “non-scientific” factors that might be part of the “equation,” especially when you’re older and “it becomes that much more difficult for it to happen physically.” She suggested that some of the factors might be how supportive your husband was, or a woman’s belief that she would “make a bad mother.”

Zoe described that she had always been “particularly in tune with [her body]...physically aware” and it gave her a “sense of structure.” She commented,

The physical aspects of it [the treatment] were in some ways fascinating.... You, cause I thought to myself, ‘God! I knew it was invasive. I knew that this was pumping my body with stuff that was making it do something that it wasn’t supposed to do.’

This awareness contributed to Zoe’s feeling in the back of her mind that, ‘Okay, you know there’s a limit.’”

Zoe commented on how she felt her beliefs about what was possible affected the “chemistry” in her body, and how sensations in her body helped her acknowledge what was happening in her body. She explained that when she was able to believe that she would get pregnant, a physical shift occurred in her body that helped her conceive: “When you can truly start to believe that it’s possible to physically do it [conceive], I think that changes the chemistry a bit.” As described earlier, Zoe felt the first physical sensations she felt in her uterus after she became pregnant helped her believe and acknowledge that she was, in fact, pregnant, and enabled her to overcome her disbelief, which had been serving to protect her from disappointment. Zoe explained how she found it difficult to believe she was pregnant even after three different tests provided confirmation that she was: a positive pregnancy test, the first sonogram at two weeks

during which she was able to see the embryo, and later “even after [she heard] the heartbeat.” As noted earlier, it was only when she felt the first gurgling” and then “thumping” sensations in her uterus two months into the pregnancy, did Zoe finally believe and accept that she was pregnant and it was going to be “okay”.

Zoe followed her description of her first awareness of these physical sensations in her uterus, with a description of her experience of feeling “physically out of control.”

And then you feel—and yet—and that was one of the things that I really struggled with because you feel so physically out of control. From the very beginning you feel physically out of—going through the—going through the IVF stuff, it feels physically out of control. You’re told you can’t do this, you shouldn’t do that.

Zoe commented on the level of commitment that was necessary to go through the treatment, “You *really* have to want this to happen to make those concessions.”

Mind-Body Insight: You Have to Create a Hospitable Environment in Your Body for Pregnancy to Occur

Zoe described gaining an understanding of what was necessary to support conception and pregnancy from the perspective of the acupuncturist she was referred to by the reproductive endocrinologist that provided treatment during the third IVF cycle:

It was so intuitive and so obvious that I thought to myself, ‘Why didn’t—I wish physicians would explain it that way,’ which was, you know, you have to create an environment where you know, basically your body says to itself, ‘Okay, this is a good place to have a kid,’ and you wouldn’t think about that at all.

Zoe described how the understanding she gained from the acupuncturist helped her reflect on how she lived and how she managed her stress. “Being physically active and being...managing stress...I was always competitive, you know, I was always competitive with myself, you know, it manifested itself with being physically competitive.” Zoe explained how the acupuncturist helped her understand the impact of managing stress through competition with oneself in physical activity:

What I didn't realize was that—until it was explained to me, that you, when you're competitive your adrenalin goes up, and there's—if it's a comfortable feeling, that adrenalin, then you're gonna want to continue to achieve that high. The problem with achieving that high is that when your body produces adrenalin, it sends a signal to your ovaries *not to* produce, and that it's an inhospitable environment.

Zoe explained that she came to realize that it was important not to be physically active during treatment cycles, as well as between treatment cycles:

It's one thing to...go through a [treatment] cycle and know that you shouldn't be physically active while you're going through a cycle. It's another thing not to get your frustrations out even between cycles. So I would go through a cycle and then I'd be like, 'Okay, it didn't work, okay, bummer, but you know, I can at least get back in the gym, I can at least get back on my bicycle. I can at least go—you know, go back and—and what I didn't realize was, you know that that's part—you know that's all part of supporting an inhospitable environment. It's, you got to really *stop*—your body has to stop.

Zoe also explained that the acupuncturist helped her understand why he suggested she stop watching the news on television. “Your body...physically reacts to hearing that there was a tsunami, even though it was—unlikely to ever happen here...your body still physically reacts to it.” Zoe commented that she knew her body reacted to events reported in the news:

Just hearing about, you know, a shooting in the subway, up, you know, thirty blocks...you react to it, even though mentally, you don't or mentally you say to yourself, 'You know, gee, that would never happen to me.' You're absorbing it, and physically, you don't separate it, you know, you don't separate an immediate threat with something that's, um, you know, very unlikely to happen. So, you know, I kind of took that all to heart and I took his advice.

Zoe commented that she started doing Sudoku puzzles to take her mind off the things that were causing her stress and felt that it was very effective.

Zoe described her experience receiving acupuncture during the third IVF cycle. She explained that the acupuncturist who specialized in fertility was very, very specific in his placement, very—and very specific how often and *when* in the cycle. “Um, so yeah,

it was fascinating, where on your body, where were the eggs, you know, was there a concentration on your right side versus left side, cause typically you get more on one side than the other.”

Zoe commented that she felt the acupuncture was helpful in offsetting the “*very, very, very clinical*” aspects of reproductive endocrinology:

You need something to offset that, you need to have that and I don’t think enough women are aware of that...they don’t realize that just simply the fact that it’s so clinical, adds a layer of stress, uh, that you know, you really have to somehow counteract.

Zoe suggested that it’s in the best interest of the reproductive endocrinologists for their patients to have a positive outcome and wondered, if this is so, “why aren’t they thinking about the things that are stressful that could have a negative outcome?” Zoe reflected on her perception of the doctors’ point of view and its limitations:

It is *pure science*; it is absolutely pure science to them. And that’s what their job is, and if you accept the limitations with that, then that’s okay, but you—but so many people don’t know that and don’t stop to think about it and...and they don’t say to themselves, ‘You know, that’s just part of the picture here.’...And that’s, you know, not even that big a part of the picture, you know, giving it fifty percent of the credit [towards a successful outcome] is, I think, pretty generous.

Zoe described how the medical system leads patients to believe its approach to fertility treatment is “kind of a sure bet.” She elaborated on her experience:

Our whole system is designed to believe that well, you know—there’s Step One, which is just, try to be aware of your cycle. Then there’s Step Two, going to see someone and maybe getting, you know, oral medication that, you know, increases your ovulations, the number of eggs you ovulate with, and then there’s—*then—then—then*—*then* there’s the invasive part of it...and then you realize after you’ve been through it...that the invasive part is so limiting, *so limiting*, and um—but that’s not what you’re led to believe. You’re led to believe that it’s kind of a sure bet if you get there [to the invasive part].

Reflecting on her experience, Zoe explained that she thought the stress of going through IVF treatment negatively impacts the potential success of the treatment, “I think

in many, many cases, the IVF process probably cancels itself out, meaning...the stress of going through the treatments cancels out the potential you have for conceiving, because you're stressed out about it." She also shared a sense of irony that she thought many women going through treatment feel: "everyone goes through that moment of, you know, I'm looking at it all with irony, recognizing that God, you know, you spent your whole life it seems, trying to *avoid* getting pregnant."

Medical Complications Requiring Unanticipated Procedures Increase Stress and Trigger Somatic Reactions When Recalled Months/Years Later

Some women encountered complications during treatment cycles that required additional procedures and exacerbated their already high levels of stress, yet remained determined to proceed in their efforts to conceive. Celia encountered several complications during treatment cycles, one building on the next that increased the level of stress she was coping with. During the follicle stimulating phase of the second IVF cycle she was undergoing, while in the care of the third reproductive endocrinology practice she had sought treatment from, Celia was advised to increase the dosage of the medications she was taking, and extend the time she took the drugs beyond the number of days she had taken those hormones for the previous successful cycle in order to allow some of the follicles to get bigger. After doing so, Celia began to sense that "something didn't feel right" and then started spotting. After being reassured by the doctor on the phone that what she felt was just the "follicles growing," and after going in for a sonogram to check the size of the follicles, during which she did not receive a pelvic exam, Celia explained she was "going a little nuts" because she knew something was wrong and she was still spotting. Celia went to the doctor's office without an appointment, "demanded" to see the doctor and told him,

“You need to look inside of me. Now.” And he finally goes, “Oh, all right.” He looks inside me and goes, “Oh my God. There’s like a pool of blood in here. Did you know that?” Hello, I’m not a doctor. Did you know that? “I tried to tell you.” So I was filled with all this blood. He says to me, “Well, you know what we can do? We can take the eggs out and freeze them...and make frozen embryos.” Well, you know I’m sitting here going, “Okay. Are these—will these eggs be any good?” And I ask questions. And he doesn’t know. And I surely don’t know.

Celia’s knowledge, beliefs, and concern about pre- and perinatal imprints influenced her decision about freezing her eggs. “I just couldn’t do it. I just couldn’t do it.” As Celia described these events during the interview she observed, “I’m feeling like nauseous.... It’s interesting, I always have to stop at this place. But I’ve gone through the rest of it.”

Following this experience, Celia lost trust in this reproductive endocrinologist and was referred to another doctor in California by a fertility therapist with whom she was consulting. At her first visit with this doctor, before he even examined her, he suggested that due to her age, it was likely she would have a much higher chance of conceiving and sustaining a pregnancy if she considered using a donor egg. Celia commented that she “kind of got anxious about that because—I hadn’t really explored it, and I’m the queen of research.” She described that when she thought about using a donor egg,

There’s something confusing about it in terms of [pause], I mean, now, I think a—I—I’m thinking, ‘Is this really how I want to bring a child in? I mean, if I’m gonna go to all this effort, what am I doing?’ And yet I was being pulled into this.

Celia explained that the doctor examined her and showed her a picture of her uterus on the computer monitor with something in it that he said could either have been a placenta and she was pregnant, or an enormous fibroid tumor in the wall of her uterus. Celia took a pregnancy test and it was negative. She expressed her surprise about having a fibroid that had gone undiagnosed:

Now I need to tell you that I’ve had a zillion hands inside of me by this point, and nobody said that? Do I have a fibroid? Now it’s enormous. It’s a month since my last Pap smear and internal exam.

The doctor told Celia she'd have to have surgery to remove the fibroid before she could go ahead with the IVF cycle using a donor egg. "Why I just didn't stop at that point, I have no idea. I felt like I, you know, I was hitting my head against a wall." Celia explained that she went to a doctor in New York to have the surgery. On the day of the operation, her blood pressure was too high to do the surgery and she was sent home from the hospital and referred to a cardiologist. The cardiologist evaluated her, did a stress test, told her she had "white coat syndrome" and put her "on drugs" for hypertension. Taking the medication for hypertension raised more questions for Celia and contributed to her level of stress, "Because I appreciate the imprint of medication—my question kept being, what is the effect of hypertension on my baby—if I get pregnant? What is the effect of this medication?" Celia received reassurance from a number of people that she shouldn't "worry" about it. The medicine was "the oldest heart medicine that's ever been around." At that point, Celia commented, "All of a sudden, my anxiety dropped—which was kind of good for me, and it was the first time in years that I had felt relaxed...and yet, I just knew that I was concerned."

Celia had the myomectomy to remove the fibroid tumor. She commented that "everything was fine, and my blood pressure went up in the middle of the surgery anyway—high, and they had to give me some other things apparently, and I realized, 'Oh, that's what happened in my birth sequence,'" again making a connection between her fertility journey and her pre- and perinatal imprints.

Celia elaborated on her post-surgical experience. At first she was fine, but a week after the surgery, she described being, "doubled over in excruciating pain. I knew something was wrong. Took my temperature, it was 102. Called the doctor, same wall, [doctor said] 'Oh, just call me in a few days. You'll feel better.'" Celia explained that a

week later she “went through the same routine again—and then I just said, ‘You know what, I’m coming over. I was on fire—by this point I had 103.4.’” Celia explained that when the doctor examined her, he told her “there must be an abscess in there. We have to go through it again—do your surgery again.” The doctor sent Celia “around the corner” for a test to “see where exactly things are.” She described being escorted by the surgeon’s nurse, “his nurse carried me, literally, there in the rain...I mean I was delirious by the time I got to the [hospital].... It was just crazy. Um boy, I’m really angry, you know?”

Celia had the second surgery to remove the abscess and recovered. The doctor told her that the myomectomy had left her uterus “uneven” and that if she wanted to continue infertility treatment, she would have to do a “test run” in which she would do a test cycle with estrogen to see if the lining of her uterus was “even all the way around.” Celia explained that doing a test cycle “was kind of a relief, I gotta say. It was like a break.”

Celia observed that what happened to her when the doctors repeatedly didn’t recognize or acknowledge her reports of the physical complications she was experiencing, she “became more anxious” because she couldn’t trust the care they were providing. She commented that each time they kept telling her, “ ‘Oh, you’re just overreacting, you’re overreacting,’ And each time I wasn’t overreacting.”

Celia explained that while she was going through all these experiences, she thought about how they would imprint a child if she were to conceive based on her understanding of prenatal and perinatal imprints:

Okay. This is gonna be imprinted as pre-conception. This is all pre-conception. How’s my child gonna feel about this? I mean, it was just so clear to me—and who else was gonna agree with me? So I’m holding all this information.

Out of concern for what her “potential baby” might experience if she was “speeding away” through treatment, Celia tried to “pace” herself. She worried about what would happen to her baby and her blood pressure if she didn’t slow down. Celia commented that she wondered how women in reproductive endocrinology treatment could be “allowed” to go through multiple consecutive cycles of treatment without considering how that was impacting their nervous systems.

Lilah provided a detailed description of her physical experience of the complications she suffered during her second pregnancy from an IUI cycle when her fallopian tube ruptured and she was bleeding internally. She provided an understanding of the intense challenge she faced trying to cope with the mind-body experience of life-threat to both herself and her fetus. She recounted how she felt in the moment before she fainted, “All of a sudden, I just got really hot and like everything in the room started sounding funny. I felt like somebody was cupping my ears, like everything just sounded like fuzzy.” Lilah described her feelings after she came to, “I felt mortified. I was so embarrassed. So embarrassed. I mean, I am not a petite woman, I mean falling flat on the floor.” She described her experience as she started bleeding vaginally and was preparing to go to the emergency room:

And then I just got freezing cold. I couldn’t stop shaking. I mean, I was literally, like my whole body was just trembling. I could not get warm, no matter what. So, called the doctor’s office and I told them, you could hear in my voice my teeth were chattering, you could hear it.

She related tearfully that she realized then she was losing the pregnancy.

At the emergency room, she began to experience excruciating pain on her lower left side. She found this confusing because she thought she only ovulated on the right side, and through the fear and pain, remembered trying to understand how it made sense

for the pain to be on her left side. When the resident examined her, she could see from his facial expression that her condition was serious, which confirmed her belief that her tube had ruptured and she was bleeding internally, but Lilah didn't fully comprehend the possible implications of her condition until the reproductive endocrinologist explained that he needed her consent to take whatever steps might be needed to save her life. She continued to be in excruciating pain and was given morphine: "The morphine helped for not even, not exaggerating, 15 minutes. I was like whoa (big sigh). It was just long enough to catch my breath and then it was like, oh my god, what the hell?"

The day after the surgery to remove her ruptured tube, Lilah felt drugged. She remembered feeling "unable to complete even a small action," like feeding herself, "I can't eat, I don't want to eat. I can't be bothered." In the following weeks, the mind-body impact of all the experiences she had had to that point was evident in her feelings of depression and symptoms of posttraumatic stress. Lilah had difficulty sleeping and requested sleep medication at an office visit following the surgery. Lilah acknowledged that the experiences she went through, though behind her, continued to impact her and her relationships, "Even though you walk away and that procedure, that test, exam is over, you carry it with you. It has become a part of you...you put it behind you, but it doesn't go away. It's part of you."

At the end of the interview, having recounted the whole sequence of events she'd been through, Lilah commented that she felt "emotionally numb": "I feel like a balloon and like you untied it and like *shooooosheeee*, and it's just sitting there now. You know? So that's like (big exhale)... I feel like deflated."

Both Celia and Lilah were faced with complications and procedures that compounded the mind-body stress of infertility treatment. Both women sought to

continue reproductive endocrinology treatment cycles as soon as possible after recovering from the procedures required to treat the complications. Concerns about the passage of time and the limited number of menstrual cycles in which they could attempt to conceive motivated them to resume in spite of the mind-body impact the experiences they had just been through had on them.

Theme 4: Changes in Appearance and Internal Sensations Evoke Negative Emotions Toward a Body that Feels Unfamiliar and Is Viewed as “Uncooperative”

The women described shifts in the focus of their attention throughout treatment cycles. At times, they described being intently focused on the internal sensations in their bodies, listening for somatic communications from deep inside that might indicate how treatment was progressing and might hint at the outcome of a particular treatment cycle. Sometimes they attended to the changes they experienced in their appearance or how their bodies felt moving in space during different phases of the cycles. For some women, the symptoms and side effects they experienced during treatment cycles persisted between and beyond treatment cycles. For some, surgeries required for complications encountered during treatment left scars on their bodies. The changes some women experienced in internal sensations and physical appearance as they went through treatment cycles were often unexpected and evoked feelings of surprise, unfamiliarity, and even a sense that their body was “foreign.”

As described in earlier themes, there were times during the treatment process that their focus moved away from their internal sensations and their sense of their bodies in space. They described intentionally or defensively separating their minds from their bodies in preparation for, or during, treatment experiences that evoked intense sensations

and emotions. These feelings were related to past experiences, the challenges and the intensity of the experiences in the present moment, and the convergence of both.

Several women described feeling as though their bodies were strange as they experienced the effects of treatment medications and procedures and that their bodies felt and looked different to them. For some, the image of their bodies that they held in their minds prior to treatment did not match their reflections in the mirror during the treatment, and some experienced differences in how they felt as their bodies moved in space. Both of these experiences rattled their perceptions of their physical selves. The rapid weight gain and physical discomfort that the women who underwent IVF treatment experienced within a short period of time during the follicle stimulating phase of the cycle often triggered these feelings. Pam and Marina explained that these symptoms lasted beyond the egg retrieval procedure.

Repeated unsuccessful attempts to conceive and symptoms that, for some, persisted even beyond the end of the treatment cycles, evoked negative feelings in some women, including anger, disappointment, and feelings of a shaken identity. Some women talked about their bodies as if they were separate “uncooperative” entities toward which they directed these negative feelings.

Pam described how unfamiliar her body felt to her during the treatment cycles:

Everything was strange. Food cravings were strange. All my sensations were strange. Physical sensations, the touch of fabrics and things, were all different and strange. My hair changed textures. My *hair* changed. I couldn't figure that one out. It was really weird. I'd get up in the morning, take a shower, and wash my hair and go, 'I don't—this is not my hair. Like you know, you get accustomed to the hair on your head, right? ...It's a very strange sensation and virtually nothing about myself—I didn't recognize anything about myself.

Pam commented that since she started infertility treatment, she felt her body “change, move, alter, become different and foreign, virtually every second.” At one point,

between the first IVF retrieval and transfer procedures, she commented to the doctor, “It seems like an alien spaceship has come down and taken my body and given me this strange one instead.”

Pam explained that her hair, “so curly and tight”, was part of her identity: “It’s so much who I am. I’ve had it all my life.” The fact that her hair had become much straighter during infertility treatment left her feeling as though,

Somebody’s stealing it [my curly hair] from me (laughs). I’m not me anymore.... I was always Pam with the extremely curly hair. It’s who I’ve always been.... It’s like foreign hair. It’s like somebody shaved my head and gave me a wig.

Pam described other changes in her body that persisted after taking so many hormone injections. She had “permanent dead spots” where she had “lost sensation in pieces of the glut muscle” from the progesterone injections. These spots itched and burned. She experienced other changes that persisted between treatment cycles, including chronic “terrible pain” down her leg that she never had before, as well as “terrible uterine pain” and severe premenstrual bloating. Even when she wasn’t taking the hormones and ovulated naturally, Pam continued to experience that same hormonal flush that had made her look sunburned during the treatment cycle.

Pam noticed that she had become especially attentive to every internal sensation in her body:

Everything in my life seems so wrapped up in, ‘Am I pregnant, am I pregnant?’ I feel a twinge, I feel a pinch. Does that mean I’m pregnant? Am I pregnant?

Pam explained that she had developed a “strong dislike” for her body because it “wouldn’t cooperate. It wouldn’t do what I would tell it to do. It wouldn’t get pregnant when I wanted it to.... It becomes your enemy. It becomes your obstacle. The obstacle

here becomes your own body.” She elaborated on the anger she felt towards her body and particularly towards her uterus:

I stood here yesterday and I was crying to [my husband]. I said, “You get really, really pissed off at your own body.... I’m angry with my own body because I feel like I have these unborn children and my body is killing them for some reason. My body won’t accept them back...and that’s a really depressing thought for me.

Pam described how the negative feelings towards her body led her to thoughts about how to get her body to do what she wanted it to:

You beat it into submission basically. You starve it to death or you feed it to death or you drug it to death until it does what you want it to do...I did go through an overfeeding phase where I was convinced if I, cause I was so thin, where if I feed myself more, it’ll get pregnant for me.... I went through force feedings of myself. I still have that feeling to some extent. The way I feel now is yes, when the embryos are transferred back in, my evil, horrible uterus kills them and I don’t know why. And I try to talk to my uterus about that. It doesn’t respond. It doesn’t answer.

Pam commented that she had started the process of accepting “my body is as my body is.” She felt she was beginning to accept the fact that there might not be anything she can do about the fact that her eggs might not be viable or her uterus is an “inhospitable environment” and commented,

After all, my uterus and my ovaries and the eggs that I produce and all are actually part of who I am and I actively talk to myself now about this... about loving my body for who it is and be nice to my body and you know, treating it nicely, eating well and healthy and I’m going to start yoga again.... Try to treat my body nicely despite the fact that it’s not really cooperating with me.

Lilah talked about her desire to be alone and let the sun cover her surgical scars. She described her fantasy of going scuba diving and lying on a beach alone to recover from her treatment experiences and two pregnancy losses. She imagined allowing the sun to tan and cover the physical scars on her body:

I just want four days. I want four days in the tropics, and I don’t want anybody to come near me. I want to find myself a private beach, somewhere where there’s nobody anywhere near me, and I want to lay buck-ass naked in the sun, and I

want to tan everything. Tan all my scars, get rid of all my belly scars that I have, and that's what I want. I want four days, four days.

Lilah explained (as mentioned in the first theme) that she experienced the accumulation of her unexpressed and unacknowledged feelings while going through infertility treatment as a build up of internal pressure. She commented that sometimes, the feeling that built up inside her was rage. At times she became concerned about how this emotion felt in her body and worried that it might become uncontrollable. At these times, Lilah arranged to go out alone and sat by herself until it subsided. Lilah's mind-body experience of building internal pressure seemed to translate into a compelling mind-body need for space and time alone:

I want to lock myself in my shower stall. If I could put up like a steel door on my shower stall, that's all I want. I want that much space. And I just want to be by myself and just leave me alone.... I don't want to talk to anybody. I don't want to look at anybody. I don't want to hear anybody. I don't want to know that there's anybody there.

As Zoe described above, she chose to stop being physically active to try to create an optimal environment for conception to occur. This was a significant change from how she was used to "being" in her body. When she did get pregnant and went through a period of rapid weight gain in the second trimester, after not having gained weight in the first, she commented on how strange her body felt and the adjustment she had to make to suddenly carrying twenty additional pounds over a short period of time.

Zoe described another abrupt change in her body that she experienced when the nurse lifted the surgical drape after the cesarean and she observed her body, still numb from the spinal anesthesia, and minus the "torpedo" that had protruded in front of her for several months. The appearance of her body, which she could not yet feel, had changed significantly in just an hour or two and seemed to surprise her.

As Celia described earlier, she enjoyed the changes she experienced in her body taking the medications required for the IVF cycles, as well as the sensations she experienced during the time she was pregnant before she experienced an early miscarriage. Celia's awareness of certain sensations in her body were indications to her that something was wrong and served to alert her to medical complications including concealed bleeding in her uterus during the follicle stimulating phase of an IVF cycle that caused the end of that cycle, the imminent early loss of a pregnancy conceived during another IVF cycle, and an abscess following her myomectomy that required she undergo an additional surgery.

It wasn't until the women took a break from or stopped treatment that they had the opportunity to pause and begin the process of adjusting to, acknowledging, and reconnecting with their bodies—bodies that had absorbed all the experiences they had been through. The pause or cessation of treatment allowed them to acquaint themselves with the rhythms that emerged in their bodies' physiological processes, processes, and rhythms that were no longer being manipulated by infertility treatment protocols.

Theme 5: Layers of Loss Unnamed and Unprocessed Contribute to the Burden of Cumulative Unresolved Grief

Many of the women described layers of loss that they carried into their fertility journeys and their experiences in reproductive endocrinology treatment. The repetitive cycles of loss that each woman endured in treatment built upon previous experiences of loss in their lives, as well as transgenerational, pre- and perinatal and other family-of-origin imprints. The women described their experiences of loss in reproductive endocrinology treatment, including the loss of multiple eggs (those that were retrieved in repeated IVF cycles, but not used), the loss of embryos that had been transferred into

their uteri during IVF cycles (but did not implant), the loss of embryos after positive pregnancy tests, the loss of a fallopian tube, and the loss of a fetus in the fifth month of pregnancy.

Health care providers did not explore the possible mind-body effects of the women's prior experiences of loss and other relevant imprints for their potential links to the women's current problems conceiving. The beliefs that emerged from the meaning the women attached to their prior experiences and imprints, and the possible impact of those beliefs on their mind-bodies, seemed to go unnamed within the relationship between the women and their health care providers, even though these factors may have had an impact on the systems of the women's bodies that were involved in conceiving and sustaining a pregnancy.

It seemed as if there was an unspoken agreement between the women and their health care providers not to explicitly acknowledge the multiple cyclical losses that the women experienced during treatment, thus leaving the women and the health care providers to process (or not) these experiences on their own. This aspect of the treatment process, as well as the women's previous losses, and transgenerational and pre- and perinatal and imprints, seemed to exist out of the health care providers' (and some of the women's) conscious awareness, as if hidden behind a veil.

Most of the women also described the loss of the vision they held prior to treatment of how and where their child would be conceived and who would be present at that time. This included the vision that their child would be conceived in an act of love with an intimate partner in a private space.

By the time most of the women sought reproductive endocrinology treatment, they had experienced months of trying to conceive without medical assistance. The

women described the loss of spontaneity in their sexual relationships with their partners over time. Sex had become a mechanical process, performed on a specific schedule, with the sole objective being that of conception. For the best chance of conceiving, the timing of sexual intercourse had to be carefully planned around ovulation. The optimal frequency of intercourse also had to be considered to ensure the likelihood of the highest sperm counts around the time of ovulation. For the women who underwent IUI and IVF, sex with a partner was not even necessary. The entire process was removed from the context of a sexual act between two people and placed in the context of medicine and technology. For the IUI procedure, semen is provided by the woman's partner or a sperm donor and introduced into the woman's uterus by the doctor. For women who underwent IVF, surgically retrieved fresh eggs were fertilized in a dish with sperm supplied by a partner who masturbated alone in a room at the medical facility where retrieval and transfer procedures were performed, or with donor sperm. For women undergoing an IVF cycle with frozen embryos from a previous IVF cycle, the embryos were thawed and transferred into the woman's uterus without the necessity for the partner's participation at all.

Each new menstrual cycle was initiated by the blood that announced the outcome of the previous month's unsuccessful attempt to conceive and marked the loss of the potential pregnancy held in that cycle, whether the women were trying to conceive without medical assistance that month, or had undergone IUI or IVF treatment.

The women who went through treatment without successfully sustaining a pregnancy also lost their dream of having a biological child. As described in earlier themes, some of the women who experienced complications also feared the loss of their own lives during treatment. Several women expressed their concerns that their lives

might be threatened or lost in the future, as a result of the potential long-term effects of the repeated cycles of drugs used in the treatment process.

Pearl

As described earlier, Pearl mentioned she had abortions earlier in her life and carried her feelings about those decisions and experiences into her experience of reproductive endocrinology treatment. Pearl commented that she wondered whether the difficulty she had conceiving was God's punishment for her past decisions and behaviors. She explained how she felt when she made the decision to have an abortion earlier in her life and how that differed from how she felt at the time of the interviews:

Since having been in this [trying to conceive]...now I really want my baby and now I really have a strong sense of—for my abortions that like, when I got pregnant with those, I was thinking it was their child [the father's]...somehow... [and said to herself] 'I don't want to have *his* baby. It was *my* baby. But I didn't get that then...and now I really get that it's *my baby*...it's both of ours...but I didn't feel an ownership toward that...baby then...I felt like it was theirs and maybe that's kind of like you feel like the seeds come in to you or something.

Pearl commented on how difficult it was getting through her feelings about the abortions:

I went through a phase where I really felt horrible about myself and I'm out of that phase now, but I know, I really felt, I went through hell about, you know, the regret about my abortions and the, you know all that stuff.... And um...and that was really, really, really hard to go through that stuff. But I think it was great for me to get through it and get to the other side.

Pearl mentioned the transgenerational/family-of-origin imprint of her mother's and sister's experiences of having difficulty conceiving. Pearl explained that she told the first reproductive endocrinologist at the first appointment,

In my family I had one sister with endometriosis, she had been through a lot of fertility problems, but then ultimately had three kids. And my mom had tubal problems and then she had a hysterosalpingogram and magically she got pregnant two months later, so obviously her tubes were a little bit blocked and the hysterosalpingogram just managed to clear out the problem cause they'd been

trying for four years. Nothing. So, those are possibly some clues to what might be going on, but we really have no idea.

Pearl commented that she “walked in there going, ‘I just want the hysterosalpingogram because I know I’m just going to have this thing and like my mom and then I’ll be able to get pregnant.’”

Pearl described pre- and perinatal and other family-of-origin imprints that she thought might have had something to do with the difficulty she was having conceiving:

I just had this thought the other day...when I was born, I was the fourth of four girls, and I knew my dad really wanted to have a boy...I think they both really wanted a boy...so there was this little thing I was reading where, go back to when they say, ‘It’s a boy or it’s a girl’ and then what feelings surround that? And I just know, like when they said, ‘It’s a girl,’ my parents probably both went (in a low disappointed voice) ‘It’s a girl. It’s a girl. You had another girl.’ And...as a kid I used to say, I was supposed to be a boy. And I would dress like a tomboy and I would run around and try to play sports and I’d go to baseball games with my dad and you know and I would really try to satisfy that for him.... I wonder how that plays into this as well, like I was busily getting my career and (hits table with hand) you know I can’t be having babies [while] I get a career together. I got to impress my dad. I got to, you know, following the son’s duties kind of thing. And I was like, isn’t that interesting. That probably plays a part in this too and there’s just so many aspects to it, so many different things.

Pearl continued with another aspect of her family-of-origin experience that she thought might have had an impact on her fertility journey:

And I know there was also the thing about my mom was very prudish and for me to get pregnant is admitting I’ve had sex and uh...my mother doesn’t talk about sex and so that’s a whole ‘nother level of uh...I think a barrier or a difficulty in conception or something.

Pearl described the experience of having to have sex on demand and the loss of spontaneity in her physical relationship with her partner during the part of her fertility journey that preceded IVF treatment:

You have this relationship with your partner...that you want to um...keep...light and airy and happy and fun and yet, you know, tick tock tick tock and you’ve got to ummm you know at those times when, you know he’d be leaving at 5:00 in the morning to go to work and he’d get home at say...6:00 and I’d have patients from

like 3:00 in the afternoon until 9:30...and then we'd have to eat dinner and so then it was now, it's 11:00, 11:30 and he's got to be up at 5:00 and we still have to have sex...[and] he was away on a trip for sometimes, like a three-day job that happened to coincide just with ovulation, and then, you know, it's like, should I cancel my patients and go on this trip with him and just sit in the hotel room and wait for him to come back in the evening so that I can like have sex? It's like so stupid, and we actually never did. But one time, I had to go to his work and he had to do a sample like in the bathroom at his job...and then I had to rush it over to the doctor so I could get my insemination. And you know, we try to laugh about it.... But you can't always. Sometimes you're not in the mood to laugh about it. And sometimes you're in a fight.

Pearl explained how sex became a "job" that had to get done and if she was ovulating, how she or her partner was feeling emotionally or physically at the time, wasn't important. She described her thoughts and her feelings when her partner asked to postpone having sex when he wasn't feeling well:

All I'm thinking about is I want to have sex, I don't care how sad he is, I don't care how mad he is, I don't care anything, just get the job done and then you can go to bed. That's all I care about...the only thing I need from you is sex...please.

Pearl commented that at those times her partner felt "used,"

It's really sad and then of course they'll say [her partner], 'Well I feel used.' Yes, in this moment you should feel used, cause that's exactly what I want from you...but then there's moments when I feel like the guinea pig, going to the freaking clinic every single day, so it's like, 'You know what? I put my ability to be a human on hold while they're poking and prodding me every day and you should put your ability to be a human on hold for this one moment or something.'...and 95% of the time you, you know, 95% of the time he's golden.... He's like, 'Well, that's it, I don't care how tired I am, I've got a job to do, dundadunn.' He's like, you know, so sweet about it, thank God, but...we all have our moments when we're just like, 'No, I don't want it to be like this. I'm sick of this. I want to just get pregnant the way normal people just get pregnant and they don't have to go get poked and prodded. They don't have to have sex on demand and they don't have to like, you know, go through all this shit and spend a fortune.

Pearl explained how difficult it was to give up the dream of having her biological child. She shared that sometimes she thought,

If I could just let go of us having our own child, and just move in to the adoption place, or the donor egg place, (lowers, softens her voice) I could put an end to all this right now.... Just stop...stop making this my life.... And move into being a parent...which is what the whole idea was for. And um...and then I go into my whole selfish thing like uh, you know, yeah, I should be able to do that, but I'm not ready to, because I want us to have *our* baby.

Pearl talked about her experiences and feelings in the months and years following the loss at 20 weeks, of the child she conceived during reproductive endocrinology treatment. She tearfully described an experience she had two or three months after the miscarriage which, once again, brought to the surface the deep feelings of grief she held following the loss of the pregnancy:

We'd lost our baby in May and we had a concert that was in July or August, and I had planned my maternity outfit that I was gonna wear to this concert. And I was so exci— I bought it extra big, and I was excited that it was really cute and I was going to be able to wear this outfit to this concert.... So, then I go to...to get dressed for this concert and I couldn't get dressed because I couldn't put on anything but that maternity outfit and I didn't need that maternity outfit.... And I'm in my room and I'm just bawling my eyes out and I can't, I can't get dressed. And so I went and I got online [a website for women going through infertility problems] and I said, 'I can't get dressed. It's so painful.'" [crying]. But the greatest thing was you know, like in ten minutes there was like these women going, 'Oh my God, I had to do the same thing, I had to go to a wedding and I couldn't wear that dress and I didn't know what to do [hits table with hand]...so...you found, you found someone to hear and understand in the instant, in an instant.... Like I was like so grateful for the internet during that 'cause, you know, even my girlfriends that love me, and family...even my friends who were going through fertility stuff, or had even had miscarriages, they hadn't had my miscarriage. They hadn't had, they hadn't been through quite like this, and so, as empathetic as they would be, they hadn't been through it. And you want someone who's been through exactly that thing. You need that exact thing. And there was a woman who had lost her baby like three weeks different from mine, mine was like 20 weeks and hers was like 23, and I mean we like we just clung to each other for a little bit there, you know, and ah, it's like you just want somebody who totally is right there with you.

At the time of the interviews, it had been three years since Pearl lost her baby.

She commented that the anniversaries of the date she lost the baby and his expected due date continued to be painful for her every year:

I got pregnant in January. We lost him in the middle of May.... I was due in October. And still when May comes around and October comes around, all the landmarks (hits table with hand) January, May, October, each landmark every year is like, you know, and every birthday, because it was just before my 40th birthday when I found out I was pregnant. And I'd been just scared to death to turn 40 because I'd always said, 'God, if I'm not pregnant by the time I'm 40, I'd just die.' You know that kind of thing and I was terrified to turn 40 and not be pregnant. And I would say, that one of the reasons that [my baby] came then was to get me through my 40th birthday.... And it got me through Mother's Day, too. 'Cause I had that Mother's Day. Mother's Day's always a rough day. Always has been.

Pearl described how healing from the loss of her baby was an ongoing process that required a lot of work, and continued to do so at the time of the interviews, three years after her miscarriage. She explained,

Just in bed this morning, my prayers this morning were, 'I forgive you Pearl for not knowing every, for not being able to prevent, how, the loss of your baby.' I mean like this was just his morning. This is how much work it takes every day...every day.

Pearl also explained that following the loss, she became aware that she held a fear that if she became pregnant again, she might lose another baby and had been working on shifting that:

And I know for me now, part of my fear of conceiving is the fear of losing another one. So then, I've been working on that...healing the trauma of the last loss and then forming the belief that that was that and the next one will be different. And that's the work that I've really been concentrating on for the last four months.

Pearl described the painful loss of the vision of the future she held in her mind during the pregnancy she miscarried, a vision of her child's life that she imagined she and her partner sharing in, as he grew up:

As soon as you're pregnant, you're imagining that whole arc [the arc of your child's life], you've already lived [in your mind] that whole arc with your child, and that's why losing a baby is so hard, because it's like, I'm not here [uses her hand to mark the beginning of her vision of her child's 'arc of life' in the air], I'm there already [uses her hand to mark the end her vision of her child's 'arc of life' in the air].

At the end of the second interview, Pearl described a deeply healing experience she had while meditating a few days earlier, related to the loss of her baby:

I was in this meditation the other day and...I'll probably start crying, but I was asking my healing angels to come and I'm really working on healing this trauma from the loss of [my baby] and so she came and she brought me to this beautiful valley that was just like unbelievably beautiful, these *gorgeous* tall mountains and then like the side of the mountains all in wild flowers and it was just this gorgeous valley and she like lays me down into the grass and she sprinkled fairy dust all over my lower abdomen, my womb and my ovaries and everything and then she said, 'I know that you're sad that you didn't get to see [your baby's] whole life, that you didn't get to experience all of his life.' And so she showed me in like a fast forward, like all, like here he is at four and five and six and ten and twelve and fifteen and twenty. And I sort of like was watching this fast forward motion of this little boy growing up and becoming a young man and a man and older man...and then, and it really was surprisingly satisfying.... And then, super fast, she [the healing angel] pulls me all the way to outer space, and I am floating in black outer space with like stars around and she takes my hand and she goes like that to me (uses her hands to make a pushing away motion) and I float off into space and she goes, 'There's no net, there's no one to tether you. I'm not holding onto you. You've been through all of this to learn how to self comfort.' And I just went 'hooooo.' And so you know like first I'm floating in space. I'm like, you know, you're like, 'Somebody tether me.' And then she's like, 'You can do it. You can self comfort.' And I just let myself float and be ok just floating without a net, without anything there, just ok within myself. And that was like...(hits the table with her hand) great (crying).

Pearl explained that after the meditation she thought to herself, "I am finally at 43, and I'm learning how to self-comfort.' You know what I mean? But that's like such a gift. Such a gift to say... 'I can, I can comfort myself through whatever. I can do it (crying).'"

Celia

Celia explained that she had been pregnant twice earlier in her life, prior to seeking reproductive endocrinology treatment. She had gotten "pregnant on the pill" when she was 19, even though she was a "very regimented pill-taker" and had an abortion, "I just wasn't ready to do that." She got pregnant again when she was in her thirties and decided to have an abortion after being "clear about my ability to support myself, because I knew my family wasn't going to be there. Um, and is this how I

wanted to bring a child into the world?” Celia noted that she was “sad to say” that she didn’t do the abortion until almost the eleventh week because,

I wanted to push myself to that limit [taking the time to try to figure out how she could take care of and support a baby by herself] and say, ‘Oh, I can do everything.’ But I knew, thank God, that I couldn’t. I knew that I had to do the work that I’m doing today [her career].

Celia reflected on a question she had about the source of some “core knowledge” she held:

I really know in my core, I know that as much as I wanted a child, in the long run, I was not supposed to have one.... I, I don’t like that, but I also know that...it’s a loss that I think I’ve also, um (sighs), you know, allowed myself to sit with and yet there’s this little part of me that still hasn’t—uh, figured it out yet, that said, most of the time, ‘This isn’t right for you.’ Or it said, ‘Are you sure?’ Or it said...there was always just this little question mark.

Celia explained that she didn’t feel sure whether the “little question mark” was one that she carried as a transgenerational issue from her mother or whether it was her own, “‘cause it very much sounded like my mother. Um, and I know that she had children because that’s what everybody did.”

Celia described another aspect of the dynamics in her family-of-origin that may have impacted her decisions and feelings about when and if to have a child. She noted that she “took it for granted” growing up that she would be a mother:

I think when we’re um, growing up, we all think we want to be moms, but, I don’t think we ever—I’ll speak for myself—I don’t think that I ever thought I wouldn’t be a mother. Um, I knew I wanted a career. I’ve always known I wanted a career. Um, my father wanted boys; he had three girls. I wanted to be, you know, like my dad.... I had some con, con, double-bind stuff around how feminine I can be.

Celia had done some personal exploration and processing of her pre- and perinatal issues and reflected on how those issues may have impacted her fertility journey and experiences in reproductive endocrinology treatment. Through the pre- and perinatal

processing that she had done, she had become aware that she had had a twin in utero who died in the fifth month of her mother's pregnancy with them. From her experience, she understood that her twin was not thriving and commented, "[he] told me to take his turn. I've cried a lot of tears about that."

Celia talked about her initial experiences in reproductive endocrinology treatment during which she waited for the man she was dating to make a firm decision about providing his sperm for inseminations. He vacillated between wanting to provide his sperm and having doubts. Celia commented, "In waiting for the guy to catch up, it was as if my—part of me, unless I had that other part, couldn't do it on my own.... I just wasn't sure I could do it alone." Celia paused and reflected on her feeling and then a question arose for her about the connection between how she felt about the prospect of undergoing infertility treatment alone and her pre and perinatal experiences of losing her twin and going on through the rest of the pregnancy alone.

She described getting to the point where she decided she wasn't going to wait for her partner to commit to his involvement in the reproductive endocrinology treatment and would use a sperm donor. Her partner had agreed to donate his sperm for insemination and then wavered on the actual day of the procedure, telling her he was "not sure" he wanted to do it. Celia felt his behavior created "double-bind stuff" for her. As she described this, she commented that coming without her twin when she was born felt somehow related to not waiting for her partner to commit to his involvement in infertility treatment.

Celia shared more about her thoughts on the connection between her lost twin and her fertility journey:

I feel some confusion around—maybe that’s why I didn’t have a child—because there’s someone—maybe I was trying to have a child to replace—you know, having a twin that dies is that search for the beloved and for me, that’s really true.

Celia made another “very powerful” connection between her prenatal experience of losing her twin and her fertility journey:

I could not let go of my jour— journey to have.... Oh, it’s so obvious—to have a child—because if I let go, it would be as if I was letting go of this child that was trying to come in, you know, when I was coming in—my twin or...myself—even, you know? If I was let—letting go of her, the child that was coming in, then I—wasn’t I letting go of myself?

Celia described other life imprints that had an impact on the decisions she made going through infertility treatment. As described in earlier themes, all her life, she had gotten the message, “If you were really strong, you could do it.” As discussed earlier, Celia commented that this belief was part of what made it so difficult for her to give up treatment. She elaborated, “You know I don’t give up...but it almost killed me.” She noted that these beliefs kept her from realizing the danger she would be placing herself in if she got pregnant, since she had developed hypertension. Celia finally came to the realization, that the potential for loss on her fertility journey also included the loss of her own life.

While she talked about these experiences, Celia made connections to other prenatal and perinatal experiences:

It also takes me...takes me back to, um, uh, how I’ve lived most of my life, which is not knowing whether I’m really here or not here. Well, I don’t even know where to go from here. I was thinking about, um, being resuscitated at birth, and then just not knowing where I am...I don’t get it. I don’t get all of this life thing—this form thing. I don’t get it.

Celia also reflected on her belief that she had had a past life and had lost a daughter in that lifetime in one of the concentration camps during World War II. Her experiences in New York in the aftermath of the 9/11 attack and the smell that emanated

from ground zero for weeks following the attack, reminded her of the loss in that lifetime, and created traumatic stress for her at a time when she was in reproductive endocrinology treatment trying to conceive.

Celia expressed curiosity about her sense that there was “another piece” to the feelings she had experienced when she lost a pregnancy in the sixth week following reproductive endocrinology treatment, something besides feeling “sad and unfortunate” that she wasn’t able to name.

Marina

Marina talked about two beliefs she held that were challenged by the difficulty she experienced trying to conceive and sustain a pregnancy. She commented that the difficulty she had conceiving brought to her awareness that she had come into her fertility journey with the belief that “feeling like a woman” was associated with being able to “conceive” and “give children.” If she wasn’t able to do so, she might lose her experience of “feeling like a woman.” She explained that part of her motivation to participate in the study was a desire to help others come to understand that having difficulty or not being able to conceive was “not something you should be ashamed of, feel guilty or you know, you’re not a woman anymore.”

Marina explained that she experienced feeling a loss of control going through reproductive endocrinology treatment since there was nothing she or her husband could do, even though they were willing to do anything that might help. “You feel like a loss of control and...you know it’s such a personal thing, but you don’t really have anything you can do...if someone told us, ‘Do this,’ you would do it.”

Her infertility experiences challenged her belief that she could get what she wanted if she worked hard enough, a belief or imprint that allowed her to have a sense of control over her life:

I suppose it's something that you've always kind of thought, 'Well, you'll get what you want as long as you work hard for it.' So you study and get a good job. You work hard at your job and you get promoted and you work at your marriage and you know.... And then there's this thing that probably you want more than anything else...or it means more than anything else...and you don't really—there's nothing...especially...because from our cycle, they're not saying there's anything wrong. So it's not like I can change my diet or I can change, you know our lifestyle. It's just in somebody else's hands.

Marina explained that she was not a religious person, but believed in something, “So, I'm not a religious person, but the, like you do believe in something. Is there a God? And I think maybe it's—when it's meant to happen, it will happen. So don't stress. You just can't help.”

Marina commented on the feeling of loss she experienced after an IVF treatment cycle resulted in a positive pregnancy test, but ended with what was apparently an early miscarriage:

You do feel that you've lost something. Especially because you—I mean I was surprised. I used to say to my husband, I thought maybe I'm just making it up mentally in my head, but before even the test, I'd say my body does feel different, and because of that, you do, even early, is that you do feel some sort of connection.

Marina described how she started to think differently as unsuccessful cycles passed and she questioned whether she and her husband were going to be able to have their biological child. She commented that, at the time of the interview, her husband still thought they would have their own kids, but she was beginning to have other thoughts, “I don't know, maybe I'm a bit more—maybe it won't happen. She explained that her thoughts moved to adoption and how adoption might fit into her culture and society.

Lilah

Lilah lost two non-viable ectopic pregnancies during reproductive endocrinology treatment, one of which required emergency surgery to remove her ruptured fallopian tube. She explained the meaning those losses held for her and connected it to the imprints of her experience of being adopted as a baby and her total loss of connection with her biological parents and other blood relatives. She discussed the urgency she felt as a result of these experiences to provide several biological siblings for her first child so he wouldn't be alone when she and her husband died.

Lilah explained that the loss of her tube had special significance to her:

I have to say, like I really feel like less of a woman. And you know, that sounds horrible and that sounds terrible, but...and I know it's not true...mentally...like I'm an intelligent person. I know that's not true, but I can't help feeling it. You know? I care inside. That's the feeling. I can't...I can't help...I can't help it, it's just there." Lilah explained that she was in the process of using her tube, and "to lose it when you're not done with them, it's a loss and it makes a really significant difference and to not have anybody understand that....

She sought support from her husband and tried to help him understand what she was feeling, but felt, even though he was trying to be supportive, "it just didn't sink in for him." Lilah experienced a sense of understanding from her husband when she used analogies to communicate how she felt:

"What if you lost one of your balls? How would you feel? How would you feel? ...Would you feel like half a man? Would you feel like less of a man if you only had one testicle?" And then, that was the first time that I actually saw a glimmer, and I can't even say it was a full complete, it was just a glimmer of somewhat of an understanding."

Lilah elaborated further on what losing the tube meant to her:

Like, not that my sole purpose as a woman is to reproduce and to carry a life...it's not my sole purpose, but...at this particular juncture in my life, that's my purpose. Like we're trying to have babies. You know? I'm the one that has to carry them, I'm the one that has to, you know, do all that portion of it.... And to only have, to be functioning half-way, you know, it's a real kick in the head.

Lilah described that it was really difficult to go through losing her tube and losing two pregnancies without having the support of someone who really understood the significance it had for her. But dealing with loss alone was something she was familiar with, “I guess, I guess to some degree, like I’m used to dealing with that emotion... ’cause I’m adopted.” Lilah expressed concerns about the implication of not providing a sibling for her son that stemmed from her own experience of being adopted. She expressed her deep worry that without a sibling, her son would have to go through the loss and burial of her and her husband, alone. Without one fallopian tube, she felt she had less of a chance of providing a sibling for him.

I don’t want him to be alone.... I don’t’ want him to be alone...it just like rips your heart out...it just kills me...it kills me...losing half of that ability, nobody really can understand, because it’s like, it’s like a compound problem now.

Lilah commented that she wanted her son to have a blood relative who had her genes. She knew what it felt like not to have a blood relative, not to know where you came from or who you looked like. She worried that her thoughts and concerns about this were “twisted,” “bizarre,” “whacked out” and “far fetched,” and felt that nobody understood her since they were related to the fact that she was adopted and the people she shared these feelings with, were not. This increased her sense of aloneness:

It’s like nobody understands, like you know...saying it’s like I’m *alone...again*. I’m alone in my feelings. I’m alone. I’m the only one that has these feelings around me. Nobody else ever has these thoughts and feelings because nobody’s in the same situation.

Lilah’s concerns about knowing who her blood relatives were brought up a lot of anxiety during her pregnancy with her first child, her son:

When I was pregnant with my son, and I would just start crying, I would be hysterical crying. And my husband would be like, ‘What’s wrong?’ And I would be like, ‘But what if he comes out looking like somebody I don’t know?’ Like you know, you look at your kids and say, ‘Oh, he’s got Uncle Joey’s nose, and oh my

God, doesn't he just look like my brother when he was a kid? Whatever it is, you know? He looks like my father's side of the family, or my mother's side of the family. I don't have that.

Lilah explained that the significance for her of not knowing her blood relatives was that her face didn't come from anywhere—that she felt disconnected from her biological ancestry, and alone: “I look in the mirror and I can't say, ‘Oh wow, I've got so and so's face. Like...this is my face. I'm the only one that has it. Nobody else...it doesn't come from anywheres, it starts with me.’”

Lilah remembered while she was pregnant with her son, being afraid he would look like the biological relatives she never had the opportunity to see or know. Lilah described awakening one night at 2:00 in the morning:

I was hysterical. Sobbing, like uncontrollably crying hysterical.... I just had a dream that he came out with like a huge afro and his face looked liked nobody.... Like it was like looking into the face of a stranger.... But this here was my child. But it was a complete stranger, like, I didn't, there was nothing, no resemblance, no coloring, nothing. He looked completely like nobody I'd ever seen in my life...because I don't even really know my heritage.

Lilah explained that her adoption papers state that her parents were Irish and Italian, but her appearance had led her to question the accuracy of that information. Lilah noticed that she blends in when she goes to Mexico and has a dark complexion. When she was pregnant, she asked her doctor to test her to see if she was a carrier for all the racially and ethnically linked genetically transmitted conditions because she was so unsure about the accuracy of the information she had received about her racial and ethnic background. She tested positive for sickle cell trait, which raised further questions in Lilah's mind. The incidence of the trait is highest in African Americans, though it is also found in other racial groups.

Lilah's son is the only person she knows who is her blood relative. For Lilah, having another child would ensure that when she dies, her son would still be connected genetically to another living person who shared his and Lilah's genes and perhaps a physical resemblance. She commented that she believed it was "her fault" that she and her husband were having problems conceiving. She also believed that perhaps her not being able to conceive was God's will. She wondered if God thought she couldn't handle two children and felt that if he thought she could handle two, she'd get pregnant.

Threatened with the possibility of losing her life, Lilah experienced intense feelings about losing connection with the one blood relative she knew. When Lilah was in the emergency room faced with the fact that she might die from internal bleeding resulting from her ruptured fallopian tube, she felt the full weight of what it would mean to lose her connection with her son, as well as her perception of what it would mean to him. During the interview, Lilah communicated the depth of pain and the fear of loss she remembered experiencing in those moments before surgery through her words, gestures, facial expressions, and tears. In those moments, she was faced not only with the possibility that she wouldn't be able to have another baby and provide a sibling for her son; she was faced with the significance of the possibility that she and her son might lose each other. Her worst fears would be realized.

Another imprint Lilah carried was the experience of being cared for from infancy by an adoptive mother who had gone through the experience of infertility and, as a result, had adopted Lilah, and later became pregnant and had a biological child. Lilah noted that she had expected her mother to provide support and understanding, but felt she said insensitive things that angered, hurt, or disappointed her, increasing both the feeling that she was alone and her desire to withdraw.

Lilah worried about having to make treatment decisions in the future that might involve more experiences of loss. She thought about whether she might opt to abort some fetuses if multiple embryos successfully implanted during IVF cycles. She tried to imagine how she might feel about the loss of those fetuses if she chose to undergo multifetal pregnancy reduction, a procedure that reduces the number of fetuses and the risk associated with a multiple pregnancy in an effort to increase the likelihood that the pregnancy will continue. The procedure involves the insertion of a needle guided by ultrasound, either through the abdomen or vagina to inject potassium chloride into one or more of the fetuses to induce a miscarriage of those fetuses and increase the chances for a positive outcome for the remaining fetus(es).

Let's say they put in two eggs [embryos] and let's say they both split and I have four babies now, and they want me to do selective reduction [multifetal pregnancy reduction]. If they tell me this, I'm gonna have a limited window of opportunity to do that before it becomes unsafe for them, for the other two, for me, whatever. So I need to seriously sit down and think about how I feel about all of that, process it so I can deal with it, so when I'm faced with it, I already know.

Pam

As described earlier, Pam's experiences of treatment included a deep sense of loss and intense grief following each unsuccessful IVF cycle. She experienced a strong connection to her embryos which was reflected in her description of how she felt when the embryologist gave her a picture of them prior to the IVF transfer procedure.

Pam described how hard it was for her when she was told her embryos didn't survive. The quality of her attachment to them was such that each time, she felt she had lost her unborn children. She tearfully described her feelings for her embryos:

I know that they're cell masses. I know they're eight cells when they transfer them back [during IVF] but when you really want to get pregnant.... They were truly my unborn children. They truly are. And I'm so afraid. I have four of them sitting in the freezer and they're gonna thaw them and they're not gonna survive

the thaw.... I feel now that they are suffering. I'm almost having some type of empathic response to it or something that they're suffering. When they thaw them out of the freezer, they're going to suffer. Even though I know logically that's not really true.

Pam attributed these feelings to her depression, anger, or frustration.

Pam explained that the number of embryos she had created had started to “haunt” her. She had created fifty-two embryos in two fresh IVF cycles and if she proceeded with another fresh cycle of IVF treatment, she might create another twenty embryos. Only six had been transferred back. She wondered about all the other ones, how many “children” there were among the embryos that never got the chance, if any of the discarded embryos might have been “the one.” Pam shared that she felt she was “mourning” the loss of her embryos.

Pam explained that she weighed the fear that the embryos wouldn't survive the thaw against her other choice, to leave them frozen, but she realized that wasn't really an option, “Sooner or later, they would just destroy them.” The thought of someone destroying her embryos without giving them “even a chance at life” was a really hard thought for Pam. She described holding the hope that “there could be a miracle actually. It is amazing. You do kind of hang on to that. One of those embryos could be my miracle child—you just don't know.” Her feelings about her frozen embryos influenced her decisions about treatment. She explained that she thought she would do another frozen cycle so she wouldn't “have to live with the thought that my embryos who were never given a chance of life, died in a freezer someplace or died in a Petri dish someplace.”

Pam explained that choosing to go through another fresh IVF cycle was also very painful for her. Part of her distress was caused by the fact that she had very little hope

that she'd ever actually get pregnant and had told her husband that "all we're doing is creating embryos that are going to die." She described feeling responsible for freezing the embryos in the first fresh IVF cycle, and then responsible when they didn't survive the thaw when they did the frozen IVF cycle. Looking back, she questioned whether they might have lived if she had pushed the doctor to transfer them rather than opted to freeze them. What was even more painful, Pam commented, was the knowledge that "once they're transferred into my body, my body itself is killing them off."

Pam's choice whether or not to do PGS (the embryo chromosomal screening test) was impacted by her feelings about the embryos and having a biological child. Pam expressed concern that the PGS procedure itself might be a risk for the embryo and it might arrest during the procedure:

What if the one viable embryo we had, got selected for transfer, but we put it through PGS and it arrests on us...my unborn child is going to die on the table again in the Petri dish. These are the decisions you feel you are making.

Another difficult aspect for Pam of PGS related to the "mosaic effect." The screening is done on an eight-cell embryo. One of the cells is pulled out for the test. Pam was told that apparently a lot of embryos have one or two abnormal cells, but the rest are normal and it could be viable. If the test happens to be conducted on the one abnormal cell, the whole embryo could be incorrectly classified as abnormal. After the embryo arrests, all cells would be tested and from the experiences shared by other women, Pam was concerned about how she would feel if she was told the embryos had been "misclassified" after they had arrested. Pam explained that she would find it "enormously painful" to think that a "misclassified" embryo might have been able to survive.

Pam explained that the pain of not having a child in her life, whether it was biologically hers or not, made the experience of being around babies “traumatic” for her and spending time with young children “borderline traumatic.” She commented that she and her husband were trying to “reaffirm” themselves as “the family of two,” but were finding it difficult. Pam observed that she and her husband had come to view their dog as their child.

Pam mentioned family-of-origin imprints that she carried into her fertility journey. She underwent reproductive endocrinology treatment with the knowledge that her sister had been trying unsuccessfully to have a child for fifteen years. She also explained that she had felt very abandoned by her own parents and family at times in her life, and having those experiences contributed to her feeling that,

...somewhere out there, born or unborn is our child and we have to keep searching for the child because otherwise, I will just feel that I have abandoned my child, born or unborn.... I know that’s kind of a distorted way to look at it, but, it is my own motivation now, that there could be a child in an orphanage or in a foster home...who is desperately waiting for us, and to not find that child, would be to abandon them.

As Pam spoke about this in the interview, she came to the realization that her concern about what to do with the embryos that had not been implanted during the fresh IVF cycles and had been frozen was connected to her feelings about abandonment. While talking about her anger and frustration with herself about the fact that, at the time of the interviews, she still cried as much as she did, that she couldn’t “get over it,” Pam explained, “the sense of loss is so overwhelming and it is...it’s like a death. It’s like a death to me. It is.” She commented that it felt like the overwhelming sense of loss went on forever and wondered if that was how parents who lost children felt.

Pam also expressed her sense of loss about not being able to conceive the way she had hoped. She described feeling,

...robbed of the experience of the beauty of conception of my child. I feel that it was stolen from me unfairly and unjustly...the visions you always have of the conception of your child and the loving moment with your spouse and the candles burning in the background and the soft romantic music playing for you, you feel that it's all been stolen and robbed. My reproductive life has now come down to a steel table, a couple of surgical instruments and a Petri dish. The last straw for me was being willing to accept the fact that I was going to go through this without [my husband's] even physical presence.... The loss of even that dream was the hardest for me.

Pam explained that, if her husband had been allowed in the room during the retrieval and transfer procedures of the IVF cycle, his presence would have provided and demonstrated support for her and their potential child, "as a father, a man, a comforter, a lover."

Pam commented that she also worried about the potential loss of her own life in the future as a result of the long-term effects of all the hormones she took as part of the treatment. She explained that some of the drugs had been linked to an increased risk of ovarian cancer. She noted that IVF treatment hasn't been around that long and that in twenty years, they might find out that the treatment kills you, "I'll die at 52...from some related disease."

Zoe

As mentioned in an earlier theme, Zoe described how she protected herself from the disappointment she anticipated feeling if she couldn't conceive, by remaining emotionally disconnected while she was going through reproductive endocrinology treatment and through the early weeks of her pregnancy with her son. She explained that the opportunity for connection with the fetus she carried wasn't realized until she was able to feel the first sensations of his presence in her uterus.

Having recently given birth at the time of the interviews, Zoe shared her feelings about her cesarean birth and the early postpartum period. As discussed in earlier themes, she experienced a sense that she'd lost an opportunity to bond with her son in those first days after his birth, due to complications she experienced following the surgery and had to create opportunities to build that bond in the days and weeks that followed.

Zoe also wondered about the implications of being conceived through IVF as opposed to being conceived in the context of an act of love and questioned if it was “the same.” She imagined talking with her son in the future about his IVF conception and showing him pictures of himself as an embryo:

It's crazy to think that, you know, someday, I'll have this conversation with my [my son], “Oh, here you were at six cells. Here you were at two weeks.” And you have to reconcile that whole notion that we grow up with which is, you know, “Conceived out of love” you know? Is it the same? It's a total head trip.

Loss of an Opportunity for Healing

Each of the repetitive cycles of reproductive endocrinology treatment holds the potential for either the emergence and embodiment of a new human being or the loss of the early sparks of life held in the eggs, sperm and embryos created in that cycle. I wonder if acknowledgement of repeated unsuccessful attempts over months and years and the losses experienced during those cycles were too much for all involved to consciously bear, contributing to the creation of a “dissociative cocoon” (Bromberg, 2006), that seemed to surround both the women and health care providers. Yet, some of the women described feeling a depth and intensity of grief that seemed to resonate from the many layers of loss, current and past, that they had endured and some expressed a feeling of responsibility for their participation in the events that resulted in these losses.

As acknowledged by many who've survived traumatic experiences and the clinicians who treat them, often some of the most difficult and painful aspects following a traumatic experience can be both lack of recognition and acknowledgement by others that the experience occurred and/or lack of appreciation of the impact on and meaning of the experience to the survivor.

The health care providers were the actual witnesses of the potential new life held in the eggs, sperm, and embryos that were lost in each unsuccessful cycle of treatment. The reproductive endocrinologists retrieved the eggs and transferred the embryos back into the women's uteri, and the embryologists presided over the fertilization process, placing eggs and sperm together or micromanipulating eggs and sperm in dishes outside of the women's bodies, and monitored their development into embryos in carefully regulated incubators. These were the very people whose hands had made contact with, and whose eyes had seen, that which the women lost.

In conception that occurs without medical assistance, eggs, sperm, and embryos are not seen, touched, or manipulated, the process occurs deep within a woman's body. In conception that occurs with the assistance of reproductive technology, there are witnesses to the process of fertilization and early embryonic development. By not explicitly acknowledging, appreciating or communicating their recognition of the women's experiences of loss at all phases of the treatment process, and the significance these losses may have held for the women, the health care providers who witnessed the cells, alive and lost in repeated attempts to conceive, may have missed an important potential opportunity to support women in the process of healing from and resolving these losses.

As described by the women in earlier themes, in order to proceed on the schedule required for each treatment cycle and to be able to maximize the total number of treatment cycles they could undergo, the women and their doctors focused on the medical and technological aspects of the process. There appeared to be no time or space for the women to share the emotional aspects of their experiences with the very people—the health care providers—who were present with them throughout those experiences. The time that might be needed to move through the stages of grief following each loss did not fit into the time between treatment cycles. Each cycle that followed an unsuccessful one brought with it the possibility and fear of yet another experience of loss, for which there would again be little time for processing and resolution. The cumulative burden of unprocessed and unresolved loss grew with each unsuccessful cycle of experience, like a ball of snow rolled on the ground while constructing a snowman, growing in size with each rotation, as each frozen layer is pressed upon the layer that precedes it.

Theme 6: The Quality of Care Received from Health Care Providers Impacts Women's Experiences of Treatment

All the women who participated in the study consulted with at least two reproductive endocrinologists and some with as many as four different practices, seeing multiple doctors within those practices during the time they were trying to conceive. The women described differences in the quality of care they received from different medical practices and from individual medical providers within group practices. Some of the women commented on differences in care received from large group practices compared to practices with only one or two medical providers.

The range of the quality of care the women described varied with the following factors: 1) the individual personalities of the doctors and their capacity to be present and

engaged in a caring and respectful way during appointments; 2) the health care providers' technical skills and sensitivity to how the quality of physical care they provided impacted the women's physical experiences of treatment, especially their experiences of pain; 3) the doctors' interest in feedback about and acceptance of the women's physical experiences throughout treatment; 4) the amount of clear, complete and accurate information provided prior to exams, tests, and procedures that impacted how prepared they felt for what they were going to experience; 5) the number of doctors seen in rotation in a practice and their familiarity with the women as individuals; 6) the doctors' accessibility and responsiveness when the women had physical problems, questions, or concerns; 7) the doctors' and medical staff's sensitivity to and interest in understanding and addressing the sources of the women's distress at critical times during treatment cycles; 8) the doctors' awareness and acceptance of the women's knowledge of infertility treatment and willingness to take the time to invite and answer questions; 9) the doctors' ability to clearly and compassionately communicate with the women with respect for their level of knowledge about the treatment, and also for the women's awareness and knowledge of their own bodies, the wisdom it held for them, and the value this information they were trying to share might have in informing treatment; 10) the health care providers' appreciation for the women's capacity during each interaction to process the information being offered; and, 11) the extent to which the various doctors involved in conducting exams, tests, and procedures on an individual woman, and interpreting their findings, results, or outcomes, consulted with each other and sensitively delivered coordinated, clear interpretations and avoided providing conflicting information that created confusion for the women and their partners.

The women's interactions with each practice as a whole and with individual health care providers evoked an array of feelings in response to the quality of the verbal and non-verbal communication and physical treatment they received. They described interpersonal and physical interactions in which they experienced kind, respectful, and gentle physical treatment that evoked trust in the health care provider and a felt sense of safety in their mind-bodies as they went through exams, tests, and procedures during which they felt most vulnerable. They described other interpersonal and physical interactions in which they experienced insensitive, disrespectful, and unnecessarily rough physical treatment, which betrayed the trust that had enabled them to place themselves in the most vulnerable positions with the health care provider during exams, tests, and procedures, and which triggered or exacerbated a felt sense of threat in their mind-bodies.

They elaborated on their feelings of vulnerability during and after interactions with health care providers and noted specific qualities of verbal and non-verbal provider communication that supported or detracted from the degree of comfort they experienced in their mind-bodies throughout the difficult treatment process. The women described their reactions to the ideas, thoughts, and feelings expressed in words by the providers, as well as the providers' non-verbal signals communicated through eye contact, facial expression, tone of voice, gestures, posture, and the timing and intensity of responses.

Some of the provider behaviors described by the women are known to support experiences of nervous system regulation in dyadic interactions and others are known to trigger experiences of nervous system dysregulation in dyadic interactions (Schoré, 2003a, 2003b; Siegel, 2004; Tronick, 2007). The women commented that they felt seen and heard as individual "human beings" with feelings, in response to attentive, compassionate and gentle care delivered by sensitive, calm, and engaged (apparently

affectively regulated) providers. They described feeling disrespected, dismissed, assaulted, frightened, and ashamed in response to rushed and forceful care delivered by insensitive, frustrated, or disconnected (apparently affectively dysregulated) providers.

Some of the women elaborated on their reactions to the quality of touch they experienced during the physical exams and procedures which involved the most intimate and vulnerable parts of their bodies—their reproductive organs. The women described their experiences of the degree of the providers' understanding of and concern for the sensitivity of their internal organs and tissues. This was communicated to them through the quality of the provider's touch and moderated by the provider's technical skills in all aspects of the treatment.

As described in earlier themes, an aspect of the women's experiences of patient-doctor interactions included their mind-body reactions to being in close physical proximity to medical providers in the most vulnerable postures while having to remain immobile during the uncomfortable and sometimes painful procedures required for treatment. Outside of the medical-technological environment, these postures are often associated with human reproductive behaviors and interactions that require activation of the social engagement system and "immobilization without fear" (Porges, 2004). The quality of care the women received supported or inhibited their capacity to experience "immobilization without fear" within the context of the medical-technological environment of reproductive endocrinology treatment.

Some of the women commented on the reasons they chose not to provide feedback to the doctors on the quality of care they received, even if they felt they were being treated disrespectfully in interpersonal interactions or experienced unnecessary forcefulness during physical exams. They expressed their need for the doctors' complete

cooperation during all phases of each costly (in every sense of the word) treatment cycle. Some women commented that one way they felt they could ensure total cooperation from the doctors and the best chance for a positive outcome was by trying to be “good” patients for the doctors, part of which meant not upsetting or antagonizing them. The women seemed to imply that they felt if they communicated with the doctors during treatment interactions about the physical and emotional impact of the care they were receiving, they might challenge and irritate the doctors and they would risk losing the doctors’ perception that they were cooperative, compliant, “good” patients.

Several of the women described having the awareness that the doctors quite literally held in their hands, the women’s hopes and dreams for a biological child when they were about to introduce into their uterus either their husband’s or donor’s sperm during an IUI cycle or their embryos during the transfer procedure in an IVF cycle. Some commented on the power differential they felt existed between themselves and the doctor in that moment. They described making the choice to override their mind-body feelings of threat and impulses to protect themselves in interactions with providers whose behaviors triggered or exacerbated those reactions, in deference to their biological drive to reproduce. The women expressed great appreciation for doctors that provided a quality of care that reduced the conflict and tension between these two basic drives (one to protect oneself in the face of perceived threat and the other to reproduce), and helped them feel a sense of safety and trust as they went through the challenges of infertility treatment.

Each of the women commented that their primary motivation for participating in the study was their intention to help even one other woman who might go through reproductive endocrinology treatment in the future. They expressed a hope that by

sharing their treatment experiences and the impact it had on them within the context of this study, they might be able to inform change in the way this care is provided to women and their partners.

The participants' experiences demonstrate the importance of the quality of care at this extremely sensitive and vulnerable time in the lives of women trying to conceive through this process. Their experiences also demonstrate the need to consider the potential implications that the experience of the quality of care provided at this time, holds for families that emerge from this treatment and these prenatal processes.

Pearl

As described in earlier themes, Pearl sought treatment from several reproductive endocrinologists. The first one she went to, whose sensitive care was not matched by any of the other doctors she saw afterwards, did not offer IVF treatment. Pearl reported feeling heard, seen, and cared for in a gentle, kind, and respectful way by this doctor. She arrived in his office feeling fragile, distraught, and desperate for help. The doctor's ability to listen, hear, and be respectful of her and her husband's "place," to provide comfort and hope at this difficult time, was deeply appreciated by Pearl. She explained:

There was this hope there that he was like, "Oh yes, what we've gotta do is" ...and he was so nice...it might even be the first time I felt heard by a care provider...and comforted by a care provider. I don't think I ever felt that. Doctors were...not comforting, they weren't warm, they were someone you went to for their mental information.... How sad is that?

The doctor's considerate way of telling Pearl exactly what he was going to do and what she might feel during the physical exam, his invitation to Pearl to provide him with feedback about what she was feeling during the exam, his careful observation of her physical reactions to the exam, his willingness to work with her body's reactions acknowledging her difficulty in controlling these reactions, all communicated his sincere

concern and intention to make the experience one in which she felt seen, heard and compassionately cared for.

Pearl described her experience of the first doctor's presence at appointments, "who's like, you know, right there listening, eye contact, heart facing you, like very much engaged with you as a human being (hits table with hand)." As described in earlier themes, this doctor made a conscious effort to "see" Pearl, to make eye contact with her when he spoke to her, even during pelvic exams, covering her vagina when he did so, which helped Pearl get through feelings of shame that she carried into this experience.

She described her experience with other doctors she saw later and the difference she noticed in the quality of their presence during appointments. She described the second doctor:

He wasn't a very touchy feely doctor...he's just not a very warm guy. He's a guy who's really in his head.... He has trouble sort of like doing the eye contact thing, and I demand that of them. I walk right in and demand that. Engage with me, I'm human.

Pearl also described a third doctor as "not very touchy feely", but commented on the positive aspects of the quality of his presence during interactions with her, "He definitely puts his heart forward. He, he engages you with eye contact, he faces you, and he leans forward and listens. He's got that aspect down and that's good."

The fact that the first doctor laid out a clear plan of treatment gave Pearl hope that there were steps to be taken to understand and solve the problem and gave her a sense that he had the knowledge and skills necessary to help her. She commented that the doctor had a cheerleader quality that inspired hope and helped her to feel better when she left his office than when she went in, which Pearl noted, was "shocking" in the world of infertility treatment. His awareness of changes in Pearl's mental and emotional states

while undergoing treatment (some of which was provided by other doctors who did procedures he did not offer) enabled him to offer much needed support at a critical time, and treatment to alleviate the high level of stress she was experiencing during the infertility treatment process. Pearl observed that the level of stress is so great because “when you’re in the fertility world it’s charged with everything and your basic desire to procreate.”

Pearl recounted that the doctor expressed an interest in learning about her work, which included using acupuncture with women experiencing fertility issues. The doctor’s interest and way of interacting with her contributed to her feeling that he respected her: “He immediately kind of gave me the kind of respect that I would have liked to have gotten from a peer who’s treating women and men in the field.” This contrasted with the condescending attitudes she encountered in speaking with some of the other reproductive endocrinologists she went to for treatment. Pearl commented that the condescending tone she experienced from some doctors reflected their attitudes towards communication with women patients in general, which she felt was based on their assumption of their patients’ lack of knowledge or familiarity with the medical terminology, and their inability to understand the complexity of their conditions. Pearl commented, “I have the vocabulary and I start speaking to them in medical terms so that they know that they have to up their game. They can’t just brush me off like some little cookie or something, you know?” She also felt that being able to communicate in this way made her “memorable” to the doctor so she wouldn’t get “lost in the shuffle” in the environment of the larger infertility practices.

Pearl explained that her insurance changed while she was receiving care from the first doctor. After a period of time paying out of pocket to continue to see him, and

coming to the point where she needed IVF treatment which he didn't provide, she reluctantly tried another group of doctors. She described the contrast in care she received from the large, multi-provider practice she consulted with next. She experienced the lack of continuity of care that can occur in a large practice and the impersonal quality of rushed interactions as she saw different doctors in the practice from visit to visit, especially at certain points in the treatment cycle when she had appointments every two days. Pearl commented that she felt there was a cold "factory" atmosphere in the large infertility practice, so different from the "cozy" environment in the first doctor's office (a sole practitioner).

Pearl commented on the nursing staff at the large, multi-practitioner reproductive endocrinology practice she went to and shared her thoughts on why they might have interacted with her and other patients in the way they did:

The nurses, you can tell they don't want to engage with you. You're just a number. They don't want to get too close. ...I really got the sense they were protecting themselves.... They've seen a lot of women come and go.... I can understand from their perspective, watching these women, I mean, you look around the waiting room in a fertility office and women aren't happy. Nobody's happy to be there. Nobody's feeling like, "Oh, I'm finally getting helped." Everybody's ashamed and sad and you know, it's just horrible and so it kind of breeds that whole energy and I think eventually.... The nurses probably come in all excited about being in fertility and then eventually learn that it's just a sad place to be and the statistics are bad....

Another aspect of care that Pearl commented on was the long wait in the waiting room she experienced at most practices for all appointments including consultations, blood work, or ultrasounds:

If you're going for a consultation appointment you can wait for a couple of hours. Very common...if you're going to meet with the doctor.... It becomes half your day.... If you're going for your early morning ultrasound or blood work appointment, you could still wait an hour or two.

Pearl commented that waiting to hear back from or see the doctor was particularly difficult when she had concerns during a treatment cycle. She explained that any symptoms that were indicative of something not going well or a complication during a treatment cycle, amplified her already significant level of anxiety about the outcome of the cycle. During one treatment cycle, when Pearl was concerned about symptoms of a vaginal infection, she felt frustrated with the delay she experienced in getting a response to the messages she'd left for the gatekeeper nurses at the doctors' office. She described her escalating feelings of fear and anxiety about trying to decide by herself what to do, while waiting to connect with and get advice from the doctor:

You just feel like you're lost in the dark, like you've been flown out to outer space and the cord was cut and now you're floating going, "But I don't know how to, I don't know how, you know? Where's the net and who's going to help me?"

Pearl commented that she felt unattended to at a time when she very much needed someone to quell her fears.

Pearl described her experience at the office when she finally went in to see a doctor in the practice, that wasn't the doctor she usually saw. The nurse had instructed her to stand in the hall and to stop and ask the doctor if she would examine her as she was walking between exam rooms from one patient to another. The nurse refused Pearl's request to be put in an exam room since they were all taken and the schedule was booked. Pearl described her discomfort standing in the hall waiting, "It wasn't like I was brand new either [in this office], but I still felt like a foreigner in a foreign land." Pearl recalled the doctor's response to her concerns when she caught the doctor between patients in the hallway:

[The doctor said] "Well, I don't know what you want me to do... It's not going to mess with your IVF cycle if that's what you're worried about." And I said "Yeah, I am worried about that. I'm spending \$14,000, which I barely have, to do this

and uh, and I'm freaking here... I'd really like you to look [examine me] because you know I lost a baby due to, we don't know, but it might have been bacterial vaginosis and I'm just paranoid now about like infections and yeast infections and cause, at first they had told me I had a yeast infection and later they said it was bacterial vaginosis and then later I found out that that can cause preterm labor....” And she's like, “But you're not even pregnant.” And I'm like, “I know, I'm just giving you the little background here of why this is so upsetting to me and why I feel like I just need to be checked.” “Well, I don't have time to check you and I'm not going to give you anything anyhow 'cause you're in the middle of a cycle and besides, you're not even my patient so, you have to really talk to [your doctor].” And I mean it was just like...I remember just leaving there going, why did I just cancel my whole day of patients, come flying over here to like hopefully get some help and meanwhile, I'm like walking out of the door with my tail between my legs and none the wiser.

Reflecting on the experience and how it impacted her, Pearl commented,

The yeast infection was just a manifestation of something and I needed to be looked at. I needed someone to see me as a human. And I was not being seen in any shape of the word at all.... I felt so unattended to.... And I went home and I was just crying and crying and crying about...all the money.... And I was just like its ‘I just know this isn't going to work, how can this work? Look at me. I'm a wreck.’

Pearl explained that she was so dissatisfied with the care she received that day, the doctor's insensitive way of communicating with her in the hall, her apparent lack of compassion and appreciation for the amount of money that Pearl and her partner had invested in this cycle and the financial strain it imposed that she called the doctor she had previously seen in the practice.

I called my doctor and left him a million messages and I was like, “You know, I just feel like I was just completely blown off and I'm in the middle of \$14,000 with you people and no insurance and this is huge”...and he called me back and apologized and [said], “Yeah, I know she can be cold, but there really wasn't anything we could do.” And I said, “You know, it's gotta be better than that. When you're spending *this* kind of money and I'm right in the middle of a cycle...it's got to be way better than that.” And we did not go back there after that.... He was like a great doctor, but...if I'm not going to be taken care of in the middle of a critical moment...I think it was between retrieval and transfer, or something.... I just felt like, you people are *not* doing it.

Pearl described what she looked for in a doctor, “Beyond your head, I just want to make sure that there’s a heart there and then we can proceed, because if you’re not gonna come at me with your heart, then, you know...leave...or I’ll leave.”

Pearl recalled her experiences of vaginal ultrasound exams and commented that some doctors offered to let her insert the ultrasound wand into her vagina herself, which she preferred. She described the differences in individual doctor’s skills in performing the exam:

Some are very gentle about when they snuggle up to the ovary and others like slam it up under like one side and the other and it’s just...(sighs) oh.... They just don’t get it. There really needs to be more female reproductive endocrinologists who understand the uh...equipment because...a man doesn’t understand what it’s like to have a wand up your vagina poking your ovaries. He just doesn’t. Unless he bothers to ask, “What does this feel like?” You know, “Is this tender when I poke them?” “Why yes, yes it is...quite tender.” You know, “Oh, yeah, it feels like you’re poking something that’s like bruised and open or something, you know?”...It’s not even...ultimately how hard the pressure is, but if you sort of come in to it slowly and press, rather than the bang bang kind of pressing *hhhhhuuhhhhhh* (voice trembles) that’s very uncomfortable.

Pearl noted that although she sometimes interacted with the doctors from a place of wanting to be a “good woman”, the first doctor tried to help her not “fall” into that role:

I know that I still fall into that sort of male-female sort of thing and that and trying to be the good daughter or trying to be the good woman or the well socialized woman or whatever kind of crap (hits table with hand) we do (hits table with hand) that um...so I know that *uhhh*...I will kind of go into that MO in a situation like that so [the first doctor] did everything he could to help me not go to that place, but I’ve certainly been to other reproductive endocrinologists who did not, that want you just (hits table with hand) to not, they want to just get in there and get out (snaps fingers repeatedly).

Pearl commented that at crucial times during a treatment cycle, she made the choice not to give feedback to the doctor about the pain she was experiencing during an exam or procedure that wasn’t being performed skillfully, because she didn’t want to

upset the doctor at a time when she felt she needed his total cooperation. She described one critical point in a treatment cycle when the doctor had difficulty inserting the speculum during a procedure:

We, he had to get the speculum in 'cause he had to, otherwise...we'd leave there with nothing. We'd just gone through everything. I had no choice but to somehow force myself to let him *shove* it into me to get it going. You know otherwise, I, I was stuck, I had to, otherwise I would have taken all those drugs and made all those follicles for nothing. So this was a critical juncture and a...I just let it hurt. After four tries, he wasn't going to be able to get it into me without hurting, so I just sqozed [her partner's] hand till it was going to break and I just...let him shove it in there.... You know, you don't want to piss him off either, that's also, you're in this very vulnerable place and you know I could have said to him, "Hey fuckhead, or whatever, and really gotten mad at him and said (softer, higher voice) "Stop fucking hurting me and what are you doing?" but then, I run the risk of pissing off the doctor who's, I'm there, he's the one holding the catheter with my precious embryos in them, you now, it's like you can't piss off the guy who's doing that.

Lilah

Lilah described the range of experiences she had while receiving care from the various health care providers she encountered undergoing exams, diagnostic tests, and procedures both within the doctors' office and outside it. She had mixed feelings about some of the providers from whom she received care. She explained that she felt respect for the technical knowledge of the first reproductive endocrinologist she saw, but was disappointed in the lack of connection or warmth she felt during his interactions with her. Lilah commented that the doctor took notes and looked down while he talked to her, which restricted the amount of eye contact he had with her. She explained that having less eye contact than she expected during her conversation with the doctor contributed to her feeling that there was a lack of connection and warmth in the interaction and that increased her fear of asking questions. Lilah suggested if the doctor made more eye contact with her during the first visit, this would have indicated to her that she was being

seen and heard. She explained that she perceived a lack of warmth and connection as a lack of interest and a sign that the doctor “wasn’t looking for more conversation.”

Lilah described her expectations before the first visit:

I kind of expected them to be...warmer.... I expected him to be more...like, “This is what we do here. What we do here is make babies.”...Like kind of giving me that warm and fuzzy experience. “We’re gonna hold your hand through this process. We’re gonna get through it together and I’m gonna be walking with you every step of the way” kind of thing. And I didn’t get that.

Lilah commented she felt awkward at the end of the first visit, and she wanted something more, but wasn’t sure what it was. Feeling new to the infertility treatment process, she didn’t know what questions to ask and when she couldn’t articulate any, the doctor went back to writing notes and she felt dismissed and left:

I don’t feel like I was educated enough to ask the questions that I think he was expecting me to ask and I don’t think he was patient enough to either guide me towards asking the right questions or providing me with the information so that there were no questions.

There were times Lilah felt the doctor was going too fast for her to absorb all the information being given and he used technical terminology she wasn’t familiar with and didn’t understand, but felt too uncomfortable to ask questions. She commented that it would have helped her if he had explicitly invited her to call if she thought of any questions she wanted to ask after she left the office and had a chance to process all the information.

Lilah explained that she felt confused when the doctor seemed to be expressing a negative feeling he had about the likelihood that her pregnancy would be viable, but didn’t communicate clearly to her why he felt that way. She felt a need to clearly understand what was happening, what was physically wrong and why she was going to lose the pregnancy. The pregnancy meant so much to her, she was frustrated about not

having an explanation that clearly communicated to her why the doctor thought it wasn't viable.

Lilah commented that she noticed that the female providers (nurses and doctors) who examined her were gentler conducting the physical exams, test, and sonograms than the male providers. A male radiologist who performed one of the physically painful HSG tests on Lilah, seemed to lack the technical skills that might have reduced the amount of pain she experienced while he was trying to insert the speculum into her vagina. Lilah felt he had no business doing gynecological tests if he didn't have the skills to insert a speculum without causing unnecessary pain.

Lilah discussed the distress and confusion she and her husband experienced when they received conflicting information about the same test or procedure, at different points in time, from different health care personnel—i.e., the radiologist, the resident, and the reproductive endocrinologist. Following her first ectopic pregnancy, Lilah underwent an HSG test to evaluate the condition of her fallopian tubes. The radiologist conducting the test was initially optimistic; then, fifteen minutes later, after reviewing the results while she dressed, told Lilah that her tube was stretched out and fluid was pooling in the tube. He added that he thought there was treatment for it, which left her hopeful. Several days later, the reproductive endocrinologist told Lilah there was no treatment for the stretched tube and recommended that another HSG test be conducted during a laparoscopy to get a clearer view of the condition of her tubes. He also indicated that if he felt it was warranted, he would remove the tube at that time to prevent the likelihood of another ectopic pregnancy in that tube if she conceived again.

Following the laparoscopy and the HSG test, Lilah received conflicting information from different health care providers and was again confused and angry. She

and her husband were hopeful following the initial information they received from a resident in the recovery room who indicated everything was fine. When she met with the reproductive endocrinologist ten days later, he reported that the test he performed during surgery had confirmed there was a problem with her tube about which he was concerned, which left Lilah and her husband very disappointed and shocked. Lilah described their confusion and her thoughts after leaving the doctor's office:

Why didn't we say something to him? Why were we told ten days ago everything was fine and now you're telling us it's not? You know like what happened? What happened between then and now...that it's not ok? Like I don't understand. But we were just so shocked. Like we weren't expecting that at all. So, you know it was just like, well, it is what it is, so I have one good tube.

In thinking about why she didn't ask more questions about her concerns during visits with the doctor, Lilah explained she felt afraid to approach the doctor. "I feel like I'm in the principal's office. That's how I feel. And I feel like I can't question him, I can't second guess him." She explained that she was afraid of being "put down" and "made to feel more of a fool" than she already felt. She commented that she felt,

He's so far above me, you know, like I'm a little peon. He's this brilliant doctor, this brilliant reproductive endocrinologist that's, you know, treating all these thousands and hundreds of women, you know, every day...that like I shouldn't be bothering him...that kind of fear. Then, I guess fear of being made to feel stupid? If that makes sense? Like that my question is idiotic or my question is beneath him to answer or I'm wasting his time...like I wasn't worth the extra five minutes.... I didn't feel worthy of his time.

In thinking about how she felt with the nursing staff in the doctor's office, Lilah commented that she felt more able to approach them and ask them questions. She wondered if it was related to her feeling that the nurses weren't "that much above" her, or to personality differences. She felt the nurses' support and compassion, and "the understanding in their voices." Lilah appreciated being asked how she was doing by the nurse who was drawing her blood during an appointment following the surgery to remove

her ruptured tube. Lilah's emotions were so close to the surface, she cried when the nurse showed interest. The nurse offered the name of a therapist for Lilah to talk to. Lilah also wondered whether the nurses could be more empathic because they were women, so they could understand what a man couldn't:

What it feels like to have that life growing inside of you and knowing that life is there. You know, he [the doctor] put it there...so he knows what's happening, but the emotional aspect of it, he can never...never really know.

Lilah also experienced the compassion of one of the nurses during one sonogram, when it was clear her pregnancy wasn't viable. She remembered the nurse came and stood by her head while she was crying, held her hand and gave her a tissue. She commented that this was the only time she remembered the medical staff offering her comfort in that way.

Insensitivity to what Lilah was going through as she tried to cope with her feelings of loss and grief over the first non-viable pregnancy she was carrying, was particularly painful for Lilah. The lack of compassion she experienced in her interactions with the female doctor who provided care at that time, made an already extremely difficult experience worse. As described earlier, Lilah felt intense despair when the female pregnant doctor, while conducting a sonogram, coldly and insensitively informed her that she couldn't see a viable pregnancy in her uterus, even though Lilah's hormone levels had indicated she was pregnant. This was the same doctor who was scheduled to do Lilah's D & C surgery on the day she decided to terminate the pregnancy, and end the emotionally and physically difficult process of waiting to spontaneously miscarry. Lilah angrily described how upset she felt waiting in the pre-op area for the surgery to terminate her non-viable pregnancy. The doctor was in the latter part of her own pregnancy. She recalled that she stood next to her, rubbing her own visibly pregnant belly and eating Doritos, oblivious and insensitive to the impact her physical condition

and behavior might have on Lilah. Lilah was outraged that this doctor, *her* doctor, could be so “clueless”, so insensitive not to be aware of how painful it was for her patient, on whom she was about to perform surgery to end a non-viable pregnancy, to watch her own doctor standing next to her affectionately rubbing her belly, appreciating her visibly viable pregnancy. Lilah commented,

It’s not like she didn’t know me. Like if she didn’t know me, I know it still would have upset me, but she would have had no clue, and I can’t fault her for that. She’s *my doctor*. She’s doing *my surgery*.

Lilah explained that she felt there was a lack of preparation given for some of the tests and procedures, in particular the HSG test, even though the radiologist indicated his knowledge of women’s reactions to this test when he noticed Lilah crying and acknowledged that pain was to be expected during the test. She felt if she had been told what she might expect to feel during the HSG test, she might have been able to prepare better, even take some medication for the cramping she experienced during and after the procedure.

Lilah suggested that preparation for the HSG test might also include being told that your clothes might become stained by the dye and that bringing a change of clothing might be advisable. She noted the radiologist’s office didn’t provide adequate personal care and feminine hygiene supplies in the bathroom to assist in cleaning the dye and protecting her clothing from any dye that might continue to leak out of her vagina following the test. This exacerbated the distress and embarrassment she experienced afterwards. Lilah suggested that the staff in the doctors’ offices ask women for their feedback about their experiences, so they would understand how to improve the quality of care they were providing. She felt that sharing honestly with a patient, the range of possible experiences that she might have, based on feedback from women who had gone

through these experiences, would prepare her for what she might feel during and after tests and procedures and would be helpful.

Lilah suggested that the doctors' office help women going through similar experiences to connect with each other to share their experiences, perhaps form a group. She commented that it would have helped her to know that other people going through these same experiences had similar thoughts and feelings:

Sometimes you just need to know it's not you; that you're not alone, that you're not crazy, that the thoughts you're having are...they're real thoughts, they're real feelings, and other people have them and other people think them...and you're not the only one who's thinking it.

Reflecting back over her experiences, Lilah commented that the health care providers who come into contact with women and their partners going through these difficult experiences should "err on the side of caution and be that much more compassionate and that much more understanding." Health care providers may not remember or be familiar with the specifics of a woman's case and therefore may not know what the woman may be going through at any given time during any interaction. Lilah suggested that because of this fact, providers should be aware of how sensitive the woman in front of them might be and how their lack of compassion in their interactions with her may affect her. Lilah noted that there's "no room for bad days" for health care providers who deal with people going through such difficult experiences.

Marina

Marina consulted a second reproductive endocrinologist after the first doctor she saw was unable to find any reason why she wasn't conceiving. She commented that the second doctor was better at explaining things and helped her understand that the reason they hadn't found anything wrong didn't mean there wasn't anything wrong, but that it

could just be that the “medical advances haven’t gotten that far.” She felt the second doctor was more specific. Marina commented that the first doctor she saw was vague and said things like, “Everything seems to be going well. Your levels are good.” She added, “And half of the levels I didn’t even know what they are, to be honest.” Marina recalled the first doctor’s inconclusive explanation after an IVF cycle of why her hormone blood levels indicated she was pregnant, but they couldn’t see anything in her uterus when they did the sonogram. She noted that the second reproductive endocrinologist she consulted provided a more complete explanation that made sense to her when she suggested the possibility that Marina might have had a very early miscarriage which could explain the discrepancy between the test results.

Marina explained she had been through several treatment cycles with the first doctor and commented on the nursing staff, “The nurses were great...they were fantastic.” She expressed frustration at having to wait several hours at times to speak to the doctor and get the blood test results, after the nurses had drawn her blood within minutes of her arrival. These long waits made her agitated and late for work.

Marina explained that there were several doctors in the practice, some male, who examined her depending on the time of day she went and their schedules. The fact that so many different people had now seen her body contributed to her feeling that her body was no longer hers and she had lost a particular special feeling that she had about her body prior to treatment.

Marina described her experience of the care she received during physical exams and tests. She commented that she thought the doctors’ speed in doing the exams reflected their sensitivity to her discomfort:

Obviously you don't feel good about it. And so, they were good about the way they handled it. They would—you know, they wouldn't spend a long time in there. They'd kind of be in and out, so you'd get ready and everything. They'd be in and out.

She also described the way the doctors interacted with her verbally during exams:

They would try and talk to you about something else, so that you kind of think about, you know.... They'd obviously get to know you because even at their own different shifts, there's only a few of, a handful of them. And you know, they'd talk to you about your charts. Say, you know, "Well, last time it was this. This time..." and then they'd do the test quickly and so you wouldn't really, you know—because your mind's somewhere else.

Marina described how the doctors would also explain what they were seeing on the computer screen during the sonograms: "'This is what we're looking for...that's what we expected.' You know, they kind of talked you through what was on the screen that they were looking at.... And you could like see it yourself." Marina commented that it was helpful to be told in advance what they were looking for and then to have them point it out on the screen during the test. She explained that this helped her not to feel as though "maybe they're just saying that to make you feel comfortable or something. You just saw it yourself."

Marina commented that although she understood that the transfer of the embryos was a medical procedure, she thought the "clinical" feel of the hospital-like environment in which it was conducted could be improved:

Could be maybe a bit better in that respect. I think it could—I think—I suppose it's just personalities, um, because I'm more—that just more lighthearted... sometimes and just with everybody being so serious there and, you know, taking off charts and stuff, it just feels like you're another one going through.

She elaborated on her feeling that she would have liked the medical staff to be more "personable" with her:

I suppose because they see lots of people going in and out, you feel that you know them a bit better than they know you and they probably won't even remember you

the next time you go in. But that's just because you've seen their faces. It just—that personal contact might be a little bit better. And you'd feel they know you.

Marina explained that some of the nurses were friendlier:

They'll chat to you and, you know, talk about things, which feels nicer. And some are very, you know—they're there to do their job and—you know, very professional and everything. So that just—I think that for me, the experience would be better, more friendly and then if maybe there was an environment where you could go to pair up with people that were going through it.

Marina felt that being told how her body might feel by another woman who had been through the treatment was helpful and reassuring to her when she went through the treatment herself and found her body felt different than it usually did. The clinical information provided by the doctors about the potential side effects of the treatment communicated in medical terminology (i.e., overstimulated) raised concerns for Marina and did not give her a sense of how her body might feel or give her a guide to what body sensations would be normal reactions to the treatment. Marina explained that she accessed the internet to find more information and try to understand what the risks and symptoms were of being overstimulated, which created more anxiety, “Then you get scared in that perspective.”

Marina explained that even though the first doctor she saw didn't explain things as well as the second she consulted with, she chose to stay with the first reproductive endocrinologist practice, because she felt they had learned something about her body from the cycles she'd been through under their care, would use that information going forward, and the doctor she initially consulted in the practice “made sure she was there to be able to do it [the IVF retrieval and transfer procedures]. So that was good. Now she's got to know my body.”

Marina commented that she had expected there'd be support groups arranged through the doctors' office for the women to share their experiences. She noted that there weren't any and the women didn't spontaneously talk to each other in the waiting room.

Celia

Celia explained that she had been to “four or five different places” for treatment. As mentioned earlier, at the beginning of the first interview, Celia commented that she felt the story of her experiences in reproductive endocrinology treatment had “certain themes”, and one of them was “betrayal”, which was reflected in her descriptions of repeated interactions with medical care providers from whom she sought treatment. She observed, “I was so struck by the recapitulation of keep getting—hitting—running into these male doctors, and running—one was a woman, but keep running into these people that's kind of, um, not kind of, that betrayed me.” She described herself as “a troublemaker kind of, because I always had questions.” Celia had repeated experiences of being treated insensitively when she asked questions—not being taken seriously when she initially reported symptoms that, in fact, required medical intervention. She described some experiences of the care she received, the communications, and in one case the physical exam, as “cruel.” Celia chose the first reproductive endocrinology practice because it was “supposed to be the best and it was the worst experience I ever had. They were so mean.” She described her first appointment with a woman doctor at the practice:

Several times like, I'd say, “Well, I have a question.” [The doctor would respond] “No, I can't answer your questions. You can go see the psychologist.” And I'm going, “I really need to get this, 'cause that's my nature.” [The doctor answered] “We don't have time for this now.” And then she gave us these instructions and all of a sudden I realized that I was gonna, if I, it was as if I'd already signed up.

As described earlier, the first reproductive endocrinologist performed a pelvic exam as part of the first visit. Celia remembered this exam as “the worst experience”, and reported that the doctor treated her roughly when she couldn’t get the speculum into her vagina, “jamming this thing into” her and telling Celia that her pelvis was “shaped the wrong way.” After responding to the doctor’s inquiry about the type of work she did, Celia recalled that the doctor forcefully jammed the speculum into her one last time, then “dropped everything” and told Celia, “Well, this obviously isn’t for you” and left the room. Celia repeatedly used the words “terrible” and “horrible” after describing this experience. She explained that after the exam she complained to the practice administrator and asked for her money back and noted, “And this is an institution that everybody talks about, you know, this is *the* place.”

The care Celia received at the second reproductive endocrinologist’s office was very different. She explained that this doctor’s office was private, not part of a large hospital. “It was like this little nice little office.... And you walk in and you feel like, relaxed.... And he has these kind little sparkly eyes.” As described earlier, this doctor took an hour and a half to talk with Celia at the first appointment, during which he was very clear, told her what treatments he could and could not offer, and explained his comprehensive approach to testing to diagnose the problem. Celia remembered feeling that when she interacted with him, her “body could relax.” The fact that this doctor did not do all the necessary tests in his office made it “a little complicated” because Celia had to go “running around” to other medical offices to get the tests done. When Celia required treatments that this doctor did not offer, he referred her to a third reproductive endocrinology practice. She noted, “This man [the second doctor]...just, he has so much integrity.”

Celia described the medical staff at the third reproductive endocrinology practice, also a private practice, not hospital-based, as “nice” and added, “I think people are nice when they know you’re going to spend money. You know? You become really important.” Celia again had questions about the treatment, initially about whether the dosage of the medications prescribed for the IVF cycle was based on body weight. The doctor didn’t seem to be able to provide an adequate explanation and appeared to Celia to be annoyed with her question when, as described above, he responded, “Well, then do whatever you want,” and walked out of the room. Celia felt that the doctors seemed to be upset with being asked questions, as though it challenged their authority, “The bottom line is, they’re the doctor, you’re asking questions?”

In thinking about her question and the doctor’s response, another question arose for Celia, “When do we trust our bodies?” Celia had other experiences with doctors, during which she felt their resistance and lack of appreciation for her sense and knowledge of her own body. In the next treatment cycle, when Celia felt that something wasn’t right and began having vaginal spotting, it wasn’t until after she had spoken to the doctor on the phone, had seen him in his office at which time he did a sonogram, but not a pelvic exam, and then she showed up without an appointment and demanded that he do one, that he acknowledged her concerns and her sense about her body that something was wrong. Celia’s concerns were confirmed when the doctor looked inside her and, to his surprise, discovered a “pool of blood”. Celia explained that she lost trust in these doctors and sought treatment from another reproductive endocrinologist, this one, also highly recommended.

Celia remembered her first visit with the fourth reproductive endocrinologist who she traveled across the country to see. Celia commented,

I will never—I'll never forget this, [the doctor said] “I will never put you in a position that will jeopardize your health, or your well being. You need to trust that I will always be supportive and present for you.” And well, all that sounded very good, and very exciting and very wonderful.

As described earlier, Celia's treatment with this doctor was interrupted because he discovered a large fibroid tumor in her uterus that had to be removed. She sought care from a surgeon who removed the tumor, but did not take her seriously when she began to run a fever after being released from the hospital. Celia was struck by the similarity between this experience and her experience speaking with the second reproductive endocrinologist who also downplayed her physical symptoms and her sense that something was wrong in her body.

After Celia recovered from the myomectomy, she returned to the fourth reproductive endocrinologist to resume treatment. At that time, Celia remembered asking the reproductive endocrinologist, “What else is it that I need to do in order to make sure this works?” And he looked at me and he said, ‘You might consider changing your personality.’ I said, ‘Excuse me?’” Celia related this experience to the fertility therapist who referred her to this doctor, who then commented, “He's not known for having the best bedside manner with his patients. He doesn't do very well by women.” Celia found it “ridiculous” for a doctor whose specialty is “dealing with women” when they are in the most “vulnerable place”, to be lacking in this capacity. She commented, “I—I cannot figure out why I stayed with him. Why I gave my power away. Why I allowed him to talk to me that way.”

Celia had another experience of not being taken seriously with this doctor during the IVF cycle in which she planned to use, as he had suggested, a donor egg. Celia didn't feel well during this cycle and when she called the doctor, he told her that her symptoms

must be the result of something else, not the treatment, and asked to speak to her partner who was with her at the time. The doctor reiterated to her partner that her symptoms weren't related to the drugs she was taking for the IVF cycle. Celia explained that the way the doctor handled the situation left her feeling like "a complete moron."

Celia commented that she thought women who were seeking reproductive endocrinology treatment when they were older,

...should be treated with much more care, because you know, obviously there's a time commitment. There's a time pressure, and somehow, most of us, myself included, walk around with this shame or guilt like we—we should have done it sooner.

Celia elaborated on the feelings of shame she experienced when she went back to the second reproductive endocrinologist's office for a regular gynecology visit:

I, you, walked around with a little bit of coming in there and all these people are trying to get pregnant and some of them do, and I didn't...I was trying to do what these very young people were doing. They weren't that young, but still.... I have to say, that after awhile, I felt shame about the fact that I hadn't gotten pregnant; that I had kept having miscarriages, when I'd go into these places. I think I was so, excuse my language, fucked up and dissociated and in shock.

Celia commented on how repeated interactions with doctors in which she felt a lack of acknowledgement or respect for her experience and knowledge of her body, began to undermine her confidence in that knowledge and led her to question her perceptions and understandings of her mind-body experiences. She noted that she needed to interact with a doctor who would hear her concerns and acknowledge and respect her experience of her body to help her restore her trust in her sense of her body. Celia described her conversation with the cardiologist she contacted to consult on the advisability of continuing infertility treatment in light of the fact that she was on medication for hypertension. She contrasted the quality of interaction she experienced with the cardiologist, to that of all the other doctors with whom she had consulted (except

the second reproductive endocrinologist). Without even knowing her, he spoke with her on the phone for forty-five minutes, took her concerns and questions seriously and responded with care. She realized,

For me, the turmoil was about, I needed some professional, because I—no one was trusting my opinion, so why should I trust my opinion? So I wasn't getting—I needed someone to say, "You can stop now." Because I felt like these men, all they were saying was, "Oh, you're just the neurotic hysterical woman."

After speaking with the cardiologist, she called the fourth reproductive endocrinologist and related the cardiologist's concerns about her health if she went through a pregnancy with hypertension. Celia reported that the doctor responded with something like, "I really had no idea. It's not my, it's not what I do. I'm a fertility...". Celia commented,

And so, the deal is that—what I realized in that moment is, their job is to get you pregnant, and that's it. At no matter what the cost is. At any cost they will get you pregnant, and even if you have a stroke or die, that's not their problem. Or your child has cerebral palsy.

Celia received a package sent by the fourth reproductive endocrinologist after she decided to stop treatment:

A FedEx box filled with all the remaining fertility drugs from—that were supposed to be for my [egg] donor. Like he knew I had quit, and he—and this is what—and this is—it just seemed weird to me, and kind of, um, not very compassionate just to, like send this all back, and have it here. What am I gonna do with it? I had paid for it, but still, give it to somebody else that can use it or something. I still have it in the closet. Just a reminder, but I'm not sure why.

Celia commented that she considered filing a law suit against the fourth reproductive endocrinologist. She consulted a lawyer who cautioned her, "Just know that your character is gonna be on the stand." Celia added, "He [the lawyer] basically said to me, 'You might as well have been raped.' And you know, I've already been seen as this hysterical person—who needs to change her own personality." She explained that the

lawyer posed the question, “So, do you really think you’re gonna get a fair trial?” Celia (tearfully) she related her response to him, “I guess not.” She commented that reproductive endocrinology is “the least regulated field of medicine” and that “most of the fertility places have their own legal counsel. So every—all the lines are crossed or they’re blurred.” She decided instead to write a “brutal letter” to the doctor.

Celia reflected on her experiences in treatment and noted, “Fertility [treatment] is abuse. You know if a doctor says, ‘Get over it’ or ‘Change your personality’, that’s abusive.” She explained that she “wasn’t willing to do it the doctors’ way in a number of cases, and the door slammed.” Celia commented on the relationship that can develop between some woman and some doctors around the treatment process itself, “I’ve had a doctor say to me, ‘I can make a child for you.’” She reflected on her thoughts about the doctor-patient power differential in the reproductive endocrinology process, and the “imprinting” that occurs, especially at the moment the doctor holds a woman’s embryos in his hands and is about to insert them into her uterus. Celia commented, “It’s like slavery.”

After describing the care she’d received from each of the doctors and how she came to the decision to stop trying to conceive, Celia said,

And um, that was the end of the story.... It wasn’t so horrible right? It’s pretty bad. It wasn’t so horrible for me to tell you about it, but the truth is, is that it’s not gonna change unless we do something. I hope people listen, but I think it’s gonna take some time.

Zoe

Zoe received care from two reproductive endocrinology practices. She described some differences in the quality of care she received from the doctors and staff at the two practices:

[At the second practice] you change the cocktail, you know, a couple of the things they did, they've got, you know, a slightly different way of doing one thing or another that can increase your odds, they believe. But the way they handle it too, you know...it's still a cattle call...they're better at least at making you feel as if there's some individuality to it, but, there really isn't at the end of the day.

Zoe explained one of the things the second practice did differently:

They were really very concerned about any variances in the outcome, anything that could possibly influence the outcome in one way or another...They did little things like they took your blood the day before you went [for IVF embryo transfer] and spun out whatever it was, the white blood cells, the red blood cells, and they used that too when they injected—when they did the transfer...and I asked them why. They said, “Well, it's almost as if it gives the embryo um, nutrients right away in the environment.”

Zoe described her experiences at the first reproductive endocrinology practice where she underwent two rounds of IVF treatment.

It was not a good experience from the *very beginning*. And...the first round is typically much more stressful than subsequent rounds if you go through...but they were just, was just from the very beginning it was a lack of sensitivity and a lack of organization and a lack of coordination that made it so much more stressful than it should have been.

As mentioned above, after two rounds of IVF, the first doctor suggested Zoe consider a donor egg. She explained that she was “a little pissed off” that he suggested that before she'd gone through three rounds, “'cause I knew that the numbers suggested that you should try to get through at least three rounds, 'cause statistically at three rounds, you know usually it's, you have a higher probability than if you just stop after one.”

As described earlier, the acupuncturist explained to Zoe the importance of creating a hospitable environment in her body that would support conception. His explanation wasn't specifically about acupuncture, but it made sense to her and inspired her to make changes in her lifestyle. She observed that the doctors didn't really address these issues with her—issues which she felt, were so important in helping to support a pregnancy. Zoe explained that the doctors at the first practice told her to “try whatever

you want” when she asked about acupuncture. The doctor at the second practice referred her to a specific acupuncturist who specialized in fertility issues.

Zoe commented that the reproductive endocrinology treatment was,

Very, very, very clinical and you’re—um, you need something to offset that. You need to have that and I don’t think enough women are aware of that.... They don’t realize that just simply the *fact* that it’s so clinical adds a layer of stress.

Zoe explained that she was surprised that the first group of doctors didn’t seem to understand what it was like for their patients:

Those guys have to put themselves, you would think they would put themselves in the shoes of their patients in order to understand a little bit more what’s going on because it is—if it’s in their best interest to have a positive outcome, why aren’t they thinking about the things that are stressful that could have a negative impact on that outcome? Simply a phone call, you know? I mean there were so many things about [the first group of doctors] that were, you know fascinating to me.

Zoe described some of the things that would have helped to reduce the stress:

So, you know, if they stopped for a second and thought to themselves, “When a patient calls and we don’t call back, that elevates their stress level, and that could have a negative impact. Why would we not call them back?”...you know within a reasonable period of time. You know, you stop and say to yourself, “Why don’t they think about this?”

She described her experiences with the first reproductive endocrinology practice before her first round of IVF:

I had been calling them up [beginning] ten days before the cycle was starting, to confirm that I had all the tests done, everything was okay, and that I was ready to go on this date...So no one called me back so I showed up and of course it wasn’t. So I had a blood test that they hadn’t done.

The first practice’s lack of communication before the beginning of the first IVF cycle caused additional stress for Zoe as she tried to plan to have the necessary drugs required for the cycle, before the start of the cycle:

Because insurance covered my drugs, I had to get them mail order. So I couldn’t fill the prescription that day somewhere, so there was a lot of anxiety going into knowing that. Now I could fill a prescription, but I was picking up the tab, and

then getting it reimbursed was um—difficult. So, for three days worth of medication...it was \$1,600 bucks. You know it was certainly an amount that you know—you don't want to worry about not getting reimbursed for it. And it took months to get it back, you know?

Zoe explained that she informed the staff at the first practice of the problem, felt they were aware of their limitations, but were hampered by a lack of continuity.

“They're aware...but there's...so many different people dealing with it...it's hard to feel like there's any continuity.” Zoe commented that she thought perhaps the problem was “just on the support level...not so much the physicians.” She suggested that it would also have been helpful to have continuity of care from the nurses who spoke to her on the phone:

Something as simple as just continuity in who you're dealing with on the—on the detail stuff. Having the same nurse, with the same name calling you every day to give you the protocol, having that same nurse calling to tell you the [test] results.

Zoe wondered whether the lack of continuity was “intentional” because of the large number of patients they were treating or “you know there's an emotional factor to it” [for the nurses—rotating them so they don't become emotionally connected with any particular patient]. She commented that connecting with one nurse would have reduced her anxiety. Zoe explained that the second practice “called you every day with your protocol, you know, it really made—it made you feel like they were—you know, they had noodled and tinkered and they were much more specific.”

When she reflected on the quality of interaction with the physicians who cared for her, Zoe noted that neither group nor any individual physician's care stood out for her, “I don't remember one group standing out any better or worse than the other group from that perspective. Um, it really came down to the individual.”

Zoe commented that she saw the “head honcho” of the first reproductive endocrinology practice at her first visit, but saw him only one other time, “I think he did one of my retrievals there, because he just happened to be on staff that day...and that was the day that I...he was the one walking around talking to other women” [in the pre-op/recovery room in which Zoe was waiting to be taken for the retrieval procedure and overheard their conversations]. Zoe commented that following that experience, she thought about the doctor’s lack of awareness and insensitivity to the lack of privacy and confidentiality, and how women might be affected hearing details of other women’s situations.

Zoe reflected on another aspect of doctor-patient communication. At the time of the second IVF embryo transfer procedure, Zoe asked the embryologist if the quality of her embryos was the same as the first time. The doctor told her, “Yeah, it’s the same.” Zoe explained, “We found out later it wasn’t...you know if the guy had simply stopped and looked at the chart a little bit more, you know...you never know who you’re gonna see, you know, whoever’s on call deals with you.” Zoe commented that the doctors, “don’t recognize that just you dwell on *every* word and your whole expectation is based in *every* word they say,” which increased the importance of the accuracy of their answers to her questions.

Zoe commented that the bedside manner of the “head honcho” who led the team at the second practice was “notoriously bad”. Zoe explained that she was able to get the soonest appointment at the second practice by making an appointment with a doctor who was on the “younger side” and she felt she “lucked out cause I did get a good guy.” In thinking about the differences between the practices as a whole, Zoe noted that the doctors at the second practice were, “in general, by far they were um...they were better,

the bedside manner was better at the second practice, including the nurses...there was nobody who was inexperienced in taking your blood.”

Zoe explained that she thought all the doctors “need to do a better job of explaining how—uh...limited they are at truly affecting the outcome.” She described hearing stories of doctors telling women, “I can make you a baby. I can do this.” She noted,

Maybe they...you know maybe they truly believe it, but, you know it doesn't make sense to me that they would honestly think that um, success or failure is solely under their control. So, in a way, they'd do a better service if they said, “Listen, this is, you know, it's still a big crap shoot, it's still a big crap shoot...There are the issues that we can help you get around,” But...as was explained to me on the third round, you know, by the acupuncturist, so much of it is simply creating an environment that's hospitable.

Zoe explained that her husband was not allowed to be present during the egg retrieval procedure because it was a “sterile environment,” but noted that he was encouraged to be present during the cesarean, “Which is crazy to think about...I'm not quite sure what the logic is behind that, um...other than it's one more thing that they have to worry about controlling, which I understand.” She commented that she felt women are not prepared for the “lack of sensitivity” that's part of the treatment process, but attributed it to the large volume of patients the doctors and nurses were seeing, “No one really prepares you for the, you know, lack of sensitivity that they...and there should...you know it should be all part of the process.”

Zoe observed that there were different “sub agendas” in the two reproductive endocrinology practices from which she received care.

And there's definitely sub agendas with each group, um—you know, one group takes insurance and the other group doesn't, and that affects the agenda. There's no doubt of that in my mind that it affects the outcomes, and the outcomes feed the process.

She explained that the first reproductive endocrinology practice took insurance and “their pitch” was “we take any case, we don’t filter the cases so that the outcomes are statistically uh, aren’t skewed toward either positive or more positive outcomes, we take anybody who has insurance.” She commented that the fact that they took insurance, ensured they had “plenty of clients” and as a result, she felt “they’re quick to um...they don’t need to encourage one person over the other to stick with it.”

Zoe explained that she thought the second reproductive endocrinology practice which didn’t accept insurance was more interested in their statistics:

More concerned—maybe more concerned about the numbers than [the first], cause [the first]—I got the feeling at [the first] they were like, “Alright, we’re gonna get the business because—it’s not as relevant to us. One way or the other we’re gonna continue to get the business cause we’re covered by insurance, we get the coverage.”

Zoe reflected on the second reproductive endocrinology practice she went to and noted they said,

“We take the hardest cases.” I’m sure they don’t refuse anybody but their view is that, you know if you look at our population, they are by far, the hardest cases that you’re gonna see, because that’s what we’re known for, all these specialties and the hard ones.

She felt they were “a little bit more, um, focused on making sure that the outcome was positive, irrespective of how many times [how many treatment cycles] you go [through].”

She noted that she knew someone who went through fourteen treatment cycles at this practice, seven to have their first child, and seven to have their second child.

Zoe clarified the distinction in cost between the practice that accepted insurance and the one that didn’t. She only had to pay a co-pay for aspects of treatment covered by her insurance plan in the practice that accepted insurance. She paid the entire fee out-of-pocket for treatment from the practice that didn’t accept insurance and had to submit

claims to her insurance company for reimbursement. Zoe noted that her health insurance covered many of the exams and procedures, but not IVF egg retrieval, embryo transfer or cytoplasmic sperm injection, or “anything that would be considered experimental in the process” which included acupuncture.

As mentioned above, Zoe explained how the cesarean, the recovery period, and the care provided in the hospital (immediately after and in the days following the surgery) impacted the opportunities for her and her son to establish a bond. Zoe described the environment in the hospital after she gave birth:

Everybody, the staff is—again, it’s a very clinical environment. Um, you have to have an advocate in there, you have to have someone who is on top of the administering of the pain medication, you have to. You can’t—you have to have someone in the room, you have to have someone there who is paying attention for you, because they [the hospital staff] aren’t necessarily paying attention for you.

Zoe expressed her belief that the quality of care and the approach to reproductive endocrinology treatment might change if more people became aware of what it was like for women to go through the process. “You know it will, I know it will, because I think enough people over enough time will be exposed to it that they’ll recognize what needs to happen.”

Pam

Pam described the first reproductive endocrinologist she saw:

[He was] the most conservative person you would ever meet in the world. He rarely speaks and if he does speak, it’s maybe two or three words at a time. It’s actually very hard to drag information out of him...even in the appointment, it’s hard to get him to actually engage, to actually talk to you.

She particularly noticed her doctor’s lack of warmth and reserved style when she went for a second opinion from another reproductive endocrinologist, whom she described as a “very gregarious kind of man” who talked to her and her husband about

“everything...about optimism and pessimism and things that are good and things that are bad and he offers personal opinions and [his] takes on things and it was very different for me.”

Pam elaborated on the first doctor she saw:

[He is] very robotic and not “personal about things at all.... He doesn’t really say, “Well, how do you feel about that?” or anything like that. He’s very factual. Very, very factual. Well here’s the deal. Here’s the medical process, here’s what you’re going to have, here’s your statistical likelihood of success.

Pam commented that he described treatment options to her without trying to influence her decision. She observed that he seemed to feel, “more comfortable in his position saying nothing at all. You know, the less said the better in his mind.” Pam explained her doctor was very inaccessible outside of an appointment; trying to talk to him was like “trying to get God on the phone. They really, the nurses, really don’t like you to talk to [the doctor] outside of an appointment.”

In contrast, the second doctor explained the treatment options and then gave his opinion about which option he thought was likely to be the best use of her money and had the best chance for a positive outcome. She experienced a “warm feeling” when she went to see him and was also struck by his accessibility to his patients. The second doctor gave his patients his email address and responded daily to their emails. Pam commented that in spite of the second doctor’s warm style, ease of conversation and accessibility, he didn’t have any different medical treatment to offer her. She chose to stay with the first doctor:

I can’t really say that I’m that interested in changing clinics at this point. You know, I’m familiar with the culture of the [doctor’s] office and what the protocols are and how the nurses already know everybody personally there and all that type of stuff. I think changing clinics would be a lot for me at this point.

As described in Theme 3 above, Pam was particularly upset about one interaction with her doctor when she explained to him while he was doing a vaginal ultrasound that she could feel her ovaries “kick in” after she took the progesterone injections that were part of the IVF treatment cycle she was undergoing. The doctor dismissed Pam’s concern and discounted her experience of her body with an answer that left Pam feeling “belittled” when he responded, “Don’t say that to the other patients and whatever you do, if your ovaries start to talk to you, seek help.” Pam commented that even if she was imagining the sensations in her ovaries and they had no significance, he could have said something supportive like, “Well, the good news is your ovaries work,” that would have acknowledged her experience, whether or not he agreed with her interpretation of her internal sensations.

Pam commented that the IVF nurses were “incredibly nice women” and she was “amazed” at what wonderful people they were. She explained,

The nurses are the people that you bond with. They are the people that you really know. They are the people who will tell you the truth and who will be honest...they were definitely the most human of the people you’re gonna deal with...they’re very aware of what you’re going through. They’re likely to pat your hand, or pull your hair back for you or something like that.

Following the very painful IVF egg retrieval procedure, she expressed appreciation for the care she received from the nurse assigned to her, who patted her hand, recognized how much pain she was in, and encouraged her to take pain medication and not be a “hero.” Pam described one nurse in the doctor’s office as “a Godsend. God broke the mold when they made her.” She explained that this nurse took her complaints about the pain at and around the site of the progesterone injections seriously and realized she needed a smaller needle due to the fact that Pam was so thin. Once Pam started using smaller needles, she experienced less pain.

Pam repeatedly reported that she was not “prepared” for what she experienced during the treatment cycles. She commented that she wasn’t told what to expect when she started taking the progesterone injections: “They [the doctors] do not tell you what you’re going to go through. They really do not.” Pam explained she wasn’t prepared for the size of the needle on the syringe used for the progesterone injections, nor was she prepared for the muscle pain she experienced after taking them. She commented that the doctor and nurses didn’t explain what to expect from the intrauterine inseminations:

You had no idea what was coming at you. The nurse would call at 4:00 pm and say, “Okay, do this tonight,” and I’d go, “What? Do what? Why?” You feel so in the dark, that they know what’s going on. They hold the key to all this information and for some reason, they just don’t want to tell you.

Pam explained that, although they took an IVF class before the first fresh IVF cycle, information was not given to them about the frozen IVF cycle and how it would be different. The class did not prepare her for what to expect during the egg retrieval and transfer procedures. She wasn’t told that she would have to move from a pre-op area to a stark operating room with big operating lights and a slab metal table and would be asked to lay on the table naked and uncovered. Pam also didn’t feel prepared for the amount of pain she experienced after the retrieval procedure. She commented,

Anything that they could do help prepare patients...even if they could branch out and just factually tell patients what’s going to happen. “You’re going to experience this. You’re going to experience that. You’re going to experience a cold table laying naked on it. You’re going to experience sharp instruments in your bleeding body.”

Pam stressed that she had a fear of the unknown and found it “very scary” to go into examinations and procedures when she didn’t know (hadn’t been told) what to expect. She wasn’t told her husband wouldn’t be able to be with her during the IVF egg retrieval and transfer procedures. Pam described the panic that she experienced when she

was told right before the retrieval and transfer procedures that her husband would not be allowed to be present, commenting that she cried and kept asking the medical staff, “Why can’t he be—he could wear scrubs or something. Why can’t he be here?”

Pam explained that she even felt uncomfortable with his absence during the interview, “It’s hard for me to sit here and have this conversation with you with him so far away as downstairs. That’s how hard it is for me now.... He’s like a lifeline. He’s like oxygen to me now.”

Pam explained that it was confusing for her and her husband when they received conflicting information from the embryologist and the reproductive endocrinologist about the condition of the embryos that had been thawed for the frozen IVF cycle. As described in an earlier theme, Pam and her husband had been told by the embryologist that one of the embryos didn’t survive the thaw, one partially survived, and one looked “really good”; and he was “optimistic.” When Pam didn’t conceive following the transfer of the thawed embryos, the reproductive endocrinologist told her, “Don’t be too disappointed that you’re not pregnant ’cause really none of your embryos survived the thaw.... We typically need at least a 60% survival rate to know that the embryo is even viable.” Pam commented she would have preferred to have a clear understanding of the condition of her thawed embryos prior to the embryo transfer procedure, so her expectations of the outcome would have been more realistic and she might not have gotten so upset when she didn’t conceive.

Pam commented that the “lack of disclosure of information” by the doctors made the process very hard. She felt she had to find everything out on her own. She remembered going for the first IUI and asking the doctor what the statistical probability was of a successful outcome. She remembered the doctor wouldn’t tell her. She

remembered finally saying to him, “Well, okay, can you give me not good, good, or very good? Can you put it in proportion for me? And he said, ‘Okay, well, I would say the likelihood of a success is good.’” Two months later, after her second unsuccessful IUI, Pam found out that the statistical chance of success for an IUI in a given menstrual cycle was 8%:

That’s what he [the doctor] deems good.... That was when I decided I will never again consent to anything in my medical treatment that I don’t feel really fully educated about because, had he been honest with me and said, “Your chances of success in an IUI are only 8%,” I probably would have skipped the IUI’s. I honestly would have.

Pam explained why she regretted spending the time trying to conceive through the IUI procedures:

I’m getting older every month and I’m aware of that. I wasted six months, if not seven, going through IUI’s where I had an 8% change of a pregnancy.... Those eight months could have been the difference, might have made the difference to me. I, at least, would have like to have considered it.

Pam expressed her frustration with her doctor’s unwillingness to share statistical information about IVF outcomes with her:

They don’t even tell you what your statistical probability is of pregnancy in an IVF. You have to look it up yourself. You have to go on to the CDC [website] yourself, at least at the clinic that I go to.... I don’t know if they think women are stupid. Sometimes I think that.

Even after Pam explained to her doctor that she was a mathematician and worked with statistics, he still continued to speak in generalities about the treatment outcomes saying, “Your odds are good.” Pam wanted to know, “Good compared to what? Good compared to being hit by a lightning bolt?”

Pam described the “very considerate” way in which the reproductive endocrinologist conducted the physical exams and explained that that was the reason she was still with him:

He's very conservative. He's very considerate of the experience that you're...he doesn't stay under the sheet longer than necessary. He tends to make eye contact with you when you're on the table. He looks at your face when he says something rather than burying his head in your body. A lot of doctors aren't that good with that.

As noted earlier, some of Pam's early experiences in reproductive endocrinology treatment, which she described as "lying naked on tables and having people stick instruments in my bleeding body, and various orifices," left her feeling dehumanized and disrespected, and not seen by the doctors as a human being with needs and in pain. She commented that she appreciated the anesthesiologist's concern about the amount of pain she was experiencing in contrast to the other doctors' acceptance that pain was just part of the process:

None of the doctors ever seem to care that you're in pain except the anesthesiologist.... He's very sensitive to how much discomfort you're in, but the rest of them don't care. The rest of them are, "Yeah. You're in pain. She's in pain [other women recovering from the IVF egg retrieval procedure]. Everybody in the room is in pain and that's the way it is when you go through IVF."

Pam explained that the doctors only seemed to be interested in what she called "the resume items." They wanted to know the biological specifics, how long her menstrual cycle was, whether she tracked it and when she ovulated, whether she had ever been pregnant before, her standard body temperature, and how much cervical mucus she had when she ovulated. Pam felt they were not interested in her experience, "They don't seem to care. You don't have a story. They don't listen to your story." She believed that knowing her and understanding her experience would make the doctor's job more difficult:

The best description is I really don't think that they see you as a person. They don't see you as a living, breathing human being who's experiencing a stressful process. I've come to believe that that's because their jobs are very stressful. I would not want [the doctor's] job. I would not want to be the person who has to look a very weepy woman in the eye and say, "You should really stop trying to

have a baby this way and move on.” I assume he’s desensitized to that. I assume he’s trained himself to not really see me as a person—it’s harder for him I suppose.

Pam suggested that all patients beginning reproductive endocrinology treatment be encouraged by the medical staff to consult with a counselor at the beginning of treatment and be offered a referral. She felt that women should be told, “You are going to experience psychological trauma from this. We suggest you see a therapist.” Pam felt a counselor could explain to the women and their partners that the feelings they were having were “pretty normal” and reassure them that they were not “going insane.”

In thinking about what other things might have helped her through the reproductive endocrinology treatment process, Pam suggested it would help women to have an “infertility advocate.” She recounted her experiences with a victim’s advocate after she was the victim of a violent crime for the second time. She was assigned a victim’s advocate from the moment she went to the police station, whose job it was to take her through every step of the process and tell her what was going to happen to her. Pam found her assistance helpful:

She was very, very good at explaining physically what was about to happen to me. Where I was going to go and why, and who these people were. Even, she described the room for me. “This room is this color, it is roughly this size. You will be sitting at this type of a table.”

Pam suggested the role an infertility advocate might play. She commented on how they might be helpful:

Somebody who’s going to explain to you that this is what’s going to happen...someone who will help you *understand* that this is what’s going to happen...potential ways that you’ll feel about it is angry, pissed or sad, these are common feelings, whatever.

Pam explained that for her, if she had had an infertility advocate, it might have lessened her anxiety. She remembered how the victim’s advocate helped her,

Greatly lessened my anxiety because, one, I had never felt surprised by what I physically encountered, the physical presence of people or the starkness of the room, or anything like that, was never, never came unexpected to me. And two, she helped me learn what to expect out of my own self. Most like when you get to this point in the process, the very normal feelings are this.... The cycle of what you go through as a victim, and what you're likely to experience and how you're likely to feel about it and different ways of processing it, and for me, it greatly lessened the anxiety. The anxiety around infertility for me is enormous because I never have any idea what to expect.

Pam repeated that if someone would have reassured her early on in the treatment process that she was “responding as a normal person in an abnormal environment...it would have alleviated some of the anxiety and stress.” Pam explained that patients who present with different conditions at the doctor’s office need different care. Patients’ different emotional needs related to the conditions they are being treated for should be considered and influence the way medical care is provided. Pam commented that a patient who comes to the doctor with a “strep throat” has different care needs than a patient who comes for help to conceive and is told they most likely “will never bear a child.” The treatment they receive should reflect understanding of their emotional needs.

A Note from Ann, Witness and Researcher

I have worked as carefully and mindfully as possible to provide you with an understanding of the multidimensional aspects and impacts of the lived-body experiences of reproductive endocrinology treatment as shared with me by the women who participated in the study. I have offered you the women’s own words, as much as possible, as the means by which to authentically convey the experience and impact of their journeys. Over the time I have worked with the recordings and transcripts of their interviews and attempted to synthesize the key themes that surfaced throughout that process; I have been collecting understandings and insights in my own lived-body of the potential implications of their experiences as seen through the lenses of the bodies of

knowledge and theories that have informed and initially inspired me to do this study. It is with deep gratitude to the women who participated, and sadness in my heart (much like the feeling of saying goodbye to people with whom you've shared a particular experience of closeness over time), that I leave their words. In chapter 5, the Discussion chapter, I will share with you the understandings I have gained through deep immersion in their narratives and my thoughts on the significance of this study and its implications for the fields of prenatal and perinatal psychology, traumatology, behavioral perinatology, and women's health care.

Chapter 5: Discussion

Summary of Results

Six themes emerged from the analysis of the interview transcripts that synthesize the multidimensional aspects of the participants' experiences of reproductive endocrinology treatment. This study contributes to our understanding of how women's lives are impacted by experiences of infertility and reproductive endocrinology treatment and expands our awareness of the meaning of these experiences in their lives.

The participants described cycles of a wide range of rapidly shifting emotions while receiving reproductive endocrinology treatment. The array of feelings described by the participants encompassed the full spectrum of human emotions including hope, joy, disappointment, frustration, anger, shame, sadness, and grief. Theme 1, *The Emotional Roller Coaster: Cycles of Treatment Evoke a Range of Intense and Shifting Emotions Challenging the Women's Capacity to Cope*, illuminates the participants' experiences of trying to cope with frequently changing and, at times, conflicting emotions that were repeatedly evoked over the course of menstrual and treatment cycles.

Theme 2, *Protecting Oneself from Painful Emotions and Physical Challenges Through Compartmentalization, Disconnection, and Dissociation*, elucidates the protective mechanisms the participants described using in the face of the physical and emotional stress/trauma of repeated treatment cycles and their outcomes.

Theme 3, *The Lived-Body Experience of Treatment Evokes Feelings that Range from Trust and Safety to Fear and Threat*, provides an in-depth understanding of the women's experiences of the physical aspects of the treatment they received.

Theme 4, *Changes in Appearance and Internal Sensations Evoke Negative Emotions Toward a Body that Feels Unfamiliar and Is Viewed as "Uncooperative"*,

elucidates another aspect of the mind-body impact of the women's treatment experiences. The women described how their attention oscillated between three aspects of their mind-body experience: 1) a focus on internal body sensations for clues to whether or not they had conceived, and, if so, ongoing signs of early pregnancy; 2) a focus on changes in their external appearance resulting from reactions to treatment medications and procedures; and 3) an awareness of how the changes they sensed in their bodies affected their experiences moving in space. The women described feelings of unfamiliarity with their bodies as they experienced their bodies' reactions to the treatment, which made it easier for them to see their bodies as separate, uncooperative, and the source of their disappointment and frustration.

Theme 5, *Layers of Loss Unnamed and Unprocessed Contribute to the Burden of Cumulative Unresolved Grief*, sheds light on aspects of loss described by the participants. This theme acknowledges the losses participants carried into and through reproductive endocrinology treatment and illuminates how multiple cyclical losses endured over repeated unsuccessful treatment cycles with little time or context for processing, compounded previous losses and created a reservoir of unresolved grief.

Theme 6, *The Quality of Care Received from Health Care Providers Impacts Women's Experiences of Treatment*, focuses on the quality of care women experienced while they were undergoing treatment and the factors they felt affected their experiences of the interpersonal and technical aspects of the care received. The theme also includes the participants' insights into the quality of care that would have supported more positive lived experiences of treatment.

It has been my intention, as a mindful researcher, to provide a respectful and compassionate "quality of care" in presenting the women's experiences. It is my hope

that you, the reader, have been left with an impression of the participants as individual embodied human beings with feelings and you have been able to hear the women both as solo voices and participants in the growing chorus of women who are attempting to conceive in this way.

Evaluation and Interpretation of the Results

The following section will discuss the multidimensional aspects of the results of this study and their significance. As described in Chapter 3, the interpretation of the results are “informed by...existing theoretical constructs” (Larkin et al., 2006, p.104) in prenatal and perinatal psychology, developmental psychology and infant mental health, traumatology, and behavioral perinatology.

Lived-Body Experiences at the Edge of a Woman’s Window of Tolerance and Beyond

The experiences shared by the participants revealed the many sacrifices each woman made at great cost to her physical, emotional, and spiritual well-being to endure the fertility journey and reproductive endocrinology treatment. Their experiences, at times, pushed them to the edge of, and, at times, beyond their affective window of tolerance (Siegel, 1999, p. 253; Ogden et. al. 2006, pp. 26-27) causing them to have difficulty integrating their mind-body experiences throughout the process. Lived body experiences of treatment triggered or threatened to trigger past unresolved trauma in some women, including prenatal and perinatal, developmental trauma, experiences of loss, abuse, neglect, and abandonment, transgenerational trauma, previous reproductive losses, and other childhood and adult trauma. For some women, the treatment exams, tests, and procedures themselves created highly stressful and even traumatic experiences which also pushed them beyond the edge of their window of tolerance.

Recurrent dysregulated states of mind along with their psychophysiological effects were precipitated by repeated and cyclical negative experiences throughout the fertility journey and reproductive endocrinology treatment process. Women attempted to cope with these overwhelming experiences by disconnecting mind from body and compartmentalizing these experiences within different self-states in their minds, using the most basic defensive adaptations evoked by perceived threat to their mind-body survival, including dissociation and depersonalization. These defenses were engaged by the women in the service of allowing the treatment, with all its physical and emotional stressors, to be performed on and in their bodies through interpersonal interactions with medical providers in order to fulfill a persistent, compelling longing—an instinctual biological drive to reproduce and create a child.

The injection of technology into the process of human reproduction has revolutionized a notion of conception that evolved with our species. The women who embark on the journey to conceive in this way are often challenged to the limit of their capacity to cope at all levels of their being.

Competing Drives Create a Double Bind

The women were faced with a mind-body, psycho-neuro-immuno-endocrinological dilemma—a conflict arising at the interface of the fundamentally aggressive and intrusive reproductive technologies and the species-specific evolutionary process of reproduction passed down through the generations. The process is now understood to be best supported by a feeling of safety at all levels of mind and body (Porges, 2001). As described by Porges, a feeling of safety is required for the activation of the human social engagement systems involved in reproduction. A feeling of safety allows for the deactivation of defenses at the psycho-neuro-immuno-endocrinological

levels, which in turn supports these reproductive behaviors and processes. The mind-body defense mechanisms evoked in the context of reproductive technologies and treatment confront a woman's instinctual reproductive drive, creating a classic double-bind at all levels—mind, body, and spirit. The process of reproductive endocrinology treatment is especially challenging for women who enter treatment already experiencing traumatic stress symptoms from prior trauma.

Reproductive endocrinology treatment processes and procedures challenged the women's most basic knowledge, beliefs, and imprints of human reproduction on multiple levels of mind-body-spirit. Many women have grown up expecting that the basic biological process of conception and pregnancy would occur within the context of a direct and intimate human connection and would not require the participation of a third party or the intrusion of technology. The newness of the technology introduced into this biological process left the women with no previous personal or evolutionary past to reference for "ways to be" in this situation. Without past personal experience—transgenerational or evolutionary imprints to call forward to inform them in this new and unique interface between technology and a basic biological and instinctual function—the women did not have access to a previously developed repertoire of self-states waiting "off-stage" (Bromberg, 2006) to call upon. The unknown and unexpected aspects of treatment increased their anxiety and fear before and during the treatment and unprocessed, unfamiliar experiences often left them struggling with a wide range of emotions, or numb afterwards.

Women were catapulted into the role of pioneers in uncharted territory. Those who came into the treatment with traumatic stress symptoms originating from identifiable or unidentifiable prior sources of trauma often found themselves making connections to

these past traumas as they engaged in treatment consultations, exams, and procedures and described experiencing states that seemed to reflect those evoked during the traumatic experiences of their past.

The women often went through these experiences without the availability of a safe container—a personal or therapeutic relationship which might have helped them hold the impacts of all aspects of the treatment. The process as it occurred often did not allow for or support women’s access to their usual internal resources or the relational support of others. Therefore, women often experienced a felt sense of a lack of safety in the technological environment in which conception was attempted while undergoing reproductive endocrinology treatment. The impacts of the treatment actions and interactions on all levels of a woman’s experience were rarely, if ever, acknowledged, processed, or repaired within the relationships between women and their medical providers. The impacts on women’s partners of conceiving a child through reproductive technologies were even less frequently acknowledged and explored. The impact of these experiences on a woman and her partner’s capacity to emotionally and physically support each other throughout the treatment process was contingent upon each person’s ability to affectively regulate themselves in the face of multiple physical and emotional stressors associated with the treatment exams, tests, and procedures and each person’s ability to cope with the outcome of each treatment cycle and the significance it held for them. The women who went through the treatment without a partner, or with a partner who was not committed to the process, faced the additional challenge of having one less potential source of support.

An unspoken, complicit agreement between women and medical providers, a “dissociative cocoon” (Bromberg, 2006), appeared to be co-created to allow for the

necessary overrides of biological social engagement systems in both people in the attempt to permit reproduction through technology to occur. Women were challenged to cope with an array of conflicting feelings, physical and emotional. They were challenged to find ways to override their most basic body-brain-mind reactions to their physiological perceptions of a lack of safety arising from the complex emotional and physical interactions with medical providers inherent in the treatment process. Even when the process of conception and reproduction occurs without the help or introduction of technology, it relies upon a context that evokes a felt sense of safety in women. This felt sense of safety is necessary to support their physical cooperation—their submission to physical experiences and postures in intimate contact with another human that render them most vulnerable in the most basic physical sense (Porges, 2001).

Women undergoing reproductive endocrinology treatment often faced tension and competition between two of the most basic human instincts—to survive in the face of a felt sense of threat and to reproduce. This conflict that was created within a woman’s body-brain-mind often demanded engagement of the most basic protective defense mechanisms. The employment of these defense mechanisms, in turn, evoked the body-brain-mind reactions and conditions that hindered the integration of these experiences and supported the development of, or exacerbation of, existing traumatic stress symptoms (Bromberg, 1998; Levine, 1997; Ogden et al., 2006; Scaer, 2007; van der Kolk et al., 1996).

As described earlier, Bromberg’s (1998) explanation of what happens to an individual in situations where they face competing “Darwinian algorithms”, or instincts, in the same moment deepens our insight into the participants’ accounts of their conflicting feelings during their reproductive endocrinology treatment experiences. As

mentioned above, Bromberg's (1998) elaboration upon how perceived threat can evoke defensive dissociative reactions enhances our understanding of the participants' descriptions of disconnection, distancing, and compartmentalization—coping mechanisms they often utilized during treatment exams and procedures. Processing and resolution of trauma did not occur for the women between procedures and cycles, integration of these experiences was inhibited, and multiple systems of complex trauma were built on whatever previous foundation a woman brought to the fertility journey and infertility treatment process.

The Explicit and Implicit Aspects of Interpersonal Interactions Between Medical Providers and Patients During Treatment

The complex and subtle aspects of the relationships between the women and the medical providers were not explicitly acknowledged or processed within the context of their relationship. The participants' descriptions suggest that they frequently experienced a lack of appreciation for and acknowledgement of the layers of meaning, emotional valence, and sensitive nature of their physical and interpersonal interactions with health care providers during treatment.

The dyadic interactions between the women and the doctors seemed complicated by the physical interactions necessitated by the treatment. This included the power differential expressed in both physical and emotional interactions. Women were faced with procedures that demanded a submissive and vulnerable posture and physical proximity to medical providers that, during unassisted conception, would be associated with intimacy. Yet, in the context of the medical setting these aspects of physical contact are not indicative of intimacy between doctor and patient. Some women described having exams, tests, and procedures that were conducted by health care providers they

had never met or spoken to prior to their encounter in the exam or procedure room immediately before the test or procedure was performed.

As noted earlier, Bentz (2001) captures the paradoxical quality of the physical experience of female reproductive health examinations in the phrase, “intimacy that is not intimate”. The process of conception when it occurs without medical assistance is one which usually occurs as the result of intimate interaction between a woman and her partner. The women expressed their concerns and questions about the significance of the context in which conception occurs, as they described the replacement of an intimate partner by a doctor as the agent for the introduction of sperm (or embryos) in the process of medically assisted conception.

The presence of multiple medical staff, including nurses, other doctors, and doctors in training who observed or participated in exams and procedures during which the women’s most intimate body parts were exposed, added stress and intensified feelings of vulnerability and exposure in the women, particularly if more staff were present than they expected. These experiences increased the women’s sense that they lacked control in these situations, a feeling that was compounded if they were not asked permission for additional staff to be present and were not introduced prior to the exam to those they didn’t know.

The women’s and doctors’ feelings about the sensitive issues related to treatment interactions seemed to be held under the surface and were only communicated implicitly in their relationships. The issues that surround the introjection of medical technology delivered by doctors into the process of conception—an event that usually occurs within the context of a private sexual act—are held out of discussion, and perhaps even out of conscious awareness, to avoid the discomfort that it would likely elicit between women,

their partners, and the doctors. There is also a sense, though not articulated, that acknowledgement of concerns and feelings about the quality and context of the experience of conception would be taboo, perhaps because the issues that arise from the recent convergence of medical technology and the process of conception would challenge widely held cultural and religious beliefs about the sacredness of the act of conception. Issues related to the importance of the events surrounding conception raised within the framework of prenatal and perinatal psychology were also rarely (if ever) acknowledged or discussed between doctors and patients involved in this process.

Imprints and Patterns from Early Dyadic Experiences and Relationships Surface in Interactions Between Patients and Their Health Care Providers

Developmental psychology, prenatal and perinatal psychology, and traumatology provide a basis for understanding the possible underpinnings of the complex interpersonal interactions that occurred between doctors and patients, and provide insight into the participants' descriptions of their experiences of doctors' behaviors. These descriptions include doctors' misattunements to, and misunderstandings of, women's verbal and non-verbal reactions to treatment, as well as their verbal and non-verbal expressions of their physical and emotional needs.

The interactions between the women and the doctors seemed to resonate with imprints from their respective early dyadic interactions. Traces of women's and doctors' attachment behavior styles surfaced in the communications between them. At times, women described feelings and behaviors that were triggered in interpersonal communications with the doctors that paralleled those observed in early dyadic interactions between infants and primary caregivers (Schorre, 1994).

As noted by Izard, Hembree and Huebner (1987), the quality of an “emotion feeling” may be consistent over the lifespan:

A particular emotion feeling is invariant over the lifespan, but the corresponding emotion expression changes developmentally as a joint function of maturation of neural inhibitory mechanisms and experience.... Eventually, individuals learn to dissociate or otherwise regulate the relation between expression and feeling, but expression-feeling concordance may occur at any time in the lifespan when a prototypical emotion expression is elicited and encoded automatically. (p. 105)

The women described times during treatment when their feelings and those of the doctors that cared for them were triggered and expressed automatically. They described times when they dissociated and when they observed apparently dissociative behavior in their doctors. Each of them, it seems, used this coping strategy to regulate and inhibit the expression of their feelings.

At times, the women described feeling intense states of shame. Sometimes this followed experiences in which they felt unseen, and other times it followed experiences in which they felt helpless, stressed, exposed, and vulnerable. Siegel (1999) noted that shame in adulthood may, at times, be related to experiences in childhood in which an individual wanted to please, but felt unseen (p. 256). Schore (1994) explored the experience of shame in early parent-child interactions and noted that shame “also occurs in helpless and hopeless stressful situations in which the individual becomes inhibited and strives to avoid attention” (p. 204). Interactions with doctors in the context of stressful physical exams and procedures, during which the women felt helpless, may have elicited the women’s “prototypical emotion expression” (Izard et al., 1987) of shame and the dissociative behavior that commonly accompanies it.

Many doctors were described as unable to make eye contact when they spoke to or examined the women. This seemed to be particularly disturbing to some of the women. Tronick's observations of mother-baby and other primate dyadic interactions illuminate some aspects of the women's descriptions of their dyadic interactions with their health care providers and enhance our understanding of the subtle and unacknowledged behaviors and dynamics that may influence patient-health care provider interactions. Tronick's still-face experiments (2007) with mother-baby dyads demonstrate babies' reactions to their mothers' unresponsive faces and resonate with the women's descriptions of their interactions with and reactions to doctors who were unable to make eye contact with them. Tronick explains:

Social interaction is a rule-governed, goal oriented system in which both partners actively share from the very beginning. The still-face violates the rules of this system by simultaneously conveying contradictory information about one partner's goal or intent. The mother by her entrance and en face position is initiating and setting the stage for an interaction, but then her lack of response indicates a disengagement or withdrawal. She is communicating "hello" and "goodbye" simultaneously. The infant, because of his capacity to apprehend this display of intent, is trapped in the contradiction: He initiates and greets but then turns away, temporarily withdraws, only to initiate again. If the infant's efforts fail to get the interaction back on track and to establish reciprocity, eventual complete withdrawal results. (2007, p. 271-272)

The state of "complete withdrawal" referred to by Tronick parallels Schore's (1994) description of the "psychobiological state of shame distress", which "represents a sudden shift from sympathetic-predominant ergotrophic arousal to parasympathetic-

dominant trophotrophic arousal” (p. 212). Schore’s explanation of the psychobiology of the “state of shame distress” links the emotion with its associated autonomic nervous system physiology. In their descriptions of doctor-patient interactions during treatment, the women shared their experiences of attempting to engage health care providers and “establish reciprocity” (Tronick, 2007), often in situations they experienced as stressful. The women’s descriptions of their reactions to health care providers, who did not respond to or engage with them, resonate with the psychophysiological descriptions of withdrawal (Tronick, 2007) and the “state of shame distress” (Schore, 1994) observed in early infant-caregiver interactions.

Tronick (2007) referred to a pattern of implicit communication that relates to another aspect of the women’s descriptions of their treatment experiences, one that elicits questions about how quality of eye contact and facial expression contributed to the implicit communication and negotiation of dominance in doctor-patient interactions. Tronick expanded on behavior observed in primates during the establishment of dominance in dyadic relationships:

As two conspecifics meet, the partner establishing or testing his dominant position initiates eye-to-eye contact but with little facial movement. The subordinate partner quickly assumes an appeasing role, turning partly away, but glancing back repeatedly, constantly changing his facial expressions in an attempt to draw the dominant partner into a more equal, reciprocal interaction. With the first partner’s continued nonreciprocal reactions, the still face becomes an aggressive signal. This is brought about by the contradictory message of the face-to-face orientation but nonreciprocal behavior. The second partner, like the human infant, attempts

to deal with these mixed messages by a repeated approach-withdrawal pattern, and finally submits. (2007, p. 272)

As with other primate dyads, the quality of eye-to-eye contact and facial expression conveyed meaningful messages that were perceived beneath conscious awareness in interactions between women and their doctors during consultations, exams, and procedures, no matter what verbal communication, if any, occurred.

Some doctors talked to the women during exams and procedures, but the participants commented that many did not acknowledge verbally what they were doing as they examined or treated the women and instead chose to carry on conversations completely unrelated to the women's physical experience in the moment. This left the women feeling unseen, unmet, and unheld in stressful situations and caused them to resort to coping mechanisms used in early dyadic interactions and experiences of stress/trauma from the past. Some women noted they appreciated being asked by doctors for feedback about what they were feeling during exams or procedures and were grateful when/if the doctors used this information to make adjustments in the way they were conducting an exam or procedure or to provide support. Conversation that was pertinent to the exam or procedure and engaged women helped some of them differentiate the present experience from past experiences, particularly those that may have been traumatic.

Women's Ambivalent Feelings for Medical Providers Parallel Approach-Avoidance Conflicts in Early Attachment Relationships

Approach-avoidance feelings about medical providers seemed to be inherent in the process itself. Women looked to the doctors for support, reassurance, and the solution to their fertility problems, and yet the doctors were also the people performing

the exams and procedures that evoked physical and emotional pain, and consequent states of fear, anger, sadness, and shame, creating internal conflict for the women. The women had to override or blanket these feelings in order to be cooperative during exams and procedures and were careful not to antagonize or irritate the doctors due to the critical and powerful role the doctors played in helping them conceive. Women understood that their embryos were literally in the doctors' hands and they depended on the doctors to place them in their bodies. Dependence on another person to complete that process introduced a factor that is not present in conception that occurs without medical intervention and marked another point in the process that triggered the need for and engagement of women's most basic coping mechanisms.

Some women described themselves as "broken" and the doctor was seen as the person who would "fix" them. Some women described having feelings of wanting to be "good" patients in order to elicit the best care from the doctors and ensure the best chances for them to conceive. At these times, the doctor seemed to be cast in an authoritarian parental role. The women who posed a challenge to the doctors in some way were often were treated insensitively or inappropriately. The women looked to the doctors for support and reassurance and described interactions where they were treated as difficult children. Some doctors were rude to and blamed the women when the physical aspects of an exam they were performing didn't go smoothly. Some doctors were impatient with women who asked many questions. Some discounted the knowledge women tried to share about their own bodies. Some doctors failed to exhibit or communicate compassion or empathy for the women in situations where the women were clearly exhibiting fear, shame, or grief. Women described feeling punished for posing a challenge to the doctors verbally, emotionally, or physically.

The women's descriptions of their ambivalent feelings in their interactions with their doctors also resonate with the approach-avoidance conflict faced by babies who interacted with parents whose faces, at times, expressed frightened/frightening dissociative or preoccupied mind-body states. Tronick's research demonstrated that these states evoked fear and full-blown defensive reactions in the babies (2007). There are similarities between the underlying dynamics of the conflict for the babies and the women. The survival of the babies in the context of infant-caregiver relationships depends on the caretaking behaviors of the very individuals who, at times, trigger terror in them, whether they inflict physical pain or communicate through facial expressions, their own frightened/frightening mind-body states. For the women, the possibility of successfully procreating and the survival of their embryos (extensions of themselves) depended on the caregiving behaviors of the very individuals (health care providers) who, at times, triggered terror in them. A question arises about how the cumulative impact on doctors of stressful, frightening, and even traumatic treatment experiences with patients may be exhibited by doctors in verbal and non-verbal behavior in their interactions with patients. Participants expressed a heightened awareness of doctors' verbal and non-verbal communications and several commented that they vigilantly scanned doctors' behavior during interactions for clues to treatment success or failure.

The psychophysiological states evoked in doctor-patient interactions may have had their origins in early dyadic experiences and certain physical and/or emotional aspects of these interactions may have acted as reminders of early dyadic interchanges that then triggered the shame and fear reactions described by the participants. Other experiences from patients' and doctors' pasts influenced their interactions, especially

those that were perceived as “severe life events” (Khashan et al., 2009) and/or those that had traumatic impacts.

Past Experiences of Trauma Haunt Interactions Between Patients and Health Care Providers

The descriptions of the interactions between the women and their health care providers seemed to be haunted by the implicit presence of ghosts from other dyadic interactions in the women’s and doctors’ lives, and seemed, at times, to trigger enactments between them of previous trauma from one or both of their pasts. Each seemed to cast the other in several different roles at different times, and sometimes simultaneously during the process. Both women and doctors also seemed to cast themselves in several roles. These were often not explicitly named but instead, were reflected in the women’s descriptions of their and the doctors’ behavior and their feelings in their interactions during treatment. These roles appeared like shadows that surfaced from the undercurrents as they shared their experiences during the interviews.

Some of the women described going into treatment concerned about how the doctor would see and judge their life choices, approving or disapproving of their earlier decisions, especially if they had abortions earlier in their lives. Women had concerns about how doctors might view their past gynecological issues, and sometimes feared the doctors could “see” evidence of these issues in their bodies without even being told about them, especially if they had any history of sexually transmitted diseases.

The mind-body feelings some women described during treatment also suggested that women may at times experience doctors in the role of perpetrators of assault or rape and themselves as victims of assault or rape. This was especially the case with, but not limited to, women who had suffered abuse and assault prior to treatment. The

descriptions of how doctors physically and emotionally interacted with women during certain exams and procedures raised questions about the doctors' states of mind at those times, how they might have been seeing (or not seeing) the women, and what roles they might have been casting the women in during those interactions.

At other times, women's descriptions of doctors suggested that some doctors may at times cast themselves in a God-like role, telling new patients, "I can make you a baby." Women so very much wanted to believe in the doctors' ability to do so, but some were offended by the doctors' assumption of a God-like power and certainty.

Misunderstandings that arose in interpersonal communication in these highly emotionally charged interactions between women and medical providers were not addressed, processed, or repaired. The women often were left to cope on their own with a wide range of lived body impacts as they went through the treatment. They were left trying to hold the explicit and implicit double-binds, the incongruent experiences, the contradictions and paradoxes, the unanswered questions that emerged from the convergence of, or collision between, the psychobiological processes, and this recently developed medical technology—a collision enacted in the many interpersonal interactions throughout the process. The prenatal and perinatal, transgenerational, and trauma imprints of all the people present were also interwoven in their interpersonal interactions, further complicating the implicit and explicit aspects of the process.

Unanswered Questions Concerning the Full Range of Treatment Impacts on Women and Families Highlight the Need for Evaluation of the Quality of Care Provided and the Benefits of Additional Support Services

During reproductive endocrinology treatment, the intimacy and environment usually associated with conception has been replaced with the medical technological environment, seemingly without recognition of the many potential short or long-term

impacts of doing so, other than those affecting physical health as medically defined. Issues relating to the potential impact of the process on the immediate and long-term relationships between the woman, a child conceived in this environment, and her partner if she has one, appear not to have been considered and are not discussed within the doctor-patient relationship.

The women and their doctors did not discuss the impact of repeated traumatic losses of embryos and fetuses through miscarriage, stillbirth, or surgery to remove ectopic pregnancies on any subsequent successful pregnancies a woman might have. Women expressed hesitancy about bonding with pregnancies that occurred after unsuccessful cycles or pregnancy loss for fear that they might also lose that current pregnancy. Hesitancy about bonding with the baby after the baby was born was also described when a pregnancy, following IVF treatment, resulted in the birth of a healthy baby. From a prenatal and perinatal perspective, this gives rise to the question, “What is the imprint on a baby that experiences this hesitancy during pregnancy and the postpartum period?”

Questions about how the environment of a woman’s body is psychophysiologicaly affected by the treatment process and how it might impact the developing embryo and fetus have not been considered. Thomson (2007) presents a “theoretical prenatal relational model” that “outlines experience-dependent prenatal development that is contingent on and concordant with maternal regulation and dysregulation.” Thomson’s model suggests that anxiety, depression, anger, posttraumatic stress, and dissociation in the mother may all affect the neurobiology of the prenat. As described earlier, recent research in behavioral perinatology demonstrates the impact of maternal psychophysiological states on the health, development, and behavior of the

offspring, throughout gestation and after birth (Field et al., 2004; Khashan et al., 2009; Wadhwa, 2001, 2005). The research in this study, as it intersects with research in behavioral perinatology, raises further questions about the psychophysiological impacts of all aspects of the reproductive endocrinology treatment process on the women and their embryos and fetuses.

Questions around the impact of technological intervention in the process of conception on lasting prenatal and perinatal imprints on the embryo have also not been answered. How does using a donor egg or sperm, or both, impact the process? In this case, how do a woman's immune, endocrine, and vasomotor systems react to the insertion of genetic material that is not her own into her uterus? If issues and beliefs around attachment resonate at the cellular/tissue/organ/system level, how does a woman's being as a whole interact with, or relate to, an embryo that is "not at all me?" Is the foreignness of an embryo conceived outside a woman's body somehow energetically and epigenetically imprinted by its experiences outside her body? How does a woman in her totality experience that? If the embryo is perceived by a woman's mind-body as "not at all me" resulting in the activation of ambivalent or conflicting feelings on some level, what is the experience or imprint on the embryo of the presence of those emotions, those psychobiological states in the woman?

The fact that these issues are not often brought up in discussion between doctors and patients or perhaps even considered may be a reflection of the structure of the medical system itself in this country, with its compartmentalized subspecialties that function in isolation from each other. Issues that are not directly related to the physical aspects of treatment are not prioritized by those care providers that specialize in physical issues, even though these issues may have an impact on treatment outcomes.

The compartmentalization of knowledge in health care resembles a dissociated mind-body. Women's descriptions of the care they received from medical providers reflected their experiences of trying to interact with a dissociated system and its dissociated representatives. The isolation of subspecialties creates a fragmented understanding of the human lived body and compartmentalized specialists view the patient through their particular narrow lens which can result in blind spots that limit how much they can see of the whole human being in front of them, and, in turn, how they conceptualize the potential impact of their services.

From the women's descriptions of their experiences, the type of knowledge they possessed about their own lived bodies was not highly, if at all, valued by the doctors. For the women, the limitations in the doctors' capacities to see beyond their subspecialty and the medical paradigm resulted in a feeling of being only partially seen, partially understood. When women tried to communicate what they knew or suspected from their internal wisdom and knowledge of their own bodies, they often felt dismissed or misunderstood by the doctors who seemed to be closed to the women's self-knowledge and the idea that this knowledge could be informative or contribute to finding a solution to their problems.

Women expressed a desire for the doctors who were treating their reproductive systems to respect and acknowledge them as whole human beings—as feeling, thinking individuals with valuable knowledge of their own bodies, even if this knowledge was not the type that could be generated through technology and seen in images or shadows on computer screens. They expressed a desire for the doctors to interact in ways that, at the very least, demonstrated their appreciation for the fact that the women were going

through an intense and challenging process which rendered them vulnerable at the most basic levels, and held powerful meaning for them in their lives.

Unanswered Questions About the Impact of Treatment Experiences on Women's Relationships with Children Conceived Through ART

The women's descriptions of their experiences also raise many questions about the multidimensional impacts of this process on experiences that follow successful outcomes of treatment. What is the impact of this process on the women's relationships with their babies should they conceive, and in turn, the babies' developmental trajectories? Most of the women described a willingness to pursue their desire to conceive a child at any cost short of risking their lives. Some of the women felt they in fact had risked their lives in pursuit of conception and motherhood. Others felt they had risked their sanity. Some felt they were not cognizant in the midst of treatment of how close they had come to doing either or both. How do these feelings affect women's interactions with their children over time, children whose very physical existence holds the potential to be a constant reminder of the risks women have taken and the sacrifices they made, the varied and intense emotional states they experienced? If the women's feelings about their experiences in treatment aren't processed, how do their unprocessed feelings about all aspects of the treatment, especially dissociated and traumatic aspects, get expressed in their interactions with their babies during pregnancy and after birth? Does the treatment trigger or exacerbate behaviors in women during interactions with their babies that are related to traumatic stress symptoms or depression that may follow the treatment process? Are these babies also faced with the double-binds that arise from being dependent on a person for survival who also may interact with them in affectively frightening or unresponsive ways? What impact do these kinds of interactions have on

the baby's development? The work of researchers and clinicians in the fields of attachment and infant mental health (Schorre, 1994, 2003a, 2003b; Siegel, 1999; Tronick, 2007) has explored the long-term impacts of these kinds of caregiver behaviors on infants and children. This study indicates a new area that warrants exploration, namely the long-term impacts of caregiver behaviors on infants and children as they relate to unprocessed and unresolved trauma that may be present following the experience of undergoing reproductive endocrinology treatment to achieve pregnancy.

Who is present in the treatment process to help women (their partners and their embryos and fetuses) to hold and regulate the complexity and intensity of these states? Who is present to help the doctors and nurses? Who is present to help the children conceived through this process after they are born? What skills are necessary to hold space for all of the participants in this process? Would a specially trained fertility doula be helpful, modeled after a birth or postpartum doula to support women in the moment as they go through stressful, potentially overwhelming experiences? These are the questions that emerged from the insights gained from the women's interviews.

Unanswered Questions About the Cumulative Impact on Health Care Providers of Patients' Losses in Unsuccessful Treatment Cycles and Its Affect on Their Interactions with Them

In listening to the women's experiences, I wondered if the health care providers themselves processed or resolved the multiple losses that resulted from unsuccessful cycles of treatment they participated in as they provided care to the women in the study over months and years, as well as hundreds of other women through hundreds of other treatment cycles over time. It is likely that some of the health care providers came into the journey of reproductive endocrinology treatment with each patient, carrying their own

unacknowledged, unprocessed, and unresolved experiences of loss, whether those occurred in the context of their role as health care providers or in their personal lives.

The health care providers, like the rest of us, carry their own transgenerational, pre- and perinatal, and family-of-origin imprints. The impact of health care providers' unresolved losses and unprocessed imprints on the quality of care they provided and the women's experiences of the care they received remain unanswered questions, but ones worth considering. Health care interactions (unlike the process of fertilization in IVF treatment) happen in the context of interpersonal relationships, the dynamics of which are thereby subject to the influence of all the people involved in those interactions.

Theoretical Consequences of the Study's Results

This study contributes to theory in psychology and specifically prenatal and perinatal psychology by elucidating the complex and interwoven lived body aspects of women's experiences attempting to conceive in the context of reproductive endocrinology treatment and assisted reproductive technology. The study expands prenatal and perinatal theory by articulating questions that arise from the participants' descriptions of the implications and impacts of this recent technological intervention in human reproductive processes. The descriptions of the participants spark the formulation of these questions and raise issues that surround the intersection of the most basic biological processes in human reproduction and the recently developed and still evolving medical and technological treatment for infertility. These questions and issues challenge the current capacity of prenatal and perinatal theory—and create new opportunities for it to expand—to support important explorations of the multiple facets and complex dynamics of this revolutionary era in human reproduction.

This study contributes to theory in traumatology by shedding light on the potential for these recently developed medical treatments—the impacts of which have not been comprehensively studied—to be sources of trauma in the lives of women and their families. This study also contributes to theory in reproductive health care by illuminating the importance of women’s psychophysiological states and their experiences of treatment and the potential for these to impact treatment outcomes. The study results suggest that how women experience the care they are provided may significantly impact treatment outcomes.

In addition, this study contributes to theory in behavioral perinatology by focusing attention on the specific maternal experiences of conceiving through ART and the impact of these experiences on the psychophysiological relationship between the woman and her offspring from conception on. It suggests the need to explore the impacts of these unique experiences apart from the impacts of the experience of conception without medical assistance. This study also challenges theory in developmental psychology and infant mental health to acknowledge and incorporate the importance and potential impact of conception through ART on early dyadic relationships and infant mental health.

This research demonstrates the value and necessity of connecting knowledge and theory from related fields, including psychology, physiology, epigenetics, behavioral perinatology, traumatology, medicine, complementary medicine, and medical technology, to gain a more comprehensive understanding of the significance and impacts of these experiences. This comprehensive understanding should be tempered with an appreciation for its limitations. An attitude of openness towards knowledge that emerges from studies that utilize varied methodologies, including phenomenology, and one that values diverse sources of knowledge, including an individual’s first person account of their lived body

experiences, can inform and support change and flexibility in clinical practice that will benefit the health and well being of the increasing number of women and families impacted by these conception experiences.

Implications for Practice

Perhaps the most important implication of this research for practice in prenatal and perinatal psychology, reproductive medicine, and traumatology is its contribution to understanding the significance of women's lived-body experiences of infertility and reproductive endocrinology treatment—the embodied psychophysiological impacts of these experiences on women's reproductive processes, and the positive impacts on treatment outcomes (for both women and their offspring, if they conceive) that may result from changes in the way care is provided and the inclusion of support services at this critical time. This study contributes to an understanding of the importance of women's lived body experiences, including maternal psychophysiological states even before conception, and provides insight into the kinds of services that may assist women in coping with the range of mind-body states they may experience when trying to conceive in this way.

The study demonstrates the need for a cooperative, inclusive, and integrated approach to the multidimensional impacts of infertility treatment experiences, whatever their outcomes. This research highlights the need for the fields of psychology, traumatology, and medicine to contribute knowledge and approaches to clinical practice that are informed by women's descriptions of their lived body experiences and their needs. As expressed by the participants, enhanced patient education that prepares women and their partners for all aspects of treatment would reduce anxiety for many women,

especially those with traumatic stress symptoms. The women explained that they found the unfamiliar and unexpected aspects of treatment particularly challenging.

The women's descriptions of their experiences call out for change in the way care is provided that will support patients' experiences of being seen as whole human beings. These changes can facilitate healing that may be necessary in the aftermath of reproductive endocrinology treatment to support optimal interactions between women and their families.

The therapeutic relationship is one that holds the potential to provide a space for processing of these experiences and healing to occur. Given the prevalence and intensity of psychophysiological distress described by the participants, it may be advisable to offer every woman facing these challenges, the services of therapists experienced in a range of healing modalities and who specialize in the unique issues that emerge during and after the fertility journey. An understanding of trauma and its body-brain-mind-spirit impacts, as well as effective body-mind-spirit modalities for healing trauma at all levels, are essential to support women through the process of integrating their experiences. If healing from these experiences is not facilitated and supported, trauma triggered throughout this process will be left unresolved. It is likely it will be passed on and continue to haunt generations to come in ways we have yet to understand and appreciate.

The women's experiences illuminate the need for all involved in this process to increase their awareness of the complex issues that surround it. Their experiences challenge all involved to open themselves to gaining new insights into a much broader array of aspects and impacts, well beyond those already investigated or understood within the limitations of the medical/biotechnological paradigm.

The women's stories challenge us to begin to envision and develop ways of assisting and healing all who participate in this increasingly common approach to conception, so we can collectively and cooperatively support healthy foundations for the growing number of children conceived in this way and the family systems that will nurture their growth and development. To do so most effectively, we must meet the challenge with a willingness to stretch our minds and hearts beyond our comfort zones to allow for the possibility that healing solutions may emerge from knowledge beyond that which we currently hold and through modalities we may not yet fully understand.

Researchers and clinicians investigating and treating the psychophysiological impacts of stress/trauma have developed methods of observing, educating, preparing, and treating patients who exhibit the lived body behaviors and symptoms that reflect the psycho-neuro-immuno-endocrine and vasomotor disturbances that can be observed in individuals following stressful and/or traumatic experiences. These same behaviors and symptoms may be observed during and following subsequent experiences that, in some way, remind individuals of past traumatic experiences. These methods and approaches can be shared with health care practitioners who provide infertility treatment to women.

Health care providers can be trained to observe lived-body expressions of traumatic stress—behaviors and physiological signs—including those indicative of autonomic nervous system hyperarousal and hypoarousal that reflect the level of a woman's distress during consultations, exams, and procedures. Inviting and listening to feedback from women about their feelings and needs as embodied humans during treatment would be crucial to understanding how to help each unique individual. While there are general guidelines for sensitive care that may be helpful, the particular needs of each woman varies with the experiences she brings into the current physical and

interpersonal environment. Health care providers can be trained to sensitively ask women questions about past trauma and any special needs they may have prior to conducting exams and procedures.

Training can also include ways health care providers can make adjustments in their behavior as they engage with patients to reduce women's levels of distress during interactions and treatment. These adaptations in the way care is provided may titrate the impact of the medical procedures that are necessary and reduce the likelihood that health care provider interactions and treatment procedures will traumatize or trigger memories of past trauma that may re-traumatize patients. Reproductive endocrinology practices can offer women counseling services on site to support women undergoing treatment.

Modeled after the role played by a birth doula, additional support from a doula specially trained to provide physical and emotional support to women going through reproductive endocrinology treatment may reduce women's psychophysiological distress and contribute to more positive treatment outcomes.

Limitations of This Study

This study explored the experiences of six women. Although the small study group size limits the generalizability of the results, it enabled a deep exploration of the participants' experiences. The study included the participation of women with a wide range of experiences which supplied an understanding of multiple aspects viewed from different points in time over the course of, and following, treatment. The inclusion of women that reported experiencing traumatic stress symptoms around the time of the interviews, as well as those who did not, contributed to the insights that emerged from the interviews.

The study's focus on the particular experiences of each of the participants facilitated an understanding of the importance and potential benefit of coming to know the unique aspects and needs of each patient that may inform treatment approaches and thereby, support positive outcomes. Given the limited research available on women's experiences of infertility treatment described in their own voices, the inclusiveness of the range of women's experiences in this study may expand insight into the most effective ways health care providers can support and care for women facing these challenges.

My own personal, academic, and professional experiences have influenced my conception, implementation, and documentation of this phenomenological study. The empathy I experienced for the women during the interviews and during my immersion in their transcripts undoubtedly influenced my understanding of their experiences. This may be viewed by some as a limitation of the study. In my view, these empathic interactions and engagement with the data enabled me to gain a depth of understanding of the women's experiences that would not have been possible if I had closed myself to feeling the intensity and range of their experiences.

Future Research

Future research may explore outcomes of reproductive endocrinology treatment in women manifesting traumatic stress and dissociative symptoms. Long-term studies on children conceived and born to women who report traumatic stress/dissociative symptoms during and following reproductive endocrinology treatment may shed light on the impact on women's offspring of these maternal psychophysiological states and assisted reproductive technology experiences.

Additional research may explore women's experiences of reproductive endocrinology treatment provided by health care providers who are trained in observing

and attending to patients' psychophysiological states during treatment. Explorations of women's experiences of pregnancy, birth, and the postpartum period following reproductive endocrinology treatment may provide additional data that will shed light on effective ways to support women, their offspring, and their partners as they emerge from these medical technological experiences of conception.

To assist health care providers in offering treatment in ways that best support women and their families, research on health care providers' lived-body experiences of their interactions with patients may illuminate health care providers' needs and indicate the types of support, training, and healing that may benefit them. This, in turn, may improve their interactions with their patients. It is likely that many health care providers do not have adequate opportunities for processing their own experiences of their patients' distressing reactions to treatment.

It is crucial that all involved in the reproductive endocrinology treatment process increase their awareness of the full range of known treatment impacts and the possibility that some impacts are as yet, unknown; these experiences hold the potential to create life-long imprints and influence the developmental trajectory of generations to come.

Looking Back on the Experience of Conducting this Research

As a researcher, I have struggled against the limitations imposed by my imprints and past traumas throughout this project. I have been challenged to hold and heal my own issues each step of the way, so I could continue to take each next step in the research process. At the same time, I have been challenged to hold and honor the experiences of each of the women as they were shared with me, a responsibility I took to heart. As I respectfully and gently held their stories throughout this work, they became a part of me.

My intention throughout has been to be exceedingly mindful in my work and caring in my efforts to communicate the women's journeys to others.

The "doing and being" necessary for the completion of this research at times brought me to the edge of my own affective window of tolerance. With the support of family, friends, healers, and mentors, I learned new ways to access resources that enabled me to expand my window of tolerance, so I could move forward and complete this project. My face-to-face experiences during interviews with the women, my experiences listening to the recordings of their voices, my immersion in the printed transcripts of their interviews, and my efforts to maintain the integrity of the women's narratives in this document have been catalysts in my growth as a researcher, but most importantly, have expanded my capacity as a compassionate human being. For this and so much more, I am deeply grateful to each woman who came forward to share their experiences with me.

Appendix A: Explanation of Terminology Used in Assisted Reproductive Technologies

In order to provide the reader with an understanding of the medical terminology used throughout this research, I am including explanations of specific ART procedures as described in the patient information publication, “Assisted Reproductive Technologies: A Guide for Patients” distributed by the American Society for Reproductive Medicine (2008).

In vitro fertilization (IVF) “is a method of assisted reproduction in which a man’s sperm and a woman’s eggs are combined outside of the body in a laboratory dish. If *fertilization* [emphasis authors’] occurs, the resulting embryos are transferred to the woman’s uterus where one or more may implant in the uterine lining and develop” (2008, p.4). IVF is used to “treat many causes of infertility...or when a couples’ infertility is unexplained” (p. 4).

The IVF cycle consists of several steps including ovarian stimulation, egg retrieval, insemination, fertilization, embryo culture, and embryo transfer.

Ovarian stimulation: “During ovarian stimulation...ovulation drugs or ‘fertility drugs’ are used to stimulate the ovaries to produce multiple eggs rather than the single egg that normally develops each month. Multiple eggs are needed because some eggs will not fertilize or develop normally after egg retrieval. Pregnancy rates are higher when more than one egg is fertilized and transferred to the uterus during an IVF treatment cycle. At present, IVF is rarely performed without the use of ovulation drugs” (American Society for Reproductive Medicine, 2008, p. 4).

Egg retrieval is “accomplished by transvaginal ultrasound aspiration, a minor surgical procedure.... [During retrieval] Some form of anesthesia is generally

administered. An ultrasound probe is inserted into the vagina to identify the mature follicles” (American Society for Reproductive Medicine, 2008, p.6). A follicle is a “fluid-filled structure in the ovary containing an egg and the surrounding cells that produce hormones. As the follicle matures, the fluid can be visualized by ultrasound” (p. 19). “A needle is guided through the vagina and into the follicles. The eggs are aspirated (removed) from the follicles through the needle connected to a suction device.... In some circumstances, one or both ovaries may not be accessible by transvaginal ultrasound.

Laparoscopy [emphasis authors’] “may then be used to retrieve the eggs” (American Society for Reproductive Medicine, 2008, pp. 6-7). The “best quality, mature eggs” are chosen and placed in “IVF culture medium” in a laboratory dish. “Motile sperm are then placed together with the eggs, in a process called insemination, and stored in an incubator. Fertilization occurs in the laboratory when the sperm cell penetrates the egg, usually within hours after insemination” (American Society for Reproductive Medicine, 2008, p. 7). A woman may attempt to conceive through artificial insemination without IVF treatment. In this instance, insemination occurs when the doctor places the partner’s or donor’s sperm directly into the woman’s uterus or cervix (p.20).

Micromanipulation techniques can be used to increase the chances of fertilization when the expectation for fertilization is poor. This includes *intracytoplasmic sperm injection* (ICSI), *assisted hatching* (AH), and *preimplantation genetic diagnosis* (PGD).

Intracytoplasmic sperm injection is a technique in which “a single sperm is injected directly into the egg in an attempt to achieve fertilization. In the United States, ICSI is performed in approximately 40% of all ART cycles” (2008, p. 7).

Assisted hatching is a technique in which “the zona pellucida (outer covering) of the embryo is partially opened, usually by application of an acid [just prior to embryo

transfer], to facilitate embryo implantation and pregnancy” (American Society for Reproductive Medicine, 2008, p. 18).

Preimplantation genetic diagnosis is a procedure in which “one or two cells are removed from the developing embryo and tested for a specific genetic disease. Embryos that do not have the gene associated with the disease are selected for transfer to the uterus” (American Society for Reproductive Medicine, 2008, p. 9).

Embryo transfer is a procedure in which “one or more embryos suspended in a drop of culture medium are drawn into a transfer catheter, a long thin sterile tube with a syringe on one end. The physician gently guides the tip of the transfer catheter through the cervix and places the fluid containing the embryos into the uterine cavity” (American Society for Reproductive Medicine, 2008, p. 9). If more embryos develop than can be transferred during an IVF cycle, a woman may choose to *cryopreserve* (freeze) them for transfer in a future IVF cycle.

Cryopreservation: “makes future ART cycles simpler, less expensive, and less invasive than the initial IVF cycle, since the woman does not require ovarian stimulation or egg retrieval. Once frozen, embryos may be stored for several years. However, not all embryos survive the freezing and thawing process, and the live birth rate is lower with cryopreserved embryo transfer” (American Society for Reproductive Medicine, 2008, p. 10).

Biochemical pregnancy: Following embryo transfer, blood tests are taken at frequent intervals to track changes in a woman’s hormone levels that would be indicative of pregnancy. A *biochemical pregnancy* may occur “when a patient’s pregnancy test is initially positive, but becomes negative before a fetus is visible on ultrasound” (American Society for Reproductive Medicine, 2008, p.18).

Appendix B: Informed Consent Form

Santa Barbara Graduate Institute
Ann Diamond Weinstein

The Experiences of Women with PTSD Symptoms Receiving Reproductive
Endocrinology Treatment for Infertility

INFORMED CONSENT FORM

I am a student at the Santa Barbara Graduate Institute (SBGI) and am conducting a study on the experiences of women with posttraumatic stress disorder symptoms undergoing treatment for infertility with a reproductive endocrinologist. Before any student at SBGI does a study, a panel of people review what the student plans to research and how they plan to conduct the study in order to ensure that the project will be conducted ethically. The panel reviews the project in order to protect the interests, comfort and safety of all participants.

I also want you to know that my primary aim is to conduct a study that benefits women trying to conceive. I am giving you this form and the information it contains for your protection and so that you have a full understanding of the study's procedures before you decide whether or not you are interested in participating. If you choose to sign it, that will mean that you have (a) received this document describing what is involved in participating in this study and what the procedures and potential benefits and risks of participating in this research are; that you have (b) been given enough time to consider the information in the document; and that you have (c) voluntarily agreed to participate in the project.

The names of the women who will be participating in this study will be kept confidential to the full extent permitted by law. Your identity will not be known to any staff member, faculty member, or student at SBGI other than myself. You will not be required to write your name or any other identifying information on the research materials unless you wish to do so. During the course of the research, you will be assigned a pseudonym to maintain your anonymity. It is possible that, as a result of legal action, I, as researcher, may be required to divulge information obtained in the course of this research to a court or other legal body. All research materials will be kept in my home office in a locked file cabinet.

The observations and interviews will take place in a non-medical professional office in Roslyn, N.Y., or your home, whichever is more comfortable for you. During our initial interview, I will ask you to complete two questionnaires. You may or may not be selected as a participant, depending on the results of the initial screening. If you are selected as a participant, I will ask to meet with you two additional times for ninety minutes each time over the following two months, during which I will interview you about your experiences receiving reproductive endocrinology treatment.

Page 1 of 4 ____ (Please initial here)

As stated in the *Description of the Study*, audio recordings will be made to assist me in writing my dissertation. I will also take written notes of observations that I make during our interviews. These recordings—auditory and written—are solely for my personal use to facilitate an accurate account of the data. They will be held strictly confidential unless your written permission is obtained to use them for some other purpose. Your identity will be kept confidential and statements attributed to you in the dissertation will be identified by a pseudonym (a name made up to protect your identity). You may choose not to answer any question I ask and you may stop the interview at any time. The open-ended questions are intended to leave you in control of what you wish to share. You have the right to withdraw from this study partially or fully at any time.

There are a number of benefits of participating in the study. Participants may find it helpful to share their experiences. Some of the results may be published in journals and publications to serve other women. The study will add to the body of knowledge in the fields of reproductive health care and prenatal and perinatal psychology. It may help women, their partners and health care providers increase their understanding of the importance of working together to positively impact the quality of a woman's experience of reproductive endocrinology treatment.

Upon completion of the dissertation, I will contact you to offer you a copy of the dissertation. You will receive compensation in the form of gift certificates to www.amazon.com for your participation in each phase of the study. I will provide you with a \$15 gift certificate for the initial screening process. If you are selected to be interviewed, you will receive a \$30 gift certificate for each interview, (i.e., \$75 total).

There are no known physical risks associated with participating in this research. However, some women may experience mental or emotional discomfort such as fear, anxiety, depression, loss of self-esteem, shame guilt, embarrassment, concern about being judged negatively, and so forth, when discussing posttraumatic stress symptoms and infertility. If this interview process elicits strong concerns or feelings and you would like to talk to a licensed therapist, please feel free to contact me (Ann Diamond Weinstein) and I will give you the names of qualified counselors in your area. You may also contact me with questions or queries about the project at 516 972-0388 or email me at weinsteinann@hotmail.com. You may register any complaint you may have about the project with Jill Kern, Director of Research, by mail (Santa Barbara Graduate Institute, 525 Micheltorena, Suite 205, Santa Barbara, CA. 93103), by phone (805 963-6896 ext. 106), or by email (jkern@sbgi.edu).

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(Please initial here)

Agreement to Participate

Having been asked by Ann Diamond Weinstein of Santa Barbara Graduate Institute to participate in a research project, I, _____ have read the procedures specified in the document. (Please print your name)

I understand the procedures to be used in this project and that the results of this project may bring some benefits to me and other women trying to conceive. I understand that some of the results may be published in journals and publications to serve other women and I consent to that.

I understand that I will receive compensation in the form of gift certificates to www.amazon.com for participation in each phase of the study (i.e., including a \$15 gift certificate for the screening process and a \$30 gift certificate per interview for each of the two interviews).

I understand that participation in this study does put me at risk of experiencing mental and emotional discomfort.

I understand that I may withdraw my participation in part or in full from this study at any time.

I understand that any notes taken by the researcher, transcripts and audio recordings will be kept in a secure location.

I understand that I may request a copy of this dissertation when it is complete.

I understand that my identity will be kept confidential and that, in reporting the data, statements attributed to me will be identified by a pseudonym (a name made up to protect my identity).

I also understand that I may contact Ann Diamond Weinstein, principal researcher, with questions or queries about the project and I may register any complaint I might have about the project with Jill Kern, Director of Research at the Santa Barbara Graduate Institute.

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(Please initial here)

I agree to participate in this project, which consists of a screening phase, and if I am selected as a participant, two interviews.

Name (print) _____

Address _____

Phone Number _____

Signature _____ Date _____

Signature of researcher _____ Date _____

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(Please initial here)

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