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PURSUING A CHILD

**AN INTERACTIVE QUALITATIVE ANALYSIS OF THE INFERTILITY TREATMENT
EXPERIENCE**

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AN INTERACTIVE QUALITATIVE ANALYSIS OF THE INFERTILITY TREATMENT
EXPERIENCE

by

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Dedication

This dissertation is dedicated to my sweet grandmother in Italy, “Nonnina, senza di te non sarei la donna che sono oggi.” Dedication to my mother does not do justice to the gratitude I owe her for her years of hard work and commitment to my successful youth. Also, I would like to dedicate this achievement to my husband who has always supported me through these years. Finally, this is also dedicated to my family and friends, who I am fortunate to have in my life.

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PURSuing A CHILD

AN INTERACTIVE QUALITATIVE ANALYSIS OF THE INFERTILITY TREATMENT EXPERIENCE

by

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The purpose of this exploratory study is to examine and compare the infertility experience of individuals who have difficulty bearing children and/or who undergo fertility treatments.

Each year, millions of individuals discover they are unable to bear children. Nearly 15% of the US population is diagnosed with infertility (NIH, 2014). Considered as a serious and unexpected condition, infertility has been linked to psychological and physiological distress, including health complaints, depression, anxiety, and complicated bereavement (Berghuis and Stanton, 2002; van den Akker, 2005). However, little is known about how people experience infertility and infertility treatments.

This study aims at exploring how infertile individuals process their medical condition and how they cope with the stress of undergoing treatments. To achieve this goal, this study seeks to identify elements that make up the infertility treatment experience.

This study uses the Interactive Qualitative Analysis (IQA) grounded framework (Northcutt & McCoy, 2004) to reconcile quantitative and qualitative data collection. Flyers in medical facilities and infertility support groups in Central Texas were used to recruit fifty individuals.

Initially, participants attended focus groups to identify common elements surrounding the infertility experience. Using these elements, the research team developed surveys and a semi-structured interview. The interviews provided participants' rich stories while the surveys measured satisfaction of experiences.

Analysis of the infertility treatment experience elements, and their interactions, show that the cost of treatments and running out of time correlate with a more negative experience. In addition, knowledge of the topic and receiving support from individuals who are also experiencing infertility are more positively rated.

The findings of this study are useful for identifying problematic aspects surrounding this experience, and for providing an opportunity to develop tools aimed at making the process of undergoing treatments easier.

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CHAPTER 1: INTRODUCTION

The goal of this dissertation is to better understand how couples process and cope with their difficulty bearing children. This study focuses on infertility and infertility treatment experiences of individuals affected by this condition and undergoing IVF treatments.

Each year, millions of individuals discover that they are unable to bear children. About 15% of the US population is not able to conceive naturally. Approximately one in six couples worldwide are infertile, with 7.3 million couples and 7.3 million women of reproductive age (approximately 12%) suffering from infertility in the U.S (Chandra, Copen, & Stephen, 2013).

Infertility is defined as the inability to either conceive or to carry a pregnancy to live birth after a year or more of intercourse (Menning, 1988; Valentine, 1986). Although often thought of as a woman's condition, male factors account for about one third of all cases, female factors account for just over a third, combined male and female factors account for 20-40%, and 10-20% of all cases are due to unexplained infertility (Corson, 1999). Infertility can be either primary or secondary. Primary infertility describes the inability to conceive a pregnancy, while secondary infertility is defined as the inability to become pregnant, or to carry a pregnancy to term following the birth of biological children.

The most common forms of fertility treatment include: 1) hormonal therapies which aim at stimulating egg production, 2) intrauterine insemination (IUI) which involves placing sperm inside a woman's uterus to facilitate fertilization, and 3) ART, which refers exclusively to treatments in which both eggs and sperm are handled. ART focuses on techniques that rely on In Vitro Fertilization (IVF). IVF involves surgically removing eggs from a woman's ovaries, combining eggs and sperm in a laboratory dish to produce embryos, and then implanting the embryos in the woman's uterus. While IVF has become a successful and routine treatment for infertility used in many medical centers worldwide, monitoring the outcome of this technology has become very important due to the challenges it poses to the physical and the psychological health of the individuals involved.

In recent years Assisted Reproductive Technology (ART) has become the most preferred method by which infertile adults can achieve parenthood (<http://www.cdc.gov/art/>). Worldwide, approximately 1.5 million ART cycles are performed each year, with an estimated 350,000 babies born (<http://www.eshre.eu/Guidelines-and-Legal/ART-fact-sheet.aspx>). In the U.S., 1.5% of the infants born each year are conceived using Assisted Reproductive Technology (<http://www.cdc.gov/art/>; <http://www.cdc.gov/art/reports/index.html>), while in several European countries, ART pregnancies represent 2%–3% of the births (Wagenaar, Huisman, Cohen-Kettenis, & Delemarre-van de Waal, 2008).

Given the increasing numbers of couples dealing with infertility it would seem important to broaden our understanding of how the experience and the procedures associated with fertility treatments affect the involved individuals psychologically (Golombok, Cook, Bish, Murray, 1995; Gibson, Ungerer, McMahon, Garth, & Saunders, 2000; Wagenaar et al., 2008; Wagenaar et al., 2009). Numerous studies emphasize the psychological effects of infertility on adults once they are diagnosed and decide to pursue treatment. Although becoming a parent involves a degree of stress for many people embarking on the experience, infertile couples are unique in that they face a range of stressors associated with biological, psychological, and social factors related to their inability to conceive. However, findings on the effects of fertility treatments on adults are mixed.

Some research suggests that people seeking IVF treatments are well adjusted overall in terms of their mental health and level of stress (Connolly, Edelmann, Cooke, & Robson, 1992; Edelmann, Connolly, & Bartlett, 1994). Other studies, conversely, indicate that experiences with infertility treatments are associated with elevated levels of depression and anxiety, feelings of loss and even marital problems (Möller & Fällström, 1991; Lalos, 1999). Moreover, fertility treatments can carry medical risks such as multiple and premature birth, higher mortality and handicap rates, ovarian hyper-stimulation syndrome and an increased risk of developing serious diseases (e.g. ovarian cancer; Eugster & Vingerhoets, 1999). Furthermore, despite the groundbreaking technology, only 30% to 60% of couples seeking treatment are able to achieve a viable pregnancy, depending on the patients' age and severity of infertility (McPhee, Papadakis, &

Tierney, 2008). Consequently, couples faced by failures are forced to either go through multiple treatments, or stop medical intervention all together.

Reasons for differences in studies' results related to the effects of undergoing infertility treatments could stem from a series of factors, including the number of times adults undergo fertility treatments, the social support they experience from others and the cost associated with the various procedures, just to mention few. The primary goal of this research is to investigate how people react to infertility and how they cope with the medical treatments. Additionally, this study aims at understanding which elements of their experience are associated with a positive or negative journey when treating the condition. The final aim of the study will be to use the data gathered to provide solutions to issues raised by the participants and develop tools to make the process easier for individuals and couples undergoing treatments.

About This Study

This study explores the broad question, *How do individuals experience and cope with infertility and infertility treatments?* To answer this question, the researcher investigates the phenomenon of a combined system, The Infertility Treatment Experience. Using Interactive Qualitative Analysis (IQA), this study identifies the elements that make up The Infertility Treatment Experience. First, this study focuses on exploring Research Question #1: "What are the elements that make up the Infertility Treatment Experience?" Research Question #2: How do these elements relate in a system of influence?" Focus Groups were used to identify the elements that make up the Infertility Treatment Experience. These elements are called Affinities. These affinities were then used to produce an interview protocol and interviews were conducted to gather rich stories about each affinity and how they relate to each other. The study concludes with practical solutions for issues raised by the participants and tools that can be developed to help individuals dealing with infertility, cope psychologically with this condition, and make the medical treatment process easier.

Chapter 2 provides a theoretical framework. The in-depth literature review presented in this chapter will be revisited and compared to this study's findings later in Chapter 5.

Chapter 3 outlines the Interactive Qualitative Analysis methodology used to conduct the study. A detailed description of the IQA process, written by Northcutt and McCoy, the developers of the process, is presented in Appendix A.

Chapter 4 and **Chapter 5** use the IQA methodology to presents an analysis narrative from the participants' perspective. Because these chapters are designed to tell the story in the participant's own words, the description of each affinity is free of commentary and interpretation by the researcher. In Chapter 4 and 5, the people's voices are heard. These chapters address the research questions from the point of view of the individuals who have lived the Infertility Treatment Experience. Chapter 4 details a composite analysis of the axial interview portion to tell the story of the group as a whole in order to answer research question #1: *What are the elements that make up The Infertility Treatment?* Chapter 5 presents a detailed composite analysis of the theoretical interview portion to tell the story of the group as a whole to answer research question #2: *How do these elements relate in a system of influence?* The participants' combined stories are shown to give the reader an idea of the range of meaning for each affinity and sub-affinity. These two chapters allow the reader to draw meaning from the participants.

Chapter 6 will present results from the statistical analysis of the infertility experience elements ratings.

Chapter 7 provides the researcher's interpretation of the findings. The researcher examines the meaning of each affinity and their relationships and how they all come together in a system. By examining the system in several ways, the researcher provides insight and solutions into common problems with the final goal of identifying how to have a positive outcome in the system. Chapter 5 begins with a detailed description of each affinity and how all the affinities interact to form a system. Next, the reader is taken on a tour of the system, explaining where the elements of the system lay and how the relationships among them work. Feedback loops are identified,

named and examined individually. In the *Exercising the System* section, the researcher describes hypothetical scenarios which predict outcomes that may result from certain conditions, as well as describes what must occur to achieve a desired outcome. Finally, Predictions, Interventions, and Practical Implications are examined to provide solutions to identified problems.

Appendix A presents a complete version of the IQA methodology, along with charts and diagrams generated by the IQA founders, Northcutt and McCoy.

Appendices B & C present the raw data used to identify the elements and relationships.

CHAPTER 2: THEORETICAL BACKGROUND

In the following section, an in-depth literature review will be provided. First, reasons for infertility will be explored. Next, studies showing the effects of infertility on adults' well-being will be described.

Causes of Infertility

Along with the more obvious and expected medical reasons, including declining female fertility, sexually transmitted diseases, environmental toxins, and unhealthy lifestyles, delaying parenthood is the leading mainstream anecdotal explanation for infertility. Over time, research has found evidence to support these popular anecdotes. According to Mills, Rindfuss, McDonald, & te Velde (2011), the mean age of first time motherhood worldwide has been increasing by about 1 year each decade since 1970. Specifically, in European countries, the average age has jumped from 25 to 29 years old in 2008 with highly educated women driving up the numbers. In modern society, as couples decide to delay parenthood, the incidence of age- related infertility has risen along with the demand for ART (Baird et al, 2005).

Among the most frequently discussed reasons for postponing parenthood is the introduction of oral contraception in the 1960s. Studies point to the “pill” as the culprit – it allowed women in the U.S. as well as Western and Northern Europe to postpone parenthood (Cibula, 2008; Goldin & Katz, 2002). However, since fertility rates are dropping globally (Mills, et al, 2011) it is important to point out that other reasons, i.e. political or economic factors, level of education, employment, must also be affecting this trend.

As women's education has increased, so has the rate of infertility (Martin, 2000). As women become more educated, they often strive to achieve better careers with high paying jobs. They hope to provide their families and their future children with better opportunities. However, the decision to pursue higher education goals has resulted in postponing parenthood because it can be difficult to balance the demands of work and childcare. Budig (2001) demonstrated that both part-time and full-time employment not only delays, but even decreases, the likelihood that

women will have a child in the USA. With higher status careers come more responsibilities, increased demands, and greater competition. As women increasingly compete for traditionally male occupations, the likelihood that they will have children declines. Postponing childbearing is more likely not only for women who study in male (vs. female) dominated disciplines, but also for women employed in male dominated fields (Mills et al 2011). These studies relied, however, on correlational data, and hence, the cause for postponing parenthood is not clear. A self-selection factor might exist whereby women who pursue higher degrees and higher status careers have different life goals, making parenthood a lower priority compared to those who bear children at younger ages.

It is important to note that studies looking at why couples postpone parenthood have focused mainly on women's issues or choices. Factors relevant to men may contribute to this phenomenon directly or indirectly by affecting women's choices. There are studies showing links between gender inequality and fertility. Traditional gender roles, emphasizing that women are the primary care providers, and an unequal distribution of household chores, have been found to impact infertility (Bianchi, Milkie, Sayer, & Robinson, 2000), but these studies are inconclusive. Some suggest that more egalitarian roles are correlated with higher fertility (Kaufman, 2000); while others demonstrate the exact opposite (Westoff & Higgins, 2009). Virtually no study has examined the demographic characteristics and psychological well-being of people before they decide to start treatments and the pathways that underlie their decisions to undergo infertility treatments.

Psychological Impact of Infertility

Infertility and Positive Well-Being

Despite the evidence that infertility is shown to be a very stressful experience (Domar, Zuttermeister, Friedman, 1993), some studies reveal that most people who seek fertility treatment are well adjusted (Edelmann et al, 1994; Anderheim, Holter, Bergh & Möller, 2005). Edelmann and colleagues (1994) conducted a study of 152 couples with no prior experience with

IVF whose infertility duration ranged from 3 months to 14 years. They assessed both men and women on several dimensions to obtain a complete psychological profile, and evaluated their coping strategies. Participants completed several assessments: the Eysenck Personality Questionnaire (EQP); the State-Trait Anxiety Inventory (STAI); the Self-Esteem Scale (SES); the Profile of Mood States-Bipolar Form (POMS); and the Coping Strategies Questionnaire (CSQ). The assessments were conducted on their first visit to the clinic before their consultation with the medical staff. Results highlighted that couples showed little deviation from normative data. Specifically, duration of fertility was not correlated with state anxiety, self-esteem or mood state. Regarding coping skills, acceptance of the condition was related to better psychological adjustment, which, in turn, was associated with direct action in pursuing treatments.

While this study yielded encouraging results, it is important to note that participants were assessed only at the beginning of the treatment, when stress is typically at its lowest. Indeed, other studies have found that measurements at different times during the IVF treatment evidence a different level of stress or maladjustment. Couples experience higher levels of stress during the initial medical visit and the diagnosis visit (Daniluk, 1988). Stress increases after the embryo implantation, while waiting to see if the embryo implants, and becomes a chronic reaction to long-term medical treatment (Berg & Wilson, 1991). However, this study lacked of a control group. Being able to compare this group to a control group would have given a more in depth understanding of differences between women who undergo IVF and those who do not, since women who experience infertility might have higher levels of stress as compared to fertile women.

It is important, also, to point out that couples who decide to undertake such a difficult journey might be well-established and have solid relationships. Infertile couples who endure aggressive treatments, like IVF, might have begun with a strong sense of self and strong relationships. It is possible that a self-selection factor exists such that only well-adjusted couples in stable relationships are emotionally strong enough to meet the treatments demands and subsequently decide to undergo IVF. Also, it is common that during the first consultation visit, patients are presented with positive scenarios and attractive statistics pointing to very encouraging outcomes.

Very little, if any, information regarding the psychological effects of treatments are discussed. Therefore, many couples decide to embark on this journey with exceedingly high expectations and confidence that their endeavors will produce positive results, grossly underestimating the difficulties and challenges ahead.

In sum, most of the studies finding few negative effects of infertility treatments are exploratory. They rely primarily on anecdotal and retrospective data, lack control groups, and have small samples. Also, longitudinal studies examining IVF outcomes in the same patients over a period of time are rare. This is particularly problematic because many couples undergo multiple fertility treatments, which become increasingly more aggressive (e.g., from assisted insemination (IUI) to embryo implantation (IVF)). Moreover, studies collecting individuals' experiences are needed. When the patient is given the opportunity to tell their story, a rich collection of data is gathered. This type of data allows for in-depth insight into the issues explored and it provides rich stories told in the participants' own words.

Negative Impact of Infertility

Although some research documents non-detrimental psychological effects of infertility, this condition is ranked as one of the most stressful experiences in life along with death, divorce, and deadly diseases like HIV and cancer (Domar, Zuttermeister, & Friedman, 1993). The majority of studies suggest that infertility negatively affects adults' well-being (Shapiro, 1988; Cook, 1987; Mahlstedt, 1987; Wichman et al., 2011). Adults who experience infertility regard their inability to conceive as a prolonged life crisis (Lalos, 1999), and are more likely to suffer from depression, anxiety, feelings of loss and even marital problems both in the short and long term (Möller & Fällström, 1991; Lalos, 1999).

People experiencing infertility have feelings of anger, hurt, fear, frustration, depression, sadness, grief, loss, isolation, lowered self-esteem, relationship distress, and sexual dissatisfaction (Daniluk & Tench, 2007). One survey found that 40% of IVF patients exhibited psychiatric disorders (Chen, Chang, Tsai, & Juang, 2004). Domar et al. (1992) found the rate of depression

among women suffering from infertility to be the second highest after cancer, with one in four experiencing severe depression.

Anger toward people with children, toward abusive parents, or even toward medical professionals along with feeling pressure to have children and a lack of control seem to fuel some of the anguish experienced during this difficult time (Menning, 1980 & 1988; Cook, 1987). Additionally, many women feel guilty about delaying childbearing, previous abortions, birth control methods, STDs, premarital or extramarital sex, or other experiences they attribute to infertility (Menning, 1980 & 1988; Valentine, 1986).

Most studies assess adults' psychological distress when patients begin treatments, as well as during the process. It is, hence, unclear whether people who have difficulty conceiving a child become increasingly overwhelmed by their condition, thus fueling or aggravating these negative feelings, or if these feelings contribute to infertility.

In a longitudinal study conducted in Sweden, Anderheim, Holter, Bergh, & Moller (2005) recruited 166 women to investigate the association between psychological stress and IVF outcome. They administered a series of questionnaires at two time points, one month prior to beginning of treatment (but after the initial informational visit), and the other on the day of oocyte retrieval. These questionnaires, aiming at measuring psychological well-being and couple relationship, included both well-established, reliable, and valid instruments such as the Psychological General Well-Being (PGWB) index, as well as less validated instruments devised specifically for the study to capture distress exclusively related to the IVF experience. Results showed that most adults reported having healthy psychological well-being prior to IVF treatment, and there was no relation between IVF outcome and perceived psychological stress or well-being.

Although this study's results are reassuring, it used only questionnaires. While convenient and inexpensive to administer, questionnaires often fail to capture participants' in-depth reactions. It is possible that adults responded positively to questionnaire items to enhance social desirability.

It is also possible that these women were motivated to depict themselves as well-functioning individuals in order to sustain the demands of treatment. In fact, Demyttenaere, Evers-Kiebooms, & Koninckx (1989) mentioned that infertility patients hide their stress because they want to show the medical team that they are functioning well both socially and psychologically. A more complete evaluation of the patients could be obtained from interviews.

In contrast to the findings reported by Anderheim and colleagues, a study conducted by Smeenk et al., (2001) demonstrated that stress related to infertility reduces the likelihood that women will become pregnant using IVF. The team recruited 291 patients going for their first IVF in the Netherlands. They measured anxiety and depression using the Dutch version of the State and Trait Anxiety Inventory (STAI), and the Dutch version of the Beck Depression Inventory (BDI), respectively. The outcome assessment was the number of follicles produced, and all pregnancies were verified with a positive urine test. Results indicated that state anxiety was a better predictor of pregnancy rates than depression, and was particularly important during the implantation phase of the IVF. There are several reasons why psychological stress may contribute to negative outcomes in some studies but not others. Smeenk et al. (2001) focused only on first IVF attempts and in their outcome included only pregnancies confirmed via pregnancy test and not viable pregnancies resulting in live birth. Also, women's age, duration of infertility, number of IVFs, and reasons for infertility might have not been teased apart and treated as possible moderating variables. A study looking at other elements that might contribute or interact to negative or positive outcomes will be able to give a more clear overall picture.

In a meta-analysis of 31 studies (N=4902 total; average sample size=158) conducted to determine whether the outcome of IVF was related to stress, anxiety, and/or depression (Matthiesen et al., 2011), only small significant associations between stress and anxiety and reduced rates of pregnancy were found. These conclusions suggest that the influence of stress on reducing the chance of having a viable pregnancy is limited. Furthermore, they did not find a significant association between depression and pregnancy. One limitation of the majority of the studies included in the meta-analysis is that they investigated only infertility-related stress, such as stress related to being infertile and stress related to IVF patients. There are other types of

stress that could have affected whether the IFV was successful, including stress stemming from relationship difficulties, or stress related to trying to balance life and job responsibilities with the demands of treatments, which could interact, and thereby significantly increase the stress related to infertility. Further, a major shortcoming was the inclusion of all types of IVF outcomes, including the number of oocytes harvested, embryos transferred, fertilization rates, implantation rates, pregnancy test result, clinical pregnancy, and live birth delivery. The researchers did not focus on viable pregnancy producing a live birth only, which is the ultimate goal of people pursuing IVF treatments. It is likely that with repeated unsuccessful IVF cycles, anxiety, stress, and depression levels become chronic and increase due to the strenuous treatments and the failure of conceiving (Klonoff-Cohen, 2008).

Although the results did not point to definitive answers or causes, they suggest a very small impact of stress on IVF outcomes. However, it is likely that relations between adults' psychological state and the experience of infertility and associated treatments are reciprocal. Thus, more studies aimed at investigating the sources of stress, the relationships, and the magnitude of stressors might help in devising tools for helping people as they undergo fertility treatments, and cope when the treatments fail. It will be important in future studies to examine how different symptoms of distress might affect the Infertility Treatment Experience and the overall outcome of the treatment.

A major criticism to the early infertility research was that most of the studies focused solely on women and grossly underestimated, or simply excluded men's reaction to this painful life event. To fill this gap, some studies have examined the dyad's response to infertility (Freeman, Boxer, Rickels, Tureck, & Mastroianni, 1985; Slade, Emery, & Lieberman, 1997; Wichman et al., 2011). A study of 200 couples who went through IVF revealed that 15% of men and 49% of women identified infertility as the most stressful time in their lives (Freeman et al., 1985). Similar to previous findings with women, Freeman et al. (1985) found higher level of distress in couples at the time of diagnosis. However, these investigators only included couples who had been diagnosed with female infertility, and they measured people only during the first consultation visit. It is plausible that women who have just been told that infertility resides with

them become increasingly more upset than their husbands because they feel that they are the cause of potential childlessness and are responsible for embarking on costly treatments in order to achieve parenthood. Indeed, Beaurepaire and colleagues (1994) studied 330 couples who underwent IVF and found that women have greater levels of depression and anxiety than do their partners, with women going through multiple cycles of being at higher risk for developing clinically severe depressive symptoms.

Wichman et al. (2011) also concluded that both women and men experienced significant psychological distress in the context of IVF. They recruited 162 couples undergoing IVF for the first time at the Mayo Clinic from 2005 to 2008. Participants were assessed pre-IVF treatment using a clinical interview and psychometric assessments, including the Beck Depression Inventory, the State-Trait Anxiety Inventory, the State-Trait Anger Inventory, the Impact of Events Scale adapted to infertility, and the Perceived Stress Scale. While most participants scored in the normal clinical range for general psychological distress, 66% of women and 50% of men reported mild to great distress stemming from infertility. Moreover, more women than men experienced mild levels of depression, anger, and perceived stress. An explanation for these findings is that the couples were in their initial stage of IVF, their first try, and the mean duration of infertility was 4.2 years. This is lower than in prior studies that reported higher stress in which the duration was 4 to 7 years. Newcomers to IVF might have more positive attitudes and higher expectations that in vitro will help them bear children. Usually, new patients are not aware of the difficulties associated with the procedure. With repeated tries, the treatments typically become increasingly more aggressive and women become more aware of the possibility that they will never bear children, elevating their levels of distress (Domar et al., 1992; Kee, Jung, & Lee, 2000). Although there could be many reasons for this result, it is worth mentioning that this study used clinical instruments to assess participants' distress, including both a clinical interview and several psychometric assessments. The strength of this study is that it relied on both clinical interviews and reliable and valid clinical assessments.

In sum, for many couples, infertility is a major life crisis and psychologically stressful. However, the literature suggests that infertility is more stressful for women than men, even when both

partners are assessed (Berg & Wilson, 1991; Daniluk 1997; Wright et al, 1991). One reason for this phenomenon may be that, traditionally, the “obligation” and social expectation to procreate has been associated with the female, such that when parenthood is not achieved, others, and the women themselves blame the woman for the couples’ inability to conceive. Moreover, women have to face their biological clock. As time passes, they become more worried about having children and experience infertility as a grave crisis, while men do not experience it as such an emergency (Butler & Koraleski, 1990). Also, women must confront the fact that they must carry the pregnancy and, in most cases, undergo extensive, costly, and painful evaluations and treatments including surgeries. Pregnancies resulting from IVF are also more risky and must be closely monitored. With extensive medical evaluation and as the treatment proceeds, the couple, and especially the woman, must be completely available and at the mercy of drugs and continuous medical check-ups that needed to be done at precise times of the cycle. Life rotates around doctors’ appointments and medication schedules, and even career decisions and vacations are placed on hold because of surgeries and medication regimens (Markestad, Montgomery, & Bartsch, 1998).

Gender socialization may also help explain why women report higher levels of stress and, in general, tend to talk more than men about their feelings of distress during difficult times. During childhood, girls are encouraged to express their feelings and emotions while boys are socialized to be more physical and tough and to hide feelings of fear, weakness, or sadness. Parents encourage gender-specific activities, reinforcing independence in boys and closeness in girls, and tend to label emotions with girls, while using more scientific vocabulary with boys (Lippa, 2005; Ruble, Martin, & Berenbaum, 2006; Tenenbaum & Leaper, 2003). Research has shown that men frequently find it difficult to express their feelings of hurt and they often avoid sharing their feelings to protect their spouses (Valentine, 1986; Williams, Bischoff & Ludes, 1992). Therefore, while women are more likely to talk about their experiences with their friends and to others who might encourage them to do so, men express themselves differently. It is possible that when men realize that their partner will carry the heaviest physical burden, they are more likely to decide to be strong and resilient so that they avoid projecting more stress onto their counterparts.

Finally, infertility affects couples' relationships and poses serious stress on intimacy. As couples learn about their condition, they first need to make a series of difficult decisions regarding whether to pursue treatment, the type of treatment to undergo, when to terminate treatments and economic considerations associated with the high costs of treatments. The costs of treatment, which is significant, must be weighed against both the benefit of getting pregnant as well as the fact that the treatment might not work. Couples' emotional, monetary, and physical resources are likely to weaken or even become depleted by the time they terminate treatment. By that time, they may have endured years of costly and invasive medical procedures that have proved extremely challenging (Domar, 1997). Also, intimacy is negatively affected. Both partners report a loss of sexual desire (Greil, Porter, & Leitko, 1990) due to the pressure to conceive, diminished privacy, and lower self-esteem. Sexual relations become tied to the ultimate goal of childbearing and less associated with a desire for closeness. Intimacy becomes tied to schedules and charts, which turn into public knowledge of doctors and medical staff. Finally, since sexual relations are associated with reproduction, infertility can make people feel "damaged or defective."

Although it has been established that psychological distress is more accentuated in women, and fluctuates at different stages of IVF treatment, it is important to understand whether psychological well-being is affected as treatment becomes increasingly aggressive and prolonged. A growing body of research suggests that women, whose IVFs are unsuccessful, experience lower levels of life satisfaction and greater marital distress than those who in vitro made it possible for them to bear children. Specifically, following women 6 months after their last unsuccessful IVF treatment, Slade, Emery, & Lieberman, (1997) found that women who did not become pregnant showed higher levels of anxiety than their spouses and were less positive than their husbands about their marital and sexual relationships. Verhaak, Smeenk, van Minen, Kremer, Kraaimat, (2005) replicated this finding, reporting that more than 20% of the women showed clinical forms of anxiety and/or depression 6 months after the last unsuccessful treatment. However, their husbands did not show increases in distress at the follow-up assessment.

Following up women after a longer period of time, 2.5 and 3.5 years after terminating in vitro treatment, there were more positive feelings and satisfaction with the treatment as well as a greater life satisfaction among women whose IVF treatments resulted in having a baby than for those whose IVF was unsuccessful (Hammarberg, Astbury, & Baker, 2001). In another study, 270 men and women were followed-up 4 to 5.5 years after their last unsuccessful IVF treatment. At the follow-up, 76.7% of these couples were raising a child. Some couples (10.7%) had a child or one partner had a child (3.7%) prior to undergoing IVF. Others obtained a child either through adoption (34.8%), surrogacy (39.6%), or fostering (3%). Those able to have a child reported a higher quality of life than those who remained childless. Specifically, compared to those able to raise a child, people who remained childless reported more depression and less positive well-being, lower self-confidence, and worse general health than those who were raising a child (Johansson et al., 2009).

In a study examining women's psychological functioning as a function of their stage of IVF treatment, Berg and Wilson (1991) investigated 104 couples across three stages of the IVF treatment: 1) Stage 1, at year 1 --when people are diagnosed and begin treatment; 2) Stage 2, at year 2 -- when couples are undergoing the full course of treatment and have high expectations for their outcome; and 3) Stage 3, at year 3 and beyond -- after people have faced some failure and are evaluating the possibility that the treatments might not be successful. They measured general psychological functioning, and marital and sexual satisfaction. Acute stress was reported at the beginning of treatments, lower stress at mid stages, and increased stress again after the treatment failed or the couple underwent multiple treatments. At stage three and beyond, scores of psychological distress were at symptomatic ranges. Also, increased marital conflicts and decreased marital adjustment after 3 years of unsuccessful treatment were found, indicating that the chronicity of the condition and failed medical treatments negatively affected not only couples' well-being. but also their relationship functioning.

Empirical studies suggests that there are long-term negative effects of failed IVF treatments, which are more pronounced when infertile people fail to achieve parenthood. While it is not always the case that people who face unsuccessful treatments want to "complete" their family

anyway, it is unclear which factors influence their decisions to stop treatment and then to either seek parenthood through the fostering system or adoption, or to remain childless. Reasons underlying different choices after IVF failure could be linked to how successfully couples may have coped with stress and resolved feelings about their losses associated to infertility. Only after the medical course is exhausted are many couples willing to pursue different routes to achieve parenthood. Looking into the factors that make up the Infertility Treatment Experience we can begin addressing these questions by understanding the role these factors play in people's lives including how they affect their relationships and the impact on their daily life and ability to also to grieve the loss they encounter with unsuccessful treatments. We are also able to look into these couples' ability to successfully cope with the stresses stemming from infertility.

With a plethora of research pointing to so many aspects of people's lives that are impacted by infertility and the treatments needed to conceive, it seems important to understand what are the factors that make up this experience and how these factors might contribute to the experience. To better understand the many aspects of this condition, this research looks into collecting insights from the people themselves. Looking at the experience through their eyes might give a more precise overall picture of the issues involved in the journey to parenthood.

Conclusion

Assisted Reproductive Technology and in particular, In Vitro Fertilization, has revolutionized the meaning of conceiving, and has contributed to reshaping the lives of many who otherwise would be unable to bear children. However, coping with infertility and associated treatments can be very challenging, and indeed, has been shown to have negative psychological effects on those involved. A plethora of research describes the psychological factors affecting the well-being of people who experience infertility and undergo treatment, including higher levels of anxiety and depression, declines in self-esteem, relationship dissatisfaction, grief and loss as a potential risk for serious emotional distress. While these are some of the factors contributing to the infertility experience more research needs be devoted to understanding the full extent of the experience. Further research is needed to find the elements that comprise the experience and examine the

extent to which these elements and their relationships might impact people. Findings from such studies can help us better understand potential risks associated with medical procedures designed to assist women in having children, as well as identify ways to minimize such risks. Since previous research has focused primarily on women's outcomes, future studies should include men's response to infertility as well its effects on their lives.

This research study, with such detailed interviews, examines complex phenomena and poses in-depth questions to define and unveil the reality within. By interviewing IVF patients, this researcher might be able to identify the unique aspects and origins of different combinations of stressors -- both general stress and infertility-specific stress. This study could identify the kinds of infertility experiences that cause the greatest distress and examine whether men and women respond differently to these experiences. Gathering this type of data will provide a more comprehensive understanding of how different types of stress -- procedural/situational stress, general stress and/or chronic stress -- affect people at different phases of the IVF cycle. In this way, appropriate tools, and possibly counseling programs, could be devised that target precise issues assisting patients through each unique step.

CHAPTER 3: THE INTERACTIVE QUALITATIVE ANALYSIS (IQA) METHOD

Introduction

The major purpose of this exploratory study is to examine the infertility experience of individuals and couples who have difficulty bearing children and/or undergo fertility treatments. Dealing with infertility and its treatments is a difficult process, and one that is experienced quite differently by the people involved. This study seeks to explore how individuals diagnosed with infertility process their medical condition and how they cope with the stress of undergoing treatments. In order to achieve this goal, this study seeks to identify the elements that make up the infertility treatment experience. Analysis of these elements and their interactions will allow this researcher to identify potentially problematic aspects surrounding the infertility experience and will provide an opportunity to develop tools aimed at making the process of undergoing treatments easier.

When the goal of research is to understand perceptions, values, and experiences qualitative research is a useful and appropriate method. Qualitative research seeks to understand human behavior by gathering firsthand experiences, truthful reporting, and quotes from actual conversations. It focuses on the task of theory generation by working *inductively*. Because qualitative research allows researchers to examine complex phenomena and questions in-depth to define and unveil the reality within, this method best fits the goals of this exploratory study of the infertility experience. Specifically, the Interactive Qualitative Analysis (IQA) grounded framework was used in this study (Northcutt & McCoy, 2004). IQA is essentially qualitative in that it draws a picture from the participants' words of how they construct their realities. While most of the existing literature has collected data through medical surveys, this study will attempt to answer the research questions by directly asking the people affected by the condition. By directly asking infertile individuals, we aim at gathering a deep understanding of attitudes, feelings, and behaviors.

This methodology allows us to gain insight into how people are experiencing the services and medical treatments, but also their perceptions of these services, and how much value they place in them. This method helps in determining what is currently working, or not working, and it

allows exploration of the reasons for why it is working, or not. Because it is also important to the researcher to measure respondents' satisfaction of the services and experiences encountered, the IQA methodology provided the opportunity for gathering quantitative data. Surveys were developed based on findings from the IQA data. Specifically, Affinities and Sub-Affinities (or themes) based on participants' stories were used to rate respondents' satisfaction with each experience. Thus, using a combination of both quantitative and qualitative methods can add to the validity of results and can strengthen this research.

As pointed out by Creswell and colleagues, "because all methods of data collection have limitations, the use of multiple methods can neutralize or cancel out some of the disadvantages of certain methods (e.g., the detail of qualitative data can provide insights not available through general quantitative surveys)" Curry, Nembhard, & Bradley (2009) also mentions that mixed methods are becoming more used and recognized because of the strengths that each approach brings to a study. In medical research, the proportion of mixed methods studies have doubled from 15% in the mid-1990s to 30% in the early 2000s (O'Cathain, Murphy, & Nicholl, 2007). Indeed mixed-methods allow one to investigate not only effectiveness of treatments, but also enable one to examine implementation of evidence-based programs, patient perceptions of services, and quality of care. While quantitative methods allow to establish the "what" or size of the problem, qualitative methods answer the "why" and "how" and hence enable to look into participants satisfaction and how a particular issue or service is experienced (Mays & Pope, 1999).

In a healthcare study of HIV patients, it was demonstrated that a mixed methods approach was beneficial in assessing HIV client satisfaction and in identifying unmet needs in HIV healthcare (Chow, Quine, & Li, 2010). The quantitative portion of the study provided a statistical picture of the clients' satisfaction of healthcare aspects while the qualitative part provided in-depth information of the levels of satisfaction and details of clients' experiences in identifying unmet needs. The authors pointed to three main advantages of using mixed methods approach. First, it increased the comprehensiveness of the findings by showing how the qualitative data corroborated the statistical data. Second, it expanded the research by enabling investigation of

different research questions. Third, it permitted comparison of findings from each method to check for consistency, which helped clarify any ambiguities and to increasing methodological rigor.

Since this dissertation study looks into understanding the factors that make up the infertility experience, and how people live and cope with the difficulty bearing a biological child, a mixed method seems appropriate. This methodology allows the adoption of a “patient-centered” approach by letting patients play active roles through voicing their opinions and perceptions more openly, and in greater detail (O’Cathain et al., 2007). This type of research has the potential not only to increase patient satisfaction, but also to pin-point issues and translate them into solutions and into policy and better practices (Chow, Quine, & Li, 2010).

Therefore, for this study, IQA appears to be an effective reconciliation between quantitative and qualitative approaches in terms of the major paradigmatic dimensions. It balances rigor and description. IQA allows drawing a picture of the system people have in their minds about the way something works. Through a very transparent procedure, IQA can map the mind with rigor, and at the same time produce powerful descriptions of the phenomenon.

IQA Methodology

What is IQA?

Interactive Qualitative Analysis (IQA) is a system approach to qualitative research, developed by Northcutt and McCoy at The University of Texas, which seeks to advance upon grounded theory. IQA reconciles quantitative Total Quality Management (TQM) rigor to a qualitative design of data collection and analysis. In fact, IQA unites quantitative and qualitative data collection and analysis by allowing for collection of participants’ own stories and of quantitative data to be conducted simultaneously. The core of the IQA methodology is a series of interdependent protocols that, when followed in a specific order, allows the researcher to identify themes and draw connections among the themes, based on a chosen phenomenon and based on collected

qualitative and quantitative data. When applying the IQA methodology, several phases are involved. These phases include: 1) Research Design; 2) Focus Group 3) Interviews; and 4) Reporting.

By utilizing protocols to develop research design, identify themes, and draw systems, IQA seeks to capture the reality of people's experiences through the mapping of their stories. This IQA study prompted the participants to examine issues with respect to the infertility experience. IQA built consensus among focus group participants by utilizing a unique approach in which the participants generated affinities (concepts/subject/topics) related to their infertility experience . Repeated affinities stated by the participants in focus groups will create the questions for the individual interview process.

An IQA study allows a group to create its own interpretive "map" and to construct individual "maps" of meaning; both individual and group maps are used by the researcher as the foundation for interpretation. The "map" is represented as a system of states (affinities) held together by roadways (relationships among affinities). Relationships are interconnected parts of a whole, so change in one part leads to changes among all parts and the system itself. IQA combines the tradition of phenomenology (which asks what is the structure and the essence of the experience of the phenomenon for the people in the study), and systems theory (which asks how and why does this system function as a whole). IQA asks two broad questions: 1) What are the dimensions of the phenomena from the participants' point of view; and 2) How do the dimensions relate to one another.

In this type of study, the questions initially considered may not necessarily be the questions the researcher ends up asking. In fact, due to the nature of these inductive and deductive group processes, a study might take a different direction based on the issues and points of interests the participants raise and with which they are most concerned. Therefore, those points of interest are used by the researcher to identify the appropriate questions to ask, thus in this context, questions are self-generated by the targeted audience for the study.

Hence, IQA is a method of qualitative research, which relies upon group processes, interviews, and observation to understand and explain naturally-occurring phenomena in a naturally-occurring state. In addition, data collection, and part of the data analysis are socially constructed by the participants under study, resulting in a theory grounded in the data. IQA is an approach to qualitative research that attempts to integrate and reconcile some of the disjuncture in theorizing about the purposes and methods of research.

The following is an overview of the IQA process used in this study based on the work of IQA founders, Northcutt and McCoy. A complete version of the methodology, along with charts and diagrams, is available in Appendix A.

IQA Methodology Overview

The IQA process combines focus groups, in-depth interviews, and in this particular research, surveys. This methodology involves a complex detailed process comprising four phases: Research Design, Focus Group, Interview, and Report.

The first phase, Research Design, involves articulation of problems of interest, identification of constituencies (participants) that have an interest in the problem, and formulation of research questions. In the second phase, Focus Groups are used to identify the elements (affinities) of a system and the relationships among those elements. Then, using a set of protocols, a system is drawn that represents a “mind-map” of the group’s reality. In the third phase, Interview, the affinities generated in the focus group are utilized to produce a protocol for interviews and surveys given to participants. Then they are transcribed, coded, and finally used to develop a system diagram used to explain the phenomenon. In the last phase, Report, affinities and their relationships are described, and comparisons among systems and individuals are made. The final phase includes Results/Analysis and Interpretation/Implications of the data.

Phase 1: Research Design

IQA research design starts with a “problem,” an issue that needs attention, which at this stage is not clearly defined. During this phase, the researcher starts with the general problem, and uses a protocol to identify those who have something to say about the problem (constituencies) and what question to ask them (an issue statement). Next, research design seeks to identify comparisons of constituencies useful to understanding the infertility experience.

The final result of the IQA Research Design Phase is the Focus Group Warm-up Exercise. This protocol uses guided imagery to ask the constituents to think about the phenomenon and provide a “dump” of thoughts.

Table 3.1: Research Problem

Scenario	
<p>Each year, millions of individuals discover that they are unable to bear children. About 15% of the US population is not able to conceive naturally and are diagnosed with infertility.</p> <p>Infertility is defined as the inability to either conceive or to carry a pregnancy to a live birth after a year or more of intercourse. Difficulty conceiving a child is often described as the ‘crisis of infertility,’ which deeply affects couples and individuals who wish to have a baby.</p> <p>Once diagnosed with infertility, some individuals give up easily in pursuing a biological child while many persist and go through heavy fertility treatments. People who pursue treatments find the process extremely difficult for many reasons ranging from financial issues to emotional reasons, to lack of information, to lack of support, to increased medical risks, to losses.</p> <p>Given the increasing numbers of couples dealing with infertility it would seem important to broaden our understanding of how the experience and the procedures associated with fertility treatments affect the involved individuals psychologically. Therefore, it is very critical to better understand the psychological toll of treatments for those who choose to continue, as well as of those who are forced to stop and find themselves choosing to remain childless or to pursue other venues in order to achieve parenthood. Understanding the reasons behind infertile people’s choice to pursue or not pursue treatments will enable this researcher to pinpoint the more difficult aspects of the process and to device tools aiming at assisting and helping these people during their journey to pursuing parenthood.</p>	
Role of the Researcher	Purpose of the Study
<input type="checkbox"/> Academic Researcher	<input type="checkbox"/> Academic Research
<input checked="" type="checkbox"/> Graduate Student	<input checked="" type="checkbox"/> Dissertation
<input type="checkbox"/> Consultant	<input checked="" type="checkbox"/> Solving a Problem
<input type="checkbox"/> Internal Organization Research	<input checked="" type="checkbox"/> General Understanding of a Problem
<input checked="" type="checkbox"/> Other: As future consultant	<input checked="" type="checkbox"/> Other: For future practical application
Readers/Users of the Study Results	
<ol style="list-style-type: none"> 1. People with Infertility Issues that need support intervention 2. Infertility clinics that might wish to provide support interventions or assistance 3. Consultants who want to provide assistance or interventions 4. Medical personnel who might be interested in ameliorating the IVF process 5. Researchers who are interested in new studies and in advancing theory 6. Academics who are interested in new studies and in advancing theory 7. Insurance Companies who look at new data to improve their service 8. Lawyers interested in medical and psychological wellbeing 9. Agencies interested in policy making 	
Problem Question	
Some infertile people stop the infertility treatments process, why?	
Domain	
Infertility Treatments	

Table 3.1: Research Problem (Continued)

Potential Causes of the Problem or Success		
♦ Beliefs	♦ Lack of Information Lack of	♦ Psychological health - stress
♦ Career	Support	♦ Religion
♦ Compassionate medical team	♦ Loss of fertility	♦ Societal expectations
♦ Coping and relaxation skills	♦ Loss of pregnancies	♦ Stress
♦ Cost	♦ Love for children	♦ Support
♦ Education	♦ Love kids	♦ The ability to have
♦ Fear of not perfect or health child	♦ Love/feelings	♦ Unable to cope
♦ Good/bad relationship	♦ Money	♦ Very demanding medical regimens
♦ Insurance	♦ Physical Health – age, treatment side effects	
♦ Know how to answer to people	♦ Preserve genes	
Constituency	Distance (Close to Far)	Power (High to Low)
Individual		
Infertile people	Close	Medium
Intermediary		
Family	Medium	Low
Friends	Medium	Low
Coworkers	Medium	Low
Counselors	Medium	Low
Nurses	Medium	Low
Authority		
Doctors	Close	Medium
Insurance agencies	Far	Medium
Counsels	Far	Medium
Policy makers	Far	Medium

The following table represents the results of the Research Design process.

Table 3.2: Research Design Results	
Problem:	Some infertile couples still pursue a child and others do not after many years of unsuccessful treatments. Why? Some infertile couples stop the infertility treatments process. Why? Understanding the reasons behind infertile people's choice to pursue or no longer pursue treatments to conceive.
Constituency:	Infertile Couples or Individuals who have undergoing IVF treatments or have stopped treatments.
Comparisons:	None
Phenomenon:	The Infertility Treatment Experience
Research Questions:	<ol style="list-style-type: none"> 1. What are the elements that make up The Infertility Treatment Experience? 2. How do these elements relate in a system of influence?
Issue Statement:	Tell me about The Infertility Treatment Experience.

Phase 2: Focus Groups

The Focus Group Phase is designed to generate the themes or affinities that make up the infertility experience. The purpose of this phase is to interact with members of the constituency in an effort to identify the affinities of the phenomenon.

The researcher conducted a total of three focus groups on The Infertility Treatment Experience, each lasting about an hour. The first two focus groups were used to identify the affinities of The Infertility Treatment Experience. Participants were recruited using flyers placed in medical clinics, as well as advertising online and through advertising with the RESOLVE community (a national infertility support group). Criteria for inclusion in the study were: individuals and couples who have been diagnosed with infertility and have decided to pursue, or were undergoing IVF treatments, as well as those who have experienced multiple IVF failures, were in the process of coping with the loss, and were evaluating alternatives. Eight to Ten individuals who had experiences with infertility and its medical treatments signed up for each focus group.

Although the majority of participants were females, at least two to three males were present in each meeting.

Identifying Affinities Focus Groups

Using a guided imagery warm-up exercise below, the participants in the first two focus groups were asked to reflect on, and write down on cards their thoughts on their experiences, one thought per card, and using as many cards as needed. Following the IQA method, the cards were then sorted and named.

Table 3.3: Focus Group Warm-up Exercise

I would like you to think for a while about The Infertility Treatment Experience.

In a few minutes, I am going to ask you to tell me about your experience with The Infertility Treatment Experience.

So let's begin.

- ◆ Please allow yourself to be as comfortable as possible.
- ◆ Put your thoughts from the day aside to allow your attention to focus on The Infertility Treatment Experience.
- ◆ Close your eyes to increase your state of relaxation and your ability to focus on The Infertility Treatment Experience.
- ◆ Now imagine yourself in The Infertility Treatment Experience. See yourself in all of the places The Infertility Treatment Experience occurs. (long pause)
- ◆ Imagine yourself across many years, both before and after diagnosing, during treatments, after treatments, (long pause)
- ◆ See all of the places, events and people The Infertility Treatment Experience. (long pause)
- ◆ See yourself engaging in the activities of The Infertility Treatment Experience. (long pause)
- ◆ Notice your surroundings. (long pause) Looking around you, take in the sights, the sounds that are associated with being in The Infertility Treatment Experience. (long pause)
- ◆ Allow yourself to become aware of your environment with all of your senses.
- ◆ Focus on what it feels like to be totally absorbed in The Infertility Treatment Experience. Be there in your mind. (long pause)
- ◆ Review all your recollections up to this moment. (pause)
- ◆ Allow all these thoughts to remain calmly in your consciousness and ready to be revealed.

Thank you for allowing these valuable observations and recollections to come forward.

Please allow yourself to gently allow your consciousness back to this time and place and when you are ready, open your eyes.

Good. Thank you.

And now, with all that you remember—and that is all that you just noticed—please write down your thoughts on these cards.

Write one thought or experience per card. Feel free to record a word, a phrase, a sentence, or a picture to capture that thought . . . and. . . Tell me about The Infertility Treatment Experience.

The researcher next facilitated a “clumping” and “naming” exercise in order to identify the affinities. Participants were asked to silently group affinities together by meaning (inductive coding) and to tape the index cards in groups on the wall, without any assistance. Grouping is followed by naming each group of cards (affinities) and then by the revision phase (axial coding). An affinity name is a general term that represents an experience to a group or individual when probed, and it should be simple enough to immediately trigger a response when asked by the interviewer the following question “ Tell me about (affinity name)". If they are too specific, renaming affinities is necessary.

Next, affinities were reconciled. The group worked together with the researcher to refine, reorganize, and narrow down the meanings of the affinities and their categories. Major categories were reviewed, and either combined or divided into hierarchical systems of sub-affinities. Affinities were given titles reflecting the meaning of the affinity. During this process, the members of a constituency defined the meaning and the range of the elements of the infertility experience and they articulated how these elements were connected. The researcher only facilitated drawing descriptions out of the group and organizing the descriptions into similar chunks. Therefore, a good affinity and description is a neutral presentation, free of bias.

Upon completing of the first two Focus Groups, the researcher reconciled the affinity names and developed a preliminary Affinity List.

Table 3.4: Focus Group Reconciled Affinity Names		
Focus Group #1	Focus Group #2	Reconciled Name
Process	Medical	Treatment/Process
Emotions Injustice/Unfair Self-esteem	Emotions	Emotions Injustice/Unfair
Knowledge/Information	Knowledge/Information	Knowledge/Information
Relationships	Relationships Family/Friends	Relationships Spouse/Partner Family Friends Coworkers Support Groups Communication?
Finances	Finances	Cost/Finances Money Insurance
Life balance	Time	Time Age Length of Process Biological Cycles
Diagnosis		Diagnosis
Loss	Miscarriage/ Loss	Results Miscarriage/ Loss
Doctors		Medical Staff
Control		Control / Power Over Situation Wealth?
	Religion	
	Positives	
	Pursuing	

To gather the most comprehensive data, IQA recommends conducting two focus groups with different participants of the same constituency and then reconciling the two sets of affinities. For this study, the researcher held a total of three focus groups. The first two focus groups allowed the researcher to generate and reconcile the affinities relevant to the constituency, whereas the last group enabled the researcher to refine and validate the final affinity names, provide data for sub-affinities and provide theoretical codes in order to build a preliminary system. Using the same process used to identify affinities, the research conducted a guided imagery and asked the participants to tell the researcher about each affinity. With each affinity, participants were asked about their experience, and to provide cards. Cards for each affinity were collected and combined

with the cards from the previous two focus groups. The researcher next sorted and named sub-affinities. Finally, participants were given an Affinity Relation Table (ART) and asked to provide theoretical coding so that the researcher could draw a preliminary system. The following table identifies the final list of Affinities and Sub-Affinities.

Table 3.5: The Infertility Treatment Experience Sub-Affinities

Affinity	Sub-Affinities	
Medical Staff	<ul style="list-style-type: none"> ◆ Doctors ◆ Fertility Specialists ◆ Surgeons ◆ Physician Assistants 	<ul style="list-style-type: none"> ◆ Nurses ◆ Lab Techs ◆ Office Staff
Diagnosis	<ul style="list-style-type: none"> ◆ Diagnostic Labs & Tests ◆ Ovulation ◆ Sperm ◆ Genetic / Physiological 	<ul style="list-style-type: none"> ◆ Medical History (Medications, Trauma, Disease, etc.) ◆ Unexplained Infertility ◆ Doctors' Opinions
Fertility Treatments & Process	<ul style="list-style-type: none"> ◆ Treatment Labs & Tests ◆ Treatment Preparation & Scheduling ◆ Medication ◆ Diet 	<ul style="list-style-type: none"> ◆ Rest ◆ Surgery ◆ Assisted Reproductive Technology (ART) ◆ Alternative Medicine
Cost/Finances	<ul style="list-style-type: none"> ◆ Insurance ◆ Medical Bills ◆ Medication Cost ◆ Out of Pocket Expenses 	<ul style="list-style-type: none"> ◆ Loans ◆ Sacrifice ◆ Missed Work
Knowledge/Information	<ul style="list-style-type: none"> ◆ From Medical Staff ◆ From the Web ◆ From Family & Friends ◆ From Support Groups 	<ul style="list-style-type: none"> ◆ From Books ◆ Asking Questions ◆ Understanding Information
Treatment Outcome	<ul style="list-style-type: none"> ◆ Medical Conditions Treated ◆ A Baby ◆ Miscarriage / Loss ◆ Continuing Fertility Treatments 	<ul style="list-style-type: none"> ◆ Donors ◆ Surrogacy ◆ Adoption ◆ Living Childfree
Time	<ul style="list-style-type: none"> ◆ Years Trying ◆ Schedules / Cycles 	<ul style="list-style-type: none"> ◆ Waiting ◆ Biological Clock
Empowerment / Choices	<ul style="list-style-type: none"> ◆ Seeking Information ◆ Choosing Doctors ◆ Choosing Treatments ◆ Controlling Cost 	<ul style="list-style-type: none"> ◆ Controlling Diet ◆ Control Over Body ◆ Support / Sharing ◆ Choosing How Far to Go
Relationships	<ul style="list-style-type: none"> ◆ Spouse / Partner ◆ Family ◆ Friends 	<ul style="list-style-type: none"> ◆ Co-workers ◆ Support Groups ◆ Medical Staff
Emotions	<ul style="list-style-type: none"> ◆ Anger ◆ Frustration ◆ Anxiety / Fear ◆ Stress ◆ Isolation / Lonely ◆ Insecurity / Self-esteem ◆ Jealousy / Unfair ◆ Depression 	<ul style="list-style-type: none"> ◆ Sorrow / Grief ◆ Coping ◆ Hope ◆ Love ◆ Excitement ◆ Happiness / Joy ◆ Acceptance

Phase 3: Interviews

The outcome of the Focus Group phase provides the foundation for the Interview phase of the IQA methodology. IQA interviews were conducted privately, one-on-one, and conducted either in person, or remotely through telephone or videoconference. Like participants of the Focus Group or Affinity Production Interviews, interview participants were also members of the constituency.

The IQA interview was an open-ended semi-structured interview. The affinities produced by the focus group were used to create the interview protocol. Interviews were structured with the same questions around affinities and were discussed in a prescribed order. The goal of the interview was to collect highly detailed and personal qualitative information about each affinity and sub-affinity—information impossible to collect during the previous phase but critical to the creation of the system. The purpose of the interviews was to add richness and depth to the meaning of the affinities by eliciting more complete descriptions of them, and to identify relationships among them. The interview process was designed with the goal of gathering data regarding people's experience of the phenomenon, to provide data representing the respondent's personal mind-map, to help code the affinities so that a system influence diagram can be created, and to provide data representing the group's collective mind-map (SID) so that a group system diagram can be developed as well.

The interview protocol consisted of two parts: 1) the open-end axial interview designed to provide rich description of affinities by the respondents; and 2) the structured theoretical interview designed to identify relationships between affinities.

The axial part of the interview was structured by affinity and sub-affinity, but otherwise open-ended. In addition, participants also rank their experiences with each affinity and sub-affinity on a scale of "Very Negative" to "Very Positive." "Not Applicable," or N/A, was also an option. The details collected during the axial part of the interview coat each affinity and sub-affinity with the lived experiences of participants.

Whereas the axial part of the interviews was designed to bring affinities and sub-affinities to life with rich and relevant histories and experiences, the theoretical part of the interviews was designed to identify potential relationships among affinities. During this step, affinities are recorded in the Affinity Relationship Table (ART), which is the basis for the theoretical interview and provides a quick reference for all of the possible relationships between affinities. Participants are presented with a copy of the table and are asked to identify and explain the nature of the relationship among all possible pairs of affinities by illustrating their experiences with the relationship. For any two affinities A and B, there are only three possible relationships: either A directly influences B, B directly influences A, or there is no direct influence between A and B.

The final result of the Interview Phase is a collection of transcripts for each respondent.

Of the fifty people initially recruited, thirty-four participants were interviewed. The interviewees were recruited using flyers, using advertising on social media and through the researcher's professional and personal network. Participants were asked to be part of the entire data collection, which included both focus group participation and interviews, or to be part of either one of the activities. All interviewees were individuals and couples who were experiencing infertility and were undergoing treatments or had already been under treatments. A combination of twenty-eight women and six men were interviewed. An additional four males and five females participated only in the survey ratings and the relationships identification presented in the theoretical part of the interview. The researcher used the IQA method to conduct and transcribe the interviews.

The following Protocol was used in the interview process. The demographic and infertility survey were provided ahead of time for the participants to fill in. Participants were given a copy of the IQA Interview Protocol so that they could follow along. Participants were asked the following question for each affinity and sub-Affinity, "*Tell me about...*" At the end of each description, participants were asked to rate the affinity.

Demographics	
Please complete the following demographic survey	
What is your gender?	
<input type="checkbox"/>	Male
<input type="checkbox"/>	Female
What is your age range?	
<input type="checkbox"/>	18-25
<input type="checkbox"/>	26-30
<input type="checkbox"/>	31-35
<input type="checkbox"/>	36-40
<input type="checkbox"/>	41-45
<input type="checkbox"/>	46-50
<input type="checkbox"/>	50+
Race	
<input type="checkbox"/>	White
<input type="checkbox"/>	Hispanic or Latino
<input type="checkbox"/>	Black or African American
<input type="checkbox"/>	Native American or American Indian
<input type="checkbox"/>	Asian / Pacific Islander
<input type="checkbox"/>	Other
What is your current marital status?	
<input type="checkbox"/>	Single, Never Married
<input type="checkbox"/>	Married
<input type="checkbox"/>	Cohabiting
<input type="checkbox"/>	Separated
<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Widowed
<input type="checkbox"/>	Remarried
Highest Level of Education Completed	
<input type="checkbox"/>	Did not Complete High School
<input type="checkbox"/>	High School Diploma
<input type="checkbox"/>	Undergraduate Degree
<input type="checkbox"/>	Masters Degree
<input type="checkbox"/>	Doctorate Degree

Demographics (Continued)

Employment Status: Are you currently...?		Full-Time	Part-Time
<input type="checkbox"/>	Employed for Wages	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Self-Employed	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Military	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Homemaker	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Student	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Out of Work and Looking for Work		
<input type="checkbox"/>	Out of Work but not Currently Looking for Work		
<input type="checkbox"/>	Unable to Work		
<input type="checkbox"/>	Retired		
What is your level of income			
<input type="checkbox"/>	Under \$15,000		
<input type="checkbox"/>	\$15,000 – \$24,999		
<input type="checkbox"/>	\$25,000 – \$34,999		
<input type="checkbox"/>	\$35,000 – \$49,999		
<input type="checkbox"/>	\$50,000 – \$74,999		
<input type="checkbox"/>	\$75,000 – \$99,999		
<input type="checkbox"/>	\$100,000 and Above		
What is your religion			
<input type="checkbox"/>	Christian		
<input type="checkbox"/>	Jewish		
<input type="checkbox"/>	Buddhist		
<input type="checkbox"/>	Islamic		
<input type="checkbox"/>	Hindu		
<input type="checkbox"/>	Atheist		
<input type="checkbox"/>	Agnostic		

Infertility Survey

1. How many people currently live in your household including you?
2. How many years have you been living with your current spouse/partner?
3. Have you ever been pregnant?
☐Yes ☐No
If yes, how many times?
4. Have you ever given birth to an infant?
☐Yes ☐No
If yes, how many infants?
5. Have you ever had a miscarriage, or a fetus or newborn that did not survive?
☐Yes ☐No
If yes, how many times?
6. Are you pregnant at this time?
☐Yes ☐No
7. Are you trying to get pregnant at this time?
☐Yes ☐No
 - a. If you are trying to get pregnant, please indicate in years how long have you been trying.
 - b. If you have been trying to get pregnant for less than one year, please indicate in months how long you have been trying.
 - c. If you are not currently trying to get pregnant, please indicate in years how long ago it was since you tried.
 - d. If it has been less than one year since you last tried to get pregnant, please indicate in months how long ago it was since you tried.
8. Have you ever been told by a physician you were infertile?
☐Yes ☐No
If yes, please indicate when you were diagnosed

9. Which of the following best describes what you have been told is the cause of your infertility?

- ☐ Female factor
- ☐ Endometriosis
- ☐ Polycystic ovary syndrome
- ☐ Male factor
- ☐ Combined male and female factor
- ☐ Unexplained
- ☐ Other, explain _____

Please indicate when you or your partner were diagnosed

10. Are you currently undergoing infertility treatments?

- ☐ Yes ☐ No

If yes, please check which of the following treatments you are undergoing

- ☐ Stimulating Medications (Clomid, Serophene)
- ☐ Intrauterine Insemination (IUI)
- ☐ Controlled Ovarian Hyper-stimulation (Injecting gonadotropins)
- ☐ In-vitro Fertilization (IVF)
- ☐ Other, Explain _____

11. How long have you been undergoing treatments?

Please indicate what type of treatments you have been undergoing

12. If you are undergoing treatments, how many and which procedures have you been undergoing?

13. Have you tried counseling or any type of psychological therapy?

- ☐ Yes ☐ No

If yes, please describe

14. Have you tried Alternative Medicine?

- ☐ Yes ☐ No

If yes, please describe

15. Are you currently a member of an infertility support group?

- ☐ Yes ☐ No

If yes, please list name or location of group or organization

The Infertility Treatment Experience Interview Protocol

Interview Part 1

In a few minutes, I am going to ask you to tell me about your involvement with the Fertility Treatment Experience. Focus groups have identified several common themes or affinities that describe their experiences in the Fertility Treatment Experience. Each of these themes is further broken down into small components or sub-affinities. We'll talk about each theme in pretty heavy details in just a minute. So, just relax and think of your experiences with Infertility and Fertility Treatments. Imagine yourself from the first day of the Fertility Treatment to now. See all of the places, events and people that are part of the Fertility Treatment Experience. See yourself engaging in the activities of the Fertility Treatment Experience. Let's look at each of these themes one at a time and tell me about your experiences with these. Next rate your overall experience with each affinity.

Medical Staff						
Medical Staff describes the people involved during the Fertility Treatment Experience. Describe your experience with each of these components of Medical Staff.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Doctors	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Fertility Specialists	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Surgeons	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Physician Assistants	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Nurses	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Lab Techs	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Office Staff	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Medical Staff Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Diagnosis						
Diagnosis describes the diagnosis experience and various types of diagnosis for the Fertility Treatment Experience. Describe your experience with each of these components of Diagnosis.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Diagnostic Labs & Tests	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Ovulation	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Sperm	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Genetic / Physiological	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Medical History (Medications, Trauma, Disease, etc.)	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Unexplained Infertility	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Doctors' Opinions	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Diagnosis Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Fertility Treatments & Process						
Fertility Treatments & Process describes the various types of treatments that may be part of the Fertility Treatment Experience.						
Describe your experience with each of these components of Fertility Treatments & Process.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Treatment Labs & Tests	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Treatment Preparation & Scheduling	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Medication	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Diet	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Rest	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Surgery	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Assisted Reproductive Technology (ART)	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Alternative Medicine	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Fertility Treatments & Process Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Cost / Finances						
Cost / Finances describes the different types of expense incurred during the Fertility Treatment Experience.						
Describe your experience with each of these components of Cost / Finances.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Insurance	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Medical Bills	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Medication Cost	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Out of Pocket Expenses	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Loans	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Sacrifice	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Missed Work	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Cost / Finances Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Knowledge / Information						
Knowledge / Information describes how one gets information and from what sources information is acquired during the Fertility Treatment Experience. Describe your experience with each of these components of Knowledge / Information.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
From Medical Staff	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
From the Web	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
From Family & Friends	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
From Support Groups	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
From Books, journals, etc.	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Asking Questions	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Understanding Information	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Knowledge / Information Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Treatment Outcomes						
Treatment Outcomes describes the various outcomes of the Fertility Treatment Experience. Describe your experience with each of these components of Treatment Outcomes.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Medical Conditions Treated	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
A Baby	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Miscarriage / Loss	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Continuing Fertility Treatments	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Donors	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Surrogacy	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Adoption	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Living Childfree	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Treatment Outcomes Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Time						
Time describes the urgency various aspects of time during the Fertility Treatment Experience. Describe your experience with each of these components of Time.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Years Trying	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Schedules / Cycles	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Waiting	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Biological Clock	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Time Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Empowerment / Choices						
<p>Empowerment / Choices describes the degree of control or power over the situation one might have over the Fertility Treatment Experience.</p> <p>Describe your experience with each of these components of Empowerment / Choices.</p>						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Seeking Information	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Choosing Doctors	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Choosing Treatments	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Controlling Cost	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Controlling Diet	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Control Over Body	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Support / Sharing	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Choosing How Far to Go	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Empowerment / Choices Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Relationships						
Relationships describe the various relationships that make up the Fertility Treatment Experience. Describe your experience with each of these components of Relationships.						
	Not Applicable	Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Spouse / Partner	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Family	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Friends	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Co-workers	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Support Groups	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Medical Staff	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall Relationships Experience		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Emotions						
Emotions describe the possible range of emotions felt during the Fertility Treatment Experience. Describe your level of experience with each of these components of Emotions.						
	Not Experienced	Very Low Very High				
Anger	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Frustration	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Anxiety / Fear	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Stress	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Isolation / Lonely	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Insecurity / Self -esteem	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Jealousy / Unfair	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Depression	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Sorrow / Grief	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Coping	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Hope	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Love	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Excitement	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Happiness / Joy	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Acceptance	<input type="checkbox"/> N/A	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
		Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
Overall Emotions Experience		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	1	2	3	4	5
--	---	---	---	---	---

Overall Infertility Treatment Experience				
Very Negative Experience	Negative Experience	Neutral Experience	Positive Experience	Very Positive Experience
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Interview Part 2

In the second part of the interview the researcher used the following text:

Many of the themes or affinities have some kind of relationship; one effects or causes the other. They can relate to each other in one of 2 ways: either A influences B or B influences A or no relationships. Let's look at each theme and decide if or how it relates to each other theme. Tell me about your experiences with such relationships. Please give specific examples of how the relationships have affected your experience.

The researcher then presented the interviewees with this survey information:

Affinity Name	Possible Relationships
1. Medical Staff	$A \rightarrow B$
2. Diagnosis	$A \leftarrow B$
3. Fertility Treatments & Process	$A \times B$ (No Relationship)
4. Cost / Finances	
5. Knowledge / Information	
6. Treatment Outcomes	
7. Time	
8. Empowerment / Choices	
9. Relationships	
10. Emotions	

Affinity Relationship Table					
Affinity Pair Relationship			Affinity Pair Relationship		
1	2		3	4	
1	3		3	5	
1	4		3	6	
1	5		3	7	
1	6		3	8	
1	7		3	9	
1	8		3	10	
1	9		4	5	
1	10		4	6	
2	3		4	7	
2	4		4	8	
2	5		4	9	
2	6		4	10	
2	7		5	6	
2	8		5	7	
2	9		5	8	
2	10		5	9	

Phase 4: Report

The last phase of an IQA study is the report, which incorporates the descriptions of the affinities produced by the respondents, the respondents' judgments of the cause-and-effect relationships among the affinities, and the comparison of systems developed from the affinities, both at an aggregate level and at an individual level, and for this study the surveys statistical results. Reporting consists of presenting the final Systems Influence Diagram, sharing results and analysis, and documenting interpretation and implications. Each shape is brought to life through constituents' stories and the lines drawn to and/or from it. Through reporting, loops and recursions are potentially given names and examined in detail. The research may suggest that a change or manipulation with one affinity may or may not impact one or more other affinities. IQA reporting closes the study not by solving a problem or proving a hypothesis, but by illustrating a phenomenon, identifying its components, and clarifying how they influence one another.

A brief description of this phase of the IQA methodology reported in subsequent chapters is as follows.

To systematically approach the report, the process is split in two parts (1) Results / Analysis and (2) Interpretation / Implications. The Results/Analysis parts will be reflected in Chapter 4 and 5, with the addition of a quantitative analysis in Chapter 6. The Interpretation/Implication occurs in Chapter 7.

In the IQA Results / Analysis chapter (Dissertation Chapter 4, 5, and 6) the researcher describes the affinities and the systems in the participants' voice, and presents the data free of interpretation. Through a rigorous use of protocols, transcripts are coded and systems are drawn. The story of each constituency group is told by aggregating axial codes of each affinity to tell the story of the group as a whole, and the system is built one relationship at a time by aggregating theoretical codes. The resulting report is an Axial Write-up, Theoretical Write-up and presentation of the Systems Influence Diagram (SID).

During the Results / Analysis Phase of the IQA report, raw transcripts are processed through a series of protocols designed with the purpose of identifying the meaning of each affinity. First, all interviews are transcribed word for word. The transcripts are formatted for quick identification of the sections. Then transcripts are edited to remove all spoken-word stumbles, poor grammar, and to remove personal identifiers. This phase also produces the relationship-by-relationship building of the composite system while telling the group story of how each affinity is related to the others.

Axial Coding

After the transcripts are prepared, axial coding takes place. The researcher examines the interview transcript, finds all statements that define a specific affinity and records the line numbers and affinity numbers in the Individual Interview Axial Code Table (ACT). The ACT is the primary documentation for all utterances that illustrate the range of meaning of each affinity for each respondent. Once all interviews are coded, the data from the interviews are summarized to create a composite of the individuals' experience with the phenomenon. Axial data are then transferred from each individual interview Axial Code Table to a Combined Interview Axial Code Table, which represents a composite of the individuals' experiences. A database for all respondents containing all Axial Codes for all affinities is produced, with each code containing a link or a reference to the transcript and line numbers that produced the code.

Composite Affinity Descriptions: The Affinity Write-up

Next, the Affinity Write-up takes place. The IQA Affinity Write-up is a composite story of the group. The researcher organizes all the interviews so that they tell the story of the group as a whole. Following the same rationale and process used to identify affinities with a focus group, quotes are organized into common themes using a "Dump, Clump, Name, Organize" procedure. In the "Dump" phase, each quote for each affinity is isolated. In the "Clump" phase, the researcher clumps together similar themed quotes. In the "Name" phase, the researcher gives

each theme a meaningful name. In the “Organize” phase, multiple quotes for each sub-affinity are woven together to develop a composite quote. The role of the researcher is to organize the data so that it tells the group’s story and is interesting to the reader.

Theoretical Coding

Theoretical Coding refers to ascertaining the perceived cause and effect relationships among all the affinities in a system by developing hypotheses grounded in the data. A rigorous protocol is used to create a picture of the system (Systems Influence Diagram or SID) that represents the mind-map of an individual or group with respect to a phenomenon represented by the issue statement.

During this process, the researcher analyzes the text of the interviews for axial codes to find relationships among affinities – theoretical coding. The Theoretical Codes are recorded in an Individual Interview Theoretical Code Table (TCT), which captures both directionality of relationships as well as descriptive explanations of how the relationships work in the respondent’s words. The TCT table is the primary documentation for all utterances that illustrate how the affinities are related for each respondent.

Once all interviews have been coded, theoretical data are transferred from each Individual Interview Theoretical Code Table to a Combined Interview Theoretical Code Table. This combined table represents a database of all the Theoretical Codes for all affinities, with each code containing a link to the transcript and line numbers that produced the code.

The Interrelationship Diagram (IRD)

Theoretical coding of the affinities results in an Interrelationship Diagram (IRD). An Interrelationship Diagram or IRD is a table that represents all the relationships among the affinities. The IRD displays arrows that show whether each affinity in a pair is a perceived cause

or an effect or that no relationship exists between the affinities in the pair. A sample of such diagram can be seen in Appendix A.

The System Influence Diagram (SID)

The ultimate goal of an IQA study is to draw a mind-map or System Influence Diagram (SID), which is a visual representation of an entire system of influences and outcomes. The SID is the simplest representation of all the relationships contained in the IRD. The SID may be considered as a set of qualitative structural equations or as a path diagram; however, unlike traditional path diagrams, a SID diagram allows for loops. A feedback loop contains at least three affinities and has no beginning and no end. The SID is a visual representation of the “theory in perception,” grounded in the specific experiences and logic of the participants.

IQA Report (Interpretation / Implications)

In the IQA Interpretation / Implications chapter (Chapter 7) the researcher begins to make comparisons and draw conclusions based on the data into the two larger contexts of theory (conceptual implications) and application (pragmatic implications). Here, the researcher interprets the data, suggests interventions and introduces other literature that reinforces the results. The researcher draws inferences, makes predictions, and suggests interventions that could change the outcome of the system. The researcher re-engages with the literature to accomplish two goals: first, to re-interpret the literature reviewed in chapter 2 in the light of what has been learned, and second, to identify other areas of literature that now have relevance in the light of what has been learned. The applications section of this chapter will look into finding the pragmatic utility of the study.

CHAPTER 4: ANALYSIS OF THE INFERTILITY TREATMENT EXPERIENCE SYSTEM ELEMENTS

This chapter focuses on the Axial coding in which the quotes from participants will be organized by their affinity. As described earlier, the participants came up with the affinities/themes during the focus group. An interview with standardized questions was created based on the affinities/themes and sub-affinities generated by the participants.. Interviews were transcribed verbatim from the audio recordings of all interviews. The researcher edited transcriptions only to for confidentiality purposes (e.g., replacing “Dr. Smith” with “my doctor”.) Quotes from interviews across participants were then paired with the affinities/themes that the participants generated and reported in this chapter,

Put another way, the composite affinity descriptions are the quotations from multiple participants organized in meaningful ways in order to frame their stories, thoughts, and opinions about the system. Composite affinity descriptions are organized by affinity and sub-affinity and are essential to capturing the “essence” of what is really happening during the Infertility Treatment Experience.

The following section is a composite description of the affinities and sub-affinities based on quotes obtained from all the interviews. The quotes about any particular sub-affinity were grouped together into common tables. This chapter is designed to tell the story in the participant’s own words, therefore, the description of each affinity is free of researcher commentary and interpretation. The interconnections among the affinities/themes and sub-affinities will be provided in Chapter 7.

Table 4.1: The Infertility Treatment Experience Sub-Affinities

Affinity	Sub-Affinities	
Medical Staff	<ul style="list-style-type: none"> ◆ Doctors ◆ Fertility Specialists ◆ Surgeons ◆ Physician Assistants 	<ul style="list-style-type: none"> ◆ Nurses ◆ Lab Techs ◆ Office Staff
Diagnosis	<ul style="list-style-type: none"> ◆ Diagnostic Labs & Tests ◆ Ovulation ◆ Sperm ◆ Genetic / Physiological 	<ul style="list-style-type: none"> ◆ Medical History (Medications, Trauma, Disease, etc.) ◆ Unexplained Infertility ◆ Doctors' Opinions
Fertility Treatments & Process	<ul style="list-style-type: none"> ◆ Treatment Labs & Tests ◆ Treatment Preparation & Scheduling ◆ Medication ◆ Diet 	<ul style="list-style-type: none"> ◆ Rest ◆ Surgery ◆ Assisted Reproductive Technology (ART) ◆ Alternative Medicine
Cost/Finances	<ul style="list-style-type: none"> ◆ Insurance ◆ Medical Bills ◆ Medication Cost ◆ Out of Pocket Expenses 	<ul style="list-style-type: none"> ◆ Loans ◆ Sacrifice ◆ Missed Work
Knowledge/Information	<ul style="list-style-type: none"> ◆ From Medical Staff ◆ From the Web ◆ From Family & Friends ◆ From Support Groups 	<ul style="list-style-type: none"> ◆ From Books ◆ Asking Questions ◆ Understanding Information
Treatment Outcome	<ul style="list-style-type: none"> ◆ Medical Conditions Treated ◆ A Baby ◆ Miscarriage / Loss ◆ Continuing Fertility Treatments 	<ul style="list-style-type: none"> ◆ Donors ◆ Surrogacy ◆ Adoption ◆ Living Childfree
Time	<ul style="list-style-type: none"> ◆ Years Trying ◆ Schedules / Cycles 	<ul style="list-style-type: none"> ◆ Waiting ◆ Biological Clock
Empowerment / Choices	<ul style="list-style-type: none"> ◆ Seeking Information ◆ Choosing Doctors ◆ Choosing Treatments ◆ Controlling Cost 	<ul style="list-style-type: none"> ◆ Controlling Diet ◆ Control Over Body ◆ Support / Sharing ◆ Choosing How Far to Go
Relationships	<ul style="list-style-type: none"> ◆ Spouse / Partner ◆ Family ◆ Friends 	<ul style="list-style-type: none"> ◆ Co-workers ◆ Support Groups ◆ Medical Staff
Emotions	<ul style="list-style-type: none"> ◆ Anger ◆ Frustration ◆ Anxiety / Fear ◆ Stress ◆ Isolation / Lonely ◆ Insecurity / Self-esteem ◆ Jealousy / Unfair ◆ Depression 	<ul style="list-style-type: none"> ◆ Sorrow / Grief ◆ Coping ◆ Hope ◆ Love ◆ Excitement ◆ Happiness / Joy ◆ Acceptance

Medical Staff

Medical staff comprises a number of specialists and health care workers. They are responsible for the quality of medical care provided to patients. Based on the position they held they have different roles varying from taking direct care of a patient, to administering drugs and procedures, to running tests, to taking care of the medical bills and the administrative paper work. The sub-affinity titles and interview responses are listed in the following order.

- ◆ Doctors
- ◆ Fertility Specialists
- ◆ Surgeons
- ◆ Physician Assistants
- ◆ Nurses
- ◆ Lab Techs
- ◆ Office Staff

Doctors

The initial doctors were rather dismissive or quick to put my experience in a box

“The initial doctors were rather dismissive or quick to put my experience in a box. I felt that I was not really treated like an individual. To one doctor I brought a lot of data I had started charting, temperatures that I had been reading and information about what is going on in my body. I had done all this work and I was hoping for a little more analysis, but she did not really look at them and first thing she said was to put me on Clomid. That turned me off because this was just after a year of trying and I felt that maybe there will be some other things we could do before I go on medication. So I did not go back to her. I just tried looking for regular primary care physician who maybe did some other lower intervention, things like just look into my structure to see if there are any structural problems going on. It was a bit of a journey trying to find somebody that takes time.”

“The last doctor blew my symptoms off. There were thyroid symptoms and she just blew them off and then I lost the baby. When I went back I asked her to run a bunch of tests, because I

researched all of these different causes of her death and came up with a list of tests I wanted to have done, she was hesitant about it because she said that was just one miscarriage and usually they do that for multiple. But this is a mid-pregnancy miscarriage, which is why I was pushing it. I decided to go to my general practitioner. I got a physical, a full thyroid panel done, and I had evidence of Hashimoto disease. She referred me to an endocrinologist [who] confirmed it. The doctors just kind of leave me an empty feeling. This is how it is. Ok. We will see you later. And I need something else to give me, a definite, something to look forward to.”

“I saw a number of doctors, some more helpful than others. Initially they were kind of dismissive, they said “Oh, you are young. You should not have any problems. We will figure this out.” It was not as comforting as they intended because it felt they did not take me seriously. My OBGYN was the one more dismissive. Then I saw a RE that I did not like. She did not take the time to get to know us. It took a while before they took me seriously and I was able to find a doctor I really liked who seemed to understand what was going on, she was comforting and took the time to talk to us.”

“Our fertility issues are not really with me, so I have mostly had well woman exams. That said, I have had some pretty nasty experiences with doctors. I remember that last one I was in a well woman exam she said I had put on a lot of weight and I said, “My father died I have had a rough year, it has been a bad year” and then I said “I had some strange periods and I wanted to ask you about that because we are trying to get pregnant and there has been some spotting in between so I wanted know if I should be worried, if is there something we should test.” She said: “No it is probably fine, if nothing happens next couple of months, it is probably not a big deal.” That was it but, I got a bill a month later that charged me for an extra exam because we talked about my weight and I was wondering how is that discussing my weight and whether or not that might be affecting my periods during my well woman exam not related to my reproductive health? I had to go through these things with the insurance, it was a 25 dollars co-pay, it was not a big deal and I could afford it, but why are you charging me for an extra exam? It is stuff like that with doctors, it is totally impersonal, they do not care about me or about my health at all really.”

“When we initially decided to have kids she went to our physician – we did not have an OB or anybody like that because we were twenty-three at the time, we were super young. It is just interesting how walking back out of the process how little just a general practitioner knows, she did not really know if my wife had cysts if she had PCOS, or if she had endometriosis. She just figured she was having miscarriages, so there is definitely a gap of thinking in knowledge or she was slow to realize that. I think of our fertility as there is two different sections Minnesota and Texas, so completely different sets of doctors. Down here we went to an OB/GYN. She just wanted us to get straight into IVF and do all that and we were “Well, let us figure out what is wrong with her, we are just not going direct in everything”. So two very different experiences, doctor in Minnesota was young, doctor here super well-established, but both of them did not really quite get it.”

Most of the doctors had crystal glasses and would always push you towards doing more fertility treatments

“The doctors were not as helpful as I would like. Most of the doctors had crystal glasses and would always push you towards doing more fertility treatments and they would not give you the statistics, they would basically say that there is a good chance. The most blatant experience was when we first began the infertility treatments. One doctor continued to do the IUI process over and over again and it never worked and when we went to the next doctor, the next doctor said he does not understand why the other doctor was even continuing through that process, because it was a useless endeavor. I wish they would have provided more guidance. Maybe that is through education, maybe that’s through hard truth, if there’s hard truth that needs to be told. Again I think I blame that mostly on the doctors; to the extent the others could have helped in that process. I think they all take a little blame.”

“We only went to one doctor. I had some sort of pre-pregnancy checkups and they said that everything was fine. I had been diagnosed with polycystic ovarian syndrome fourteen years ago. But what they describe polycystic ovarian syndrome now is not the same as what I was diagnosed with. I do not have any of the normal markers. I am not overweight, I am not super

hairy and I do not have any of those. It took them six months to figure out what my overwhelming pain was. I was having regular cycles, but I was releasing more than one egg at a time and when they did an ultrasound of my ovaries, it looked like a bunch of grapes. This is back when I was sixteen. They called that polycystic ovarian syndrome, which makes sense to me because all the follicles were causing cysts on the ovaries. Now what they are calling polycystic ovarian syndrome is a lack of ability to ovulate. So, I am not sure what to call what I went through. So, I had this awareness this might be hard for me or I might be prone to multiples. The first time I got pregnant I was actually on birth control, I was advised not to continue it for a variety of reasons, and I was not ready, I was eighteen. I figured that when I was ready to get pregnant, it would not be a problem, obviously that would be fine. Our first real doctor experience was getting my husband checked out, you start there first to see if there is something going on because that is easier and less invasive. Healthiest man I have ever met in my life... non-obstructive azoospermia. He does not make sperm at all, zero, none. They tried hormones and things like that to stimulate him, but there is nothing. So, the only doctor besides my regular gynecologist and the people years ago who said well this might be a problem, was the urologist and he was great. He was the one who diagnosed him. Actually we did not see a fertility specialist. He said, "I can put you in touch with all these people and do all these options" but our insurance does not cover any; it covers infertility diagnosis but no treatment. We do not have whole lot of money. Sperm is pretty easy to come by depending on how flexible you want to be about getting it. So we were exploring other options and saving up money before we have to say, "Well what else do we want to go through?" I feel like there was a little bit of pressure to pursue more mainstream western approaches. I think there was little bit of pressure like, "Well, hey what have we got to lose?" and I am like, "Well, you know twenty thousand dollars on a less than 5% chances." That is a lot of stress, that is a decent amount to lose. So I felt there was a little bit of pressure there of the doctor relating to us almost too much. But otherwise he was really great."

I really liked the guy personally but he did not do very well by me medically

“The first doctor that I saw when I was concerned about not being able to get pregnant was my gynecologist. We have been trying for eight months. I told him that before another doctor had mentioned I probably had PCOS and he agreed that I probably did. He offered to put me on Clomid for several rounds unmonitored; just gave me the prescription and sent me home. I went home believing that it was not really that big of a problem and I had read Clomid had helped other people. Back then I was grateful he prescribed that, but since I have come to think he was probably well meaning but I do not think that was the best treatment option. I wished I had been more willing to go to a reproductive endocrinologist from the first. I was afraid that going was admitting that you really have a problem; so I did not. I did five rounds of Clomid unsuccessfully, I got pregnant once but I miscarried very early on. And since I have found out that can be a side effect of Clomid because it thins the uterine lining so you get pregnant but then you cannot carry it. Then he referred me to another doctor, a RE, in the same building. It has not been great. I know that some people have developed a relationship with their doctors, they like them and believe everything they say and they just hung on their every word almost like a religious leader. I definitely have not felt that. I really liked the first guy personally but he did not do very well by me medically. I am sure if it had worked then I would feel much better about my experience with the first doctor. So I think it all comes down to one really know how it all feels until we get a result one way or another.”

“For a couple of years prior to even trying I just had regular experiences with my doctors. The OB did the initial work up and then after we had been trying for certain amount of time, she referred me to the RE. I started seeing the RE and we did a couple of cycles medicated with Femara. There was no diagnosis at that time. They said “everything works great, I am sure you will have no problem.” I had been trying for a year by then, so obviously we were having a problem, but they could not find any medical reason.”

“With my daughter, I have been trying to get pregnant for five years and it just was not happening. I had gone to some doctors and they just told me I needed to keep trying, because I

was still relatively young at the time. I finally got referred to an OB/GYN doctor here. With him, it was a relief because as soon as I went in he started listening to me about the pain I was having every month with my menstrual cycle. He immediately did an ultrasound and saw two cists and could feel the endometriosis. He did a surgery, did a couple of IUIs, we were trying on our own and got pregnant relatively quickly. This experience was fantastic and it continued to be good with him. When my daughter was nine months old, we started to try again for a second and we started having problems. After six or seven IUIs he looked back to the charts and realized they had not done FSH testing. We found out that it was not only endometrioses I was battling but I was also premenopausal, so he encouraged me to go to a more intense fertility specialist, but I refused. Now I regret that because I just kept thinking that IUIs would work.”

Just another case, just another number

“There is just the sense that everyone is treated the same and that was sometimes frustrating or they were not taking you seriously. They were in a rush, you were just another person and they did not seem concerned. They just were not really involved in your particular case or situation.”

“I had my OB/GYN for years prior to even marrying or even thinking about having a child. He has a very big practice. He is a great doctor, absolutely fabulous. Initially I was seeing him for maybe four or five years, it was great and I did not have any issues. I thought maybe the practice in itself was almost robotic, it is like herds of cows where they come and go, if that makes sense. When I expressed that we wanted to try to have a family, all he suggested that I do was IUIs. I did IUIs, several at least a handful of IUIs. So, we attempted to do that four or five times with no success. The doctor had never really educated me enough and he did not advice to do IVF, he wanted to continue doing IUIs. That maybe seemed to be more about financial gains in terms of the practice perspective. He was doing the IUSs, but there were times that he would actually did pass it on to his nurse. I was not as happy, they are just too busy that you do not have the time or you do not have an option as a patient to say no because you are in the process doing it and they still do the procedure. But at the same time you obviously know that you want to see the doctor himself. I kept that to myself and went through the process. As a physician and as an OB/GYN,

he is absolutely phenomenal. I have no doubt about that. But I was not really feeling he gave me the attention in time that I deserved and then after five attempts made maybe IVF would have been something that he would have suggested. So through my own research, I discovered that there was another fertility clinic right here on far west. I reached to them and they are the ones who followed me then.”

“I think of doctors and fertility specialist as the same. We saw a number of doctors. The first one was not very friendly and very quickly in the process she was just gone. She left the practice and did not know why or hear anything about it. Next thing I know we had been reassigned to another doctor, we liked working with her. She is very friendly but we never got really any results from her. There was at least one occasion where we tried a process using donor egg and my sperm and we made it to a heartbeat we made it to a heartbeat and she told us it is a ninety percent (90%) chance that you are out of the woods and then the next week it was gone. It is hard not to blame her for that statement. The statement end up and making the loss much worse but we still worked with her. We worked with a doctor up in Dallas. At first he seemed to offer us a lot of hope, but then after reviewing our file, the second time we drove up to Dallas to see him he basically said you should go with a surrogate. Than we saw another doctor in Houston. He was supposed to determine whether or not there was some issue with my sperms that would not be detected by a standard test. It was very expensive and had to take off work and drive to Houston, wait a very long time to see him in his office. Pretty uncomfortable, I am not used to that, it is not something a man goes through as part of his doctor experience. He raised some concerns and issues and said he was going to run this test that takes four weeks. It is pretty expensive. There was mix up of the test, it did not run or they did not run the test. We needed to do it again and we had to go back again, and there were no apologies or anything like that. So our whole experience had been put on hold for months waiting for this result. I was calling and calling and finding out and they took forever to tell me they did not do it. We had to re do it and I got a phone call from the doctor basically saying “it does not quite look normal. We cannot really tell you much more, we cannot really tell you what the results mean, you should see a geneticist.” It was just complete waste of time and money. It did not make me feel good about myself and it did not clear up whether or not I was the piece that needed to be removed from the equation and I still

have some thoughts about. I still do not know whether it is me or my wife or both of us at the same time. Then we worked with a clinic in Atlanta called RBA and we worked with a couple of doctors who we did not really get to know. I never felt like we were much more than just paid attention as you come in the door to get the thing done then you are out the door.”

“I was first diagnosed at my regular OB/GYN’s office and I was told by a nurse practitioner “well now, since you are categorized as infertile” just because it had been a year of trying, I said “what? Infertile really?” Just hearing the term it felt like they lightly threw it around. I knew I had been trying for a year and that means that there is an issue but having this term applied to you was hard to deal with. I remember coming home and crying after that first appointment. They wanted to start tests. My OB/GYN was nice, but I felt frustrated at their office because they wanted to try some basic things and I felt they did not know what they were doing. Every month I believed that Clomid was going to be the answer. Then I remember a different doctor from my regular doctor office doing the IUI and I was frustrated because that was a lot more painful than I thought it was going to be and it was not that way at the RE’s office. When that did not work I took a break for a couple months and then decided to see a reproductive endocrinologist, because this just was not working with them.”

“I feel the doctors have a very medical model style of treatment. It feels very rushed. This is what you need to do here now. They are going to do it and then they leave and it has been ten minutes, and I think, “But wait, I have these questions, you have not asked how I am doing.” When they talk to us it is kind of unemotional; it feels very impersonal. My gynecologist had shared her personal experience, what she had had, which was nice to hear that she had success. Also my primary care did too. So that was nice and it is not just about the personal story, I do not need their personal experience, it is that they understand and have some empathy towards that, but it still was a very rushed, “Oh yes, I had that too, it worked out for me, and you will be fine.” I am not fine right now and so it is hard for me to envision down the road that I will, “sure I will be, but...”

It's not personal, It's business

“I guess, we saw just about every fertility doctor in town before we even started the process. There is certainly an element of sales involved from the doctors, almost like car dealers talking with folks, because they are trying to win your business in that sense. Most were very nice. Everyone said you will get pregnant, everyone essentially promises the same thing. A few said you should just go ahead and do IVF, because we have seen this, that, and the other. But none of them really outlined all the steps that you may have to go through. They would give the big picture, but they were too broad with it, because the big picture is you are having a fertility problem, so we will start with IUI and then if IUI does not work you need to move onto IVF. So to me I guess they gave the big picture there, but what they do not tell you is that aside from those two procedures, there are four hundred other steps involved to get to each one of those positions, on the road map. So none of them ever talked about any of the other stuff.”

“The way I relate to it is that they are doing a job, and everyone that goes to a job that is eight to five becomes just a job to them. I think the doctors and the medical staff potentially lose sight of what is like to go through that issue every time. They can say certain things and I think they are trying to be empathetic but to they do it all day every day. So it certainly can become a little more robotic. I have low sperm count and it is all low numbers So one doctor when we first saw him tested right away and everything was good. Then for whatever reason in the last two years, it is just gone down incrementally. We went to one doctor, they said that IUI would be fine but then they did not test me. They just did it. The numbers were almost 75% lower than the first doctor that I had seen, and they do not really say what to do for men. Doing something without testing? It Is very frustrating. I also have antisperm antibodies, which we never tested until we did our first round of IVF. They tested for them a week before we did our first retrieval. So, here we have been doing IUIs and timed intercourse for almost four years, and no one of the other doctors ever tested for the antisperm antibodies, which basically will not allow you to get pregnant unless they do the ICSI. So that was really the frustrating part, and so frustrating that this doctor who first was doing the IUIs is an OB/GYN we do not even want to go back to him

for delivery if we get pregnant. I do not know why they do not have a checklist of things to check for. They should.”

“My first doctor was my OB/GYN and I was pretty frustrated with her because, I got married at 38 and started trying on my 39th birthday and I saw her because we did not get pregnant right away. She was very lackadaisical about it and the more I have learned overtime, at 39 I was already pretty old so I felt she let me down by not being more pro-active early and giving me better information to spur me into action sooner. I felt that was wasted time. I went to another doctor just because it was cheaper than an R.E. and she did IUIs. I am still really mad at that doctor, because she did 7 IUIs on me, which is a lot. In retrospect you figure out that was too many, that was a waste of time and on top of that, that doctor was blaming my infertility on what she said was ‘scar tissue in my uterus.’ That was just a lot of wasted time because as soon as I went to an R.E., he looked at my uterus and he said “You have Uterine Polyps, that could be what is causing problems. You need to get those removed.” He did a laparoscopy to remove them. I felt that the second doctor, who did not have the right training, who was not an R.E. was presenting herself like she was a fertility expert. Because she had some training, they allowed her to do IUIs. I wasted a lot of money and time with her and aggravation and heartache. After several IUIs I was telling her “I think I am going to find a fertility doctor.” She said something really awful, told me to skip IVF and adopt, she said “Well if I was you I would not do any of that, because if I was you, I would want to be sure that it would work and IVF is not likely to work” and I thought “Wait a minute, you have been taking all my money and you have been taking all my time doing IUIs because you thought IUIs would work. To say that you think IVF will not work” Anyway, it was just very awful. I would love to make a formal complaint against her.”

“Well the first doctor we had missed couple of things. She hindered us into progressing into having a child. After six months with her, we went to another doctor and he found some things that were probably inhibiting or preventing us from getting pregnant. I think it is polyps or whatever, and he caught them pretty quickly. That created little bit anger with the first doctor because it seems like something she should have caught right away. he caught them within first

twenty-thirty minutes of an observation. So that was a little disconcerting but we are happy we found him and we tried with him for four years or so and he is a very good doctor, very good bedside manner, just did not work out. Then we went overseas to have an egg donor, and that whole process was kind of frightening but it worked out for us in the end.”

“The first doctor was an OB/GYN and she told me she could perform IUIs. She was not a fertility specialist, but it was a way for me to try to get pregnant for a lesser cost than going to fertility specialists. I went with her and she is very confident. I liked her direct style, but looking back on it, I feel maybe I should have gone to a specialist to begin with. I cannot say anything about her. She was honest, direct and I think she did the right tests. She did not do ultrasounds, which I think should have been done. That would have determined that I was not ovulating every month, but she did what she thought was appropriate for my age and my health status.”

No early testing here: Just Keep Trying

“All this started back in 2009. My husband and I had been trying to get pregnant for about a year at that point and were having trouble. We had seen an OB and she was encouraging me to keep on trying because I was young and I would probably get pregnant. She said we could have a trial of Clomid if I wanted to, but I wanted to go straight to the big. So we decided to see a fertility specialist. I did not have a real good connection with her and so I really wanted to move on and see a specialist.”

“We actually planned for a year before we started trying to conceive because we wanted to have everything perfectly in order. We actually tried to see doctors then to make sure that we can maximize our fertility and maximize our health, nobody was willing to see us and talk to us about that. So we said that is OK, we will just look some stuff up and we will eat really healthy. We changed our diet, we ate healthy before too, but we got really really healthy with physical exercise, we got our finances in order and budgeted how we were going to afford a child etc. We talked to our general practitioner and he said “Well, you need to try for one year before anyone is willing to see you and help you.” We tried for twelve cycles and we did not have any luck, that is

when we went to a general practitioner. My husband had a semen analysis. It came back with low numbers, low motility, and they said you need to see a specialist.”

They have our best interest

“Yeah the two doctors that we have – well three, as two of them are partners, I feel they have our best interest. I had never disagreed with anything they have said or done, and they really listen to what I have to say as well.”

“I was, diagnosed in 1994. I was married at that time. I had gone through a series of ectopic pregnancies, and on the final time my doctor was not able to save the tubes. He said “we got to remove your tube and at this point you will not be able to have children.” He was a good doctor, he was really sympathetic, really compassionate. It was in 1994 and IVF was relatively new. I mean, the first test-tube baby was a couple of years old. He told me about this process called in-vitro, I asked how much it cost, and he said \$50,000 for one try. This is before they were freezing, and he could have said a million dollars, I knew it would not happen for me at that time. So I gave up hope at that moment. I really had given up the whole notion because I did not think it would ever be affordable for me. It was about ten years ago, when as I started going back into, researching it, and deciding whether or not this was an option for me. My OB/GYN, encouraged me, she gone through IVF treatment herself, so it was really helpful. In terms of doctors, those are the only two that I have had experience with fertility.”

“I would say my experience with my OBGYN and the fertility specialist were great. The staff was supportive and they always pointed me to in the right direction and gave me options, so my OBGYN, he has been my OBGYN for probably the past ten years, referred me to the fertility specialist, which is really popular here, after I experienced a couple of two miscarriages. I was referred to a specialist and started the process of blood work and figure out what was wrong and my experience with the office and the staff was great.”

Fertility Specialists

No time to get to know you: He is running a really big operation

“This doctor listens and really goes in depth, but at the same time it is such a long wait. So he did listen more, which I appreciated, but there was crazy waiting room full of people and for the appointments were always waiting an hour- an hour and a half.”

“The second doctor I went to was a fertility doctor; at a really large company in town, and my husband and I both were very turned off by his attitude. We actually made the appointment with him because of a friend’s recommendation but my husband and I felt he was very distant, he is running a really big operation; a big company. He does not need our business. We felt treated just like another person, another number, another way to make lots of money. We did not feel any connection. After that bad experience, we went to a different clinic in town and we really liked him [the doctor]. He got along with my husband very well. They kind of joked around, it was a very comfortable atmosphere, and we liked the fact that his brother could do the work with my husband, which would be required because he needed to have his sperm extracted. We liked the idea that we could do both procedures within the same office. That was very helpful. The first fertility doctor was not helpful in that aspect. It seemed like he did not do that procedure very often or he did not know much about it. So we were kind of turned off by that as well. We decided to go with the second doctor and everyone in his staff was great for the first round.”

“We went to a fertility specialist and the experience was very neutral and very impersonal - again they did not really seem to care at all. I remember the times we have been to see the specialist, but there is not really much to say, you just sit in there and they run some tests and that is it.

We finally went to another doctor here, the practice was very reputable and we did an in vitro cycle with my eggs; that was not the best experience. The first initial sit down with him was great but then once you got in it was more like you were a number and personal care and bedside manner went outside the window. Because I was so hard to stimulate he had me on the highest

dosage of Gonal-F and everything imaginable. Out of these three years I was one of the two people he had kept on the drugs for almost a month to try to stimulate, I was a wreck towards the end from all the drugs, and of course our budget had gone out the window. That was frustrating as well, because we had been told 25,000 dollars and then we were close to 35,000 dollars because of the expense of the drugs. At the very end this doctor decided to tell me that he thought I just needed to do an IUI. I kind of came off the table a little bit being on hormones, I looked at him and said, "I did not come to you for an IUI we will do an in vitro" and he said, "Well, you do not really have enough so I want to keep you on for a couple of days" I said, "Do what you have to do, but we will be doing in vitro" I did not really give him a choice, and maybe some poor choice of words on my part were used at that point in time out of frustration. They were only able to pull out three eggs and they tore one, so [they] were really able to pick one, but we were able at least to get one in after all that. That experience was not so great it was great one on one when they literally just spit out statistics."

"I had a very negative experience with almost all of the fertility specialists I have seen. We started out with a local clinic. On the very first visit I had some questions and the doctor yelled at me and said, "You came to me for help" and I said, "That is right and it is your responsibility as a doctor to answer my questions or I will seek treatment from someone else." We worked with her for a while. She was very difficult to work with. I think I was thirty-three at the time and all my numbers came back normal, we just had male factor. I tried to talk to her about why cannot we do something about the male factor. She said, "Your only option is to do IUI" and I said, "Why are we making me the patient if we have sperm issues. Let's focus on the sperm issues and see if we can do something about that." She said "No, that is not an option." We did three IUI treatments and they all came back negative. At the end of that, we asked for my husband's records from each of those treatments, and the numbers came back so low that there was no chance IUI could have worked for us. We contacted the clinic and said, "Why did you have us do IUI and waste four months and spend all this money if there was no option that it would work?" They said, "Oh, yes we should have told you IVF is your only option." So we were very frustrated. We moved to a clinic in a nearby city. We were there for a year at that clinic and they kept pumping me for all of these drugs. They kept trying to do IVF and they kept treating me and

said, “IVF is your only option. We cannot address your husband’s issue.” With IVF they try and hijack your system, they get your system doing what they want it to do and then they introduce the treatment. But they could never hijack my system and they kept saying, “We are going to do this and this could happen or this could happen.” Then something totally different would happen. I was growing this huge cyst, they were giving me all these medicines and they had me coming back every two weeks for a year to check things and we just could not get off the bench for IVF for a year. So that was a terrible experience. Then I came back to the local clinic and went with another doctor and she was able to hijack my system and get it under control the first time she tried. We were able to do two IVF rounds and both of those came back negative. At that point they said “Well, you have already been trying for three years. We think you have gone from being completely fertile to being too old. So you started with a male factor issue and now your age is contributing so we got male and female.” We had no faith in the doctors. We did not like them. It was really discouraging and at that point we decided to move on to adoption. So it was a bad bad experience with the fertility doctors. We went through adoption for a few years with three failed adoptions, actually two failed adoptions with three kids, and then we ended up going to a clinic in Czech Republic where we had success.”

“It is frustrating. We quit because I needed a break. It was too much mentally and so we took a break and I do not think they cared either way. My husband feels like it is more of a money thing to them. They maybe withhold information to get you coming back and keep doing these things. They do not ever talk about male factors that potentially could be going on. They did not refer him back to his doctor to make sure that there is nothing going on with him. He is exploring those options now. At the time it is very much like, “Yes, yes, we will figure this out,” and, “Oh, I do not know why it did not happen. Let us keep going.” Well, let us talk about what is not happening and why it is not happening and kind focus on here and now instead of let us keep going, keep going because it is expensive.”

“I saw three or four. First I went to the fertility clinic, started with one doctor, she left the practice so I switched to a different doctor, then I went to a clinic in Atlanta and finally I got another opinion in Dallas. So, we have seen many doctors and even at the Fertility clinic here

sometimes you will see a different doctor. Some are good and some are bad. I did not doubt anybody's credentials or ability to diagnose anything, it was just more personality. Like the doctor in Atlanta was not very personable, so I did not like him."

"The first] fertility specialist kind of came off at least to me, as railroad to IVF "We just need you to get to IVF as quick as possible" it was not a lot of thinking or consulting with me. It was hard for me to get them to explain why they wanted to jump right into that and the second person I consulted agreed but he was able to explain it a little bit better. I also feel I was pretty pushy by that point because I tried a number of things over a large period of time and just did not have patience."

You are Miss Fertile Myrtle

"I ended up going to three different specialists. After my initial experience with my regular OB, I saw an Asian woman, she just did the regular exam and a sonogram and saw that I was about to ovulate. She told me to go home, have intercourse and see what happens. She also said everything looked great and I had a very good chance. I got a positive pregnancy test two weeks later. I sent out a mass text and told everyone I was pregnant. It was so exciting. But the next day I started bleeding. It was very hard. I was devastated. After that I went back to my OB because my insurance did not cover fertility. It made more sense financially to see my OB, the fertility doctor made me feel I was fine and we would get pregnant. The OB said that chemical pregnancies were very common and to keep trying. We tried for about another six months, then we started Clomid. Each time I produced only two follicles. Then she suggested to try an IUI. That was a negative experience, it was painful, I bled and it was not just a good experience compared to the experience with the fertility doctor. After our first IUI with my OB I did not want to do this anymore. So, I went to a different specialist. I saw an Asian male, it was back in 2010. He looked at my intrafollicle pattern and he said, "You are Miss fertile myrtle and you are going to get pregnant. You have great odds." He just made me feel very optimistic. I did Clomid and an IUI with him, then my lining started to get thin. We switched to Femara. We did one round of Femara and an IUI, then we did one round of Femara within injectables and that ended

up in a cancelled cycle because I over-stimulated. I felt that he gave me false hope. When we moved here, I found an OB. By then I had been doing research and I felt that probably laparoscopy would be a good idea to look inside. Previously they had looked in my tubes and they were open. That is what we did and they found very mild endometrial cells but nothing else that would suggest that it would cause difficulty getting pregnant. Some organs were stuck to others and she had to separate them. She made me feel they could but probably would not be affecting my ability to get pregnant. At that point I started seeing a fertility Doctor. She gave me a run down, knowing how long I have been trying to get pregnant my chances for IUI were 15-25%, something within that range. With her we did IUI twice with Femara. Then during a sonogram she saw what looked like a polyp. She ended up doing a HSG, took it off and she then said, "I do not know. You just seem you are fine and I do not know why you are not getting pregnant." She added, "You can continue to try with IUI maybe a couple of more times. After that I really would suggest IVF, that is your best chance." During all this time my husband does not want to do IVF. He was totally against it. He was even against the injectable medication. But, we did injectables and we had to cancel the IUI again because I was over stimulated. Tried one more cycle with injectables on a very tiny *tiny tiny* dose, and again it failed. This obviously is not working."

"Altogether I end up seeing three fertility specialists. First I went to the most popular clinic in town, because my brother and sister went there and they said, "Go there, my doctor is great." We went and met with a doctor. The first time he met me he said something that I thought was very pretentious. He said, "This will be easy," and when he said it I chuckled. He made it sound like getting me pregnant was going to be simple and easy. He put me on Clomid and I got a huge cyst. I had to call him in the middle of the night, I was in severe pain. I hyper-stimulated so they put me on birth control to get rid of the cyst. With this doctor we did some IUIs, then we switched to another doctor and we did an IVF, then backed off a bit. Finally I went to a doctor in another clinic and with him we did a frozen transfer, but did not take. Shortly after I got severely sick and for the past two years I have not been able to focus on fertility. So it was stages of different doctors and I would say the second doctor at the big clinic was the worst experience for us. We transferred to her because we were thinking she was a bit more open-minded and she

would guide us in a good direction. Originally I wanted to switch with another. I have heard wonderful things about him and I told a nurse I was looking to switch. She said that doctor is great but very busy and not to get upset if we have to reschedule appointments or if he is running super late because he is very hands on and all over the place as far as conferences and papers. The nurse suggested another doctor. Since she was younger I thought maybe we would connect better, for me the connection is important and so I felt when we walked in. She is really personable and listens to us. But when it came down to doing the IVF, she dropped a few balls. What the clench here was I had a really bad transfer. The morning of the transfer, she called me to her office wanting to check me and said, "I see fluid and the ovaries are kind of large." here is the messed up part, that day we asked her if we should do the transfer or freeze the embryo she advised to go ahead and do it. So we did. As soon as I was wheeled back in the recovery, I started having severe pain and they could not give me anything and they sent me home. I would call the doctor's office in severe pain and talk to the nurse and it was a lot back and forth. "Let me talk to the doctor, I will call you back." After the third round of back and forth, she said, "yes, we are thinking we should not have done this, because of the hyper-stimulation, instead we should have freeze the embryos. Have you recover and do the transfer later" I was shocked. All that goes by. I do not get pregnant. I go in for a follow up. Now I am thinking after all the phone calls I made to the office she walked in like I was a brand new patient, "You really do not remember who the heck I am?" There was no recognition. It was disturbing. I asked her why it did not stick. She just said, "Well, things like this happen, sometimes it could be genetic." I am like "Do you know the hell that I have just been through? Did the chart tell you all the phone calls that I have made?" Not once did she call and say, "This is Doctor... I am just calling to see how you are doing." Nothing. After my IUIs the other doctor would call to check on me. The last doctor, after the frozen IVF cycle called me himself too to check on me. So it was very disappointing. This is where the issue lies with the medical and the infertility. They are very intelligent, they know what they are doing with infertility, but they do not know what they are doing with humans. This is not a disease that they are dealing with. They are dealing with humans and I think after they do it for so long, they have a disconnection. And you know that clinic is growing. The place is huge, they are constantly hiring."

It is so un-integrated, these doctors are not able to work together

“It is hard. I feel like as you go into that kind of thinking everyone is created equal without really having any understanding of the doctor that you are seeing. They are in their own fields doing their own things.”

“[With] The first doctor I saw we tried some things and after it did not work I ended up going to a clinic in San Francisco. We picked one really based on an emotional connection and we stuck with her through two IVF cycles that never worked. But I really loved her as a doctor and I still think she is really great. She is very straight as an arrow. I did not have a bad experience with her. I am not upset at the doctors. I am upset at the way the whole thing works. It is so un-integrated, that these doctors are not able to work together and they are pitted against each other. I feel the field has problems. After, I went to see a RE doctor who did half of the proper immune testing that he should have done and gave us a general picture that my immune system was a bit of a whack. He wanted to do this IVF protocol that was super expensive, which it never had anything to do with finding a cause. It was just about how to get me pregnant and circumventing these immune problems. Then three months after that I read a book that someone in my resolve group recommended and I discovered the reason I have this immune problems is because I have this bacterial problems. We ended up with a Doctor in New York City who studies bacterial causes of infertility. So we had to fly into New York for treatment from California, and my husband and I were both treated, I had multiple surgeries. So we went into treatment and now that we are going into this third IVF cycle. But it did not make me feel a whole lot better in terms of monitoring moving forward, for that I found this woman in Los Angeles who is a reproductive immunologist PhD, who went through infertility and ended up having immune related infertility and so she has created her own practice as a consultant to people like me. She has been really great and she has been able to tell my local doctors what to test me for and to give us an analysis of how I am doing. She is not an MD and she cannot prescribe stuff, but she knows exactly what all these doctors know. I feel so good that someone is monitoring my immune system. Here no doctor is open to immune stuff. My OB was just completely hands off and does not want to

prescribe anything related to it. I feel like we were failed by this overall arching system in that we were never advised where to go and what to do, you just had to figure it out.”

I feel sort of stuck

“After few IUI attempts, through my own research, I discovered that there was another fertility clinic right here and I saw the doctor there and I only had one opportunity with them to go through a good IVF cycle. As I found out about it and the expense involved, I knew that that was maybe one of my only chances to go through that process. I did one treatment and that overall was a fairly good experience other than the injections and the medical sides of it. The process itself was a little tough for me as well as my spouse to have to deal with that. I was on the highest dose of medication that they can prescribe, which is not only the most expensive but as well as the way that I felt... I was not the same. But as far as the facility, great practice. The doctor himself was I guess you can say assertive, he was very diplomatic about telling me that odds were not that good. So in that sense I appreciate it. But I think that maybe for many other women who are going through the same process, you land in a denial phase about listening to that or accepting that as a final answer when you want to keep going. So I respected him as a professional in terms of what he had to say and diagnosed me with. We were actually successful with getting pregnant, but it turned out to be a tubal. I thought I was going through miscarriage, which turned out to be a very long time. After I was bleeding for longer than a week’s period he suggested that I come in and we found out. I immediately went to surgery and that was taken care of.”

“That is the reproductive endocrinologist my OB referred me to after my miscarriage. Since I live in a small town and this is the only reproductive endocrinologists that actually comes here once a week, I do all my treatments with him; travelling to his city office when I need to. I do not like him nearly as well as my gynecologist just in terms of personal liking. He is very busy. He does not have that personal touch that my small town GYNO does. He calls me sweetheart all the time and he likes to have conversations with me about my treatment options after he is done with the examination while I am naked and he is putting his hands on my knees. I feel kind of stuck

with him because he is the only one in my town and I cannot be driving three hours to the city to get a sonogram every week; that is crazy. So I feel sort of stuck with that.”

It took years to know

“First doctor I met, his personality did not mesh with ours. He was very rushed and fast. He was not listening. It is a doctor a lot of people love. I guess it was not the right personality for me. I guess he is one of the best ones in the practice. He was too rushed for me. I need to ask questions. He is a specialist in endometriosis, and if I had that problem I would have stayed with him. So we switched to another one within the practice, who I liked, patient, sweet, kind bedside manner. I never felt embarrassed. I cried, I asked him questions. He would write down all these statistics and all the percent chance. At start they said I had very low ovarian reserve. I started out doing IUIs at first. A very single time I would do one I would have less follicles growing. So we did four of those and I never had a pregnancy. After four we moved to IVF and he just did the regular protocol that I do not think a lot of doctors use now. He did the long Lupron protocol, so I hardly stimulated at all and we had it canceled. That was super traumatic and it was not even [with my] doctor, it was on a weekend with another doctor. That was frustrating because at that point I was maybe 36 and if you are over 35 they should not even use that protocol, but a lot of times they just do the same. So that is when I got mad at them and went to another doctor in another city. I heard a lot about him, everybody had twins. He tried to do a hysteroscopy in his office and it was horribly painful and traumatic and it would not work. That was the worst thing that happened to me the whole time. It was so painful. My husband walked in. I was just sitting there and there was blood everywhere. It was awful. So then, I came back to my previous Doctor because I truly could not be out of town again for another IVF. I did another one and it did not work and there just were not any indicators on why it was not. It was horrible being unexplained. The whole time I told them my mom was exposed to this drug. They are like, “Oh Your uterus is kind of small but it is fine. So I went to another doctor in Colorado and the doctor there said, “You know your uterus is T-shaped, it is completely malformed, it is so small and such a bad shape. The embryo could have never attached and if it had, you would have lost the baby. You

could not have carried a pregnancy. You would have lost it in your first or second trimester.” So we are really relieved, you know we finally found someone who told us what was wrong.”

It comes down to communication of knowledge

“With the first visit both my husband and I went, he sat us down, he spent a lot of time with us and just outlined pretty much all of what the potential options could be, the potential outcomes. So he would draw everything out and just basically saying, “This is where we want to be and the least invasive is but this is where it could go from here.” He gave us this whole big picture, and we felt very comfortable with him. He would joke around and say, “Now you will probably get pregnant because that is usually what happens when people come to see me and then boom! It just happens” and he just had some jokes without which, I guess it might be difficult for some people.”

“They explained it a lot better as to what they were doing, why and what my options were. They gave me percent chance “this procedure has this percent chance but it costs this much more. I felt better with them then I did with my OB/GYN as to what they were doing.”

“My direct experience with the doctors were minimal and peripheral until I actually met with the andrologyst and at that point it got very face-to-face. Before that, my wife and I had also explored going to one clinic rather, so really that is where my experience with doctors started with the guy that we passed on. The doctors that I spoke to even the one that we passed on whom it might be considered like to have been almost a scripted presentation on his part, he was still open to questions and I had some fairly objective questions to ask to him. They seemed to be sensitive to my questions and I am sure it was in the range of material he had heard before, so as scripted as his whole monologue might have been, he had succinct answers ready.”

“Two buckets, the doctors out there in Minnesota and the group down here that we have worked with. Not knowing it at the time, I felt going to the group in Minnesota was going to be great – my wife mom was across the street from one of the pioneer of IVF so we got his

recommendation of whom should go see so I am thinking “Ok, this is the best of the best, excellent, I do not care if they are completely incapable of any conversations, I do not care about anything, I want the best scientists there are.” I do not know if these guys just missed everything, or if they were more cautious. We did three IUIs and it did not yield a positive outcome. I also understand statistics and I know a IUI does not work every single time and there is a chance that she could do it six or seven times and it just would not work. Then we moved here and we got connected with a fertility doctor and his group and I do not even know how or where do I begin to compare the two experiences. The fertility doctor was incredible, still very much of a scientist like, “I am not going to sit and hold your hand and cry with you and things like that.” For me that is not what I want, I want the best person around to do what I am paying them to do. He was better at explaining things, better at answering the questions we had than the group in Minnesota. The doctor up in Minnesota was totally awkward and you could not hold a conversation with him, the fertility doctor you go drink a beer with after you saw him at the office. I am sure they are both as equally qualified to do the work and, but just from a communication perspective, one group was much better at communicating than the other group.”

“It was very informative. One thing I like about him, it was that my personality does better with “Tell me the truth and tell me how it is”. I do not need to be cuddled or sugarcoated, just “Tell me my options and then I will worry about the emotional stuff later.” He was very compassionate too.”

“A different OB referred me to a fertility Doctor. The first time I went to see him he said “you have about six follicles on each side.... maybe a little bit less than average for my age. So I decided to keep trying naturally for a while, two months, and then I went back to him and he did an ultrasound and said “you have got only three follicles on each side.” A normal person my age has eight to ten follicles. So my chances of conceiving by myself every month are five percent (5%). To normal person it is like twenty percent (20%) or whatever. He told me I have unexplained infertility and just threw all the stuff at me that I probably will not get pregnant on my own, that I can do the shots to help me ovulate and then I can do the IUI or in vitro and all the stuff is hitting me. When I left his office I felt so pressured. My husband was not with me

because he had to work, so I was by myself. I felt pressured. You know and so I left. I went to my car. I just poured my eyes out because I am like, I am infertile! It was not the worst. It was just negative information thrown at me.”

Good bedside manner

“My OB/GYN referred me to a fertility specialist here and he is very charismatic. He just makes you feel so much better and it could be that he is promising to fix your problem and he is very personable. I met the doctor without my husband the first time and it was hard to explain to him how comfortable you are with him and when my husband met him he said, “I think I have a male crush!” So, yes, he is very charismatic. He had me do some blood testing, and maybe there were two things that were off that he described as normal like, “This could have been something you ate.” So that made me feel really good, there was anything terribly wrong. He wanted to prescribe me Clomid and he thought I could get pregnant pretty quickly. Because I am a very frugal person, I would hate to spend all this money on medicines and treatments, fertility is not covered by our insurance, only to find out six months down the road that there is something wrong with my husband, so I asked to get him tested before he would call on my medicine. The nurse called me back when they got his results saying the doctor was not going to prescribe me medicine, my husband needed to go see a male fertility specialist, and they could not give any information over the phone, I had to go in for an appointment. It was very frustrating, I was in a panic and in tears. I thought I was so close to having everything fixed. I just refused to pay another co-pay for the lab results since we have to go see this other doctor and Lord knows what kind of tests we have to do. My husband saw a doctor who was horrible. She has no bedside manner. She is very rude. Just bad experience with her, he got put on Clomid and after about six months we went back to the fertility specialist here and I started doing Clomid too with no success. So we stepped up to IUIs but my husband’s numbers were on the low end of normal. So after three tries we started seeing a male fertility doctor who offered male fertility. Also very charismatic.”

“Then I went to this R.E. and he was really great. First of all he had the best bedside manner of any doctor I had ever seen in my life and he is very accessible, He got me in right away, and then he got me in for a laparoscopy surgery right away. He is also extremely compassionate, a nice person. In fact, I was worried if he was really the best doctor, maybe I am falling for his bedside manner, but he was a very good doctor to work with. He was the surgeon who did my 3 hysteroscopy.”

“We went to a fertility clinic with a team of doctors; you get assigned one; they are very professional, mostly with very good experience. But anyone who does not get pregnant by their infertility center always has that question that maybe there was another doctor or another thing we could have done. But overall I would say our doctor did as much as she could. We always had a lot of embryos really high quality but when we transfer them, they turned to two chemical pregnancies and now we have four remaining and we decided to use a surrogate. When I first started looking at fertility treatment, my diagnosis was not difficult because we knew it was tubal factor, I did not have tubes, cannot have baby. I started off very early, I was in a relationship with my husband at that time, but my husband was putting it off. We go to the process and the local fertility doctor tells us, “Everything looks great but do not come back here in two years expecting things to be the same. You are in your thirties now” and that window was closing. Sure enough I come back two years later he is like, “Everything looks great but do not expect to come back here in two years.” I kept doing that and I just got embarrassed going back. When I got really serious about it I was watching TV and I saw this doctor on a talk show. He had just moved here and he was getting ready to open a clinic. I thought, ok, I am going to see him. We went and when I talked to him I immediately knew that is where I needed to be. He was amazing. He has been honest from the beginning, this is a process, it is expensive process and we will keep going but if your ovarian reserve is off, we are going to stop. We are going to keep moving forward until that point. So we did. He has been a fan and a cheerleader and a father at the same time, he has been really good.”

Surgeons

It is kind of the same people

“The second fertility doctor did my surgery, and it went really well. I had endometriosis. then my last doctor just look inside the uterus with the scope found tiny little polyps that he cleaned off. It is kind of the same people. The fertility specialist was the surgeon and one of the doctors. For diagnostic they did the basic laparoscopy. They were checking to see if I had any endometriosis. They found some polyps to remove. I also went through an MRI with them to look because there were inconclusive ultrasounds. For about six months I thought that I had uterine abnormality because one doctor told me that I did. And so I spent six months researching uterine abnormalities. When I finally got to see the fertility specialist he sent me to an MRI, which revealed that I did not have uterine anomaly. I felt relieved, but I also felt so frustrated because I spent all this time researching it. I had a laparoscopy and a hysteroscopy with my fertility specialist. That was a little frustrating because they leave by the time you wake up so I had to hear about what happened from my husband, and so it would take until the follow up appointment for me to really understand what they found because what they relayed to him was they found fluffy stuff. What the heck is fluffy stuff? Is that good is that bad?”

“Before we went to Czech Republic, I had a hysteroscopy. It was a not surgical hysteroscopy because they were just going to look. That was a negative experience because it cost a lot of money even through my insurance and they told me to come in on this day, like three days after you stop bleeding from your period and we will be able to see everything and tell you if you are set to go to Czech Republic. She comes in to tell me the results and she says “We just could not really see anything.” I was like “Wait a minute. This is twelve hundred dollars out of my pocket. You could not see anything?” and she was like “No, inconclusive.” She was saying that there was some blood in there from my period and she could not see. She said we can do it again in a couple of days.”

“The only one I remember in terms of surgeons were after the miscarriages and the removal, I would say the experience was bad but I do not think that the surgeons had anything to do with that. We had a miscarriage and so we had day surgery for that and I think I do not remember who did that. Then I had a hysteroscopy also and our fertility doctor did the hysteroscopy. It was fine I did not have any complications. I did just hysteroscopy, just looking. I never really had that kind of experience. He tried to do that [HSG] and it was horribly painful and traumatic and it would not work. That was the worst thing that happened to me the whole time. It was so painful. My husband walked in. I was just sitting there and there was blood everywhere. It was awful. Any time I was under anesthesia it was great. I ended up doing most of my transfers under anesthesia because it was so painful. I said, “I will not do it unless you...” My wife’s general OB/GYN down here did her Endometriosis’ surgery. She did not kill her so [*laughs*], so that was a good outcome. Basically it was the same doctor who did the procedures. Good procedure. The recovery for my wife sometimes was a little hard. It was through the OB/GYN. That was great. There was no problem at all. The nurses, the facilities, everything was fabulous. I have had six laparoscopies all through the OB/GYN doctor and very little side effects. It is a lot to go through but he has taken good care of me and we have got the results we needed.”

“I did just that one spermectomy or whatever they call it. All told it was a positive experience, again pain is a doorway through which we must walk if other events are to unfold, I walked that painful doorway so many times in my life this just needed to be done and as such better that guy then some medieval idiot with a chisel, he was a funny guy who got it over with, cracked a few jokes necessarily and done.”

Physician Assistants

They are missing the personable part

“Everyone seemed nice. It is almost like they are missing the personable part. They seem nice but they do not relate to me. I felt like there were times that I was there more often than most but they just did not remember me. So in that sense, you always think how many patients do they really see that they do not really remember or recognize who I am or what I am going through. Also there were different ones that I doubt they were under the same doctor. I start feeling of being one of the many going through the process and they are doing what they have to do. The only physician assistant we saw was related to the OB/GYN office. They just piecemealed us the information as we went rather than giving up to as a front.”

Some are good and some are very bad

“They were actually the most positive part of this. They just did the best as far as explaining things in detail. When I disagreed with the doctor they were willing to go and push them to get more of an explanation because of the obvious cost of all this. Every time you go and see him you have to pay so they were willing to do a lot more over the phone. That was very fiscally helpful to me. That has been the one thing that I have been surprised about, that they have been really good especially with the fertility doctor. Anyone of them I can call at almost any time of the day and they have answers for me, they are open, they are responsive. If I call and have to leave a message I will hear back from somebody within an hour. They are really on top of their game. I was seeing PA at the last doctor’s office and that was a positive experiences, just because I like her. She is well spoken and she is super nice. Runs on time all the things that matter to you as a patient. She did not get me pregnant. That much I would have liked. But overall, I thought she was a good PA.”

“I had either really poor or really good experiences. With the bad experience there was one. It was during the early days of my infertility. Anyone who works in a fertility clinic needs to be aware that you are working with women who have high emotions. I remember she was talking about my husband needing to bring in his sperm sample. She was really rude and kind of said, “And make sure that he has not just shoved them in. They do not like that. And make sure this and that,” really? I remember I went in in a good mood, but then I was in tears. So maybe she was having a bad day, but really rubbed me the wrong way. One of the fertility doctors talked to her and she apologized etcetera. That was a bad experience. But I found out later she did not last very long. So I think it was just a bad fit. And then I have had ones who are really sweet and nice. You know they remember your name and all that. The first time when I heard the term ‘infertile’ applied to me was from a physician assistant at my OB/GYN’s office. That day I did not end up seeing the doctor herself it was the assistant and that was negative”

Nurses

Down in the trenches

“My mom is a nurse. So, I grew up in a medical family. I always get this impression like the PAs and the nurses are down in the trenches with the regular people whereas doctors have sometimes very little idea of what is going on, they see you for five minutes and you are done. But the nurses and the PAs are the ones who are actually interacting with you. They deal with all the everyday stuff that the doctors do not, you know, are not interested in. I feel they listen a little bit more. They have a little bit more interpersonal awareness and they use that. The fertility specialist has some great nurses because they were very accommodating. I was working and a lot of times I had to come in very early before work and it was before the doctor came in and so the nurse ends up to do the IUI or a lot of the ultrasounds and the lab works. And the nurse was very skilled. His nurses were always helpful, they always remembered my name, I liked that I went into the place and they seem to know who I was. I appreciated that a lot. Nurses are down in the trenches with the regular people. Loved them. I think the nurses, in both states, helped us try to get trial drugs because they knew the cost; nothing was covered by insurance. I had my nurse email address and her personal phone number and I could ask any questions all the time. I really like that. It was like one on one attention. You were not calling the line and waiting for the next person to answer. At the fertility clinic we were so satisfied, they were just a little bit more sympathetic than the physicians themselves. They were just a little bit more understanding; you become really attached to your nurse for sure. Interestingly in Minnesota the nurses were just as good as the nurses down here, it was more of a physician issue. The nurses just want the best for you, and they want to make sure you are comfortable; they want to make sure that you are warm when you are in the room, all that kind of stuff. So yeah, it was good experience; I cannot say it was bad. Communication was fine. On the OB/GYN side as well as the fertility specialist side. I would say they were very caring more so than the PAs. I think they had more knowledge and more experience. They were almost like the doctors.”

They keep the madness running smooth

“The fertility doctor has several assistants or nurses, and when you start with his office you are assigned a person, you go to a person that you can always call. I think it is a nurse. His nursing staff was very on top of it; there was not anything waiting around for days, kept on top of their scheduling and made sure you had your lab appointments and things like that. If you called and had a question, someone was always there to speak on the phone instead of leaving a message and all of that. So his nurses and the whole staff are very knowledgeable and attentive and I think in those times they learned that is probably needed. Quick response, which in that situation you are anxious and there was always an e-mail or a call.” I would say all the nurses are good and friendly even at the big clinic. That is their strong suit. I think that is what keeps their patients the good nurses. They were actually really good. They were incredibly kind. In fact I even had the email address of one of the nurses and I would e-mail her and she would e-mail me back by the end of the day. At that time when we went through the medications everything is so crazy, knowing that we had so many questions and I never felt like there was inconvenient to e-mail or call.”

It is really impersonal

“I did not have a lot of interactions with nurses. The nurses in Houston office were inappropriate toward me. They made inappropriate comments. It was a very isolated incident but it was uncomfortable. The nurses here were always very professional. I know that my wife had are very mixed experience with nurses returning phone calls. It is really impersonal, every time I have been in I see a nurse for a couple of minutes, they are in there as long as the doctor is and you wonder if any of them really do anything. I did not have a lot of interaction, most of the information I got came from the doctor, and they just shuffled you from one place to another and there was not a lot of communication. I think that they show empathy but sometimes it is just their job, they do this every day and there is no emotion involved with it. Same with doctors, they have a set plan of how things go: it is all science. This is how it is.”

Some are really good, some are bad

“Most of them were pretty great. There is the occasional nurse that is not either very well trained or she is super busy, but otherwise I feel they have been helpful. Some are really good, some are bad. The good nurses, will say things like “Oh I am so sorry, I know this is hard for you” or anything like that. The bad nurses do not say anything or they do not really understand the anxiety you are going through. All the nurses I met have been kind hearted and very positive. I had to go in the day after Christmas to do a sonogram and one nurse opened the office just for me. You may get a good one or you may get one that is not as good. Some nurses are pretty good sometimes, then you feel they are not proactive or returning your phone calls. But once I was there in person, they were fine personality wise.”

“I have had good and bad experiences with nurses. It is been frustrating. The nurses at my regular doctor’s office have not been so good. At the fertility specialist’s it was nice because they assign you to one, but I still had a lot of frustrations trying to communicate through them to the doctor. Before moving ahead I was telling them that I had all this spotting that I was concerned and was wondering if I needed to do a test. They did not seem to understand or be able to convey that to the doctor and so I had a lot of frustration with communication.”

“There were some sweet ones too. My doctor’s office had a support group, which was managed by one of the nurses but I was the only one who showed up twice, they did not seem to have it very organized. It was nice because I got 2 hours to talk to a nurse and ask her questions and she was really sweet and supportive so that that was good but she was not the regular nurse that I would see.”

“Most of the nurses I am dealing with are at the local fertility clinic now. With the fertility clinic, they do not tell you things before they do things. Just last week I got a call from a specialty pharmacy to pick up more progesterone, and I did not know that I needed more. They did not tell me. There have been a couple of incidences with his office where the only reason I feel I know

something is because I ask. I am in the medical field, so I ask the right questions. Their communication could be a little better I think.”

“The nurse I had for my retrieval was amazing. The IVF nurse that I have been assigned could be better, but I like her. I think she is good. I have had some really good nurses. When I went through IVF in 2012, which was my first cycle, we put back two blastocyst and they did not take. The IVF nurse that was helping through the whole process had also been through IVF herself, so she was so encouraging. She was like, “Do not worry about it. Do not think about it, you are doing the right thing. It is going to be amazing” just so encouraging during the ordeal. I still think about her from time to time.”

“When we had the IVF done here in the states I remember the nurse at the clinic was very good. She was a RN. She is very strong and wanted things to work out with us. You felt she was really in there for... She was pulling for us and every time we showed us she just seemed she gave us full attention. The second [IVF] round they had a new nurse and that nurse and I did not get along. I just felt she was very abrupt and kind of rude. I was very over sensitive at that time, because I was upset that this was not working. I am sure that I was very sensitive but I did not like the way she talked to me. In the nearby city, there was a nurse and she was basically, I do not know what word to use, she was so impossible to work with. She would not give us any straight answers to any questions. We had a good nurse here who we really liked.”

Lab Techs

You are sent around town to get blood draws

“You had to get blood drawn at clinical pathology labs because your doctor’s office is closed and you are sent around town to get bloods drawn at odd places in town. They always seemed fine; the technicians. I have had positive experience. They all seemed to realize, like a couple of them would tell me “you are a hard stick” And I know this of me and I would appreciate when I would have a really skilled. A difference is in Minnesota they did their lab work in-house, here we did our lab work through a third party company, but all in all they would take your blood, they provide a good service. My wife has a small vein so, it is always a pain in the butt, and they feel bad. With the clinic we had to go everywhere else to get our blood work done. With the last doctor they draw blood right there in the office, which I really liked because you do not have to go find a CPL somewhere open especially when you are all messed up on IVF drugs. That is the last thing you want to do. You wake up at 7 AM to go get testosterone and stuff done and you just go to the doctor’s office. It helps to stay more relaxed that way. I did a lot of blood draws. Those were fine. They are not associated with the office.”

More personable than the physicians

“I had one I really liked. I was going to the lab a lot of times and she was nice, we never talked about anything too serious but I like her. I think they always were just a lot more personable than the physicians. You see him a lot especially here every Monday we were going in. I had such a good experience with everyone. I had a woman who took my blood who we gave each other hugs every time. We became really close. Then there was the embryologist who called me herself and we talked about some questions I asked the doctor about some of the charting. I really appreciated the time she spent with me. The lab techs have been really good too, other than the fact that you see them every other day when you going through the process. They have always been really *really* good and the embryologist we had who worked with the fertility

specialist was just amazing. He is incredible. The two times that I had experiences with him, as I had been put under when they were doing the egg retrieval, he came back and he spoke to my sister. He was just excited about the egg retrieval. When we got ready to do this last transfer, same thing, they gave me something to put me to sleep and so my significant other was there and spoke with him. When I woke up he told me that he had been by to give us pictures of the blasts and He is very *very* encouraging.”

Good and Bad and Plain Human

“I had two very different experiences. We had the phlebotomist who drew the blood. She was really young, she took four times to get my blood; really hard experience. Finally we learnt things like drinking a lot of water, use of hot warm comb for us to get the blood and all of that. So sometimes they are really nice, but if they do not know what they are doing, that is a bad thing. Then we had the embryologist who was just excellent. The embryologist was really good. Some of the lab techs when she would had blood draw would not do a very professional job or when the doctor would say “I need this stat,” sometimes they would not get it to him right away. Most of the time it was good, but from what I can remember there were times where the communication was not strong. At times the lab office was not associated with the doctor or the fertility specialist, and that is an issue because is it not good that you have to go somewhere else and they do not communicate fast and this is very time sensitive when you do an IVF. I have my veins roll, so there was one woman who knew me and after having so many IUIs back to back she would just grab me and take me saying, “I am going to handle her because she has rolling veins. They forgot one of my labs so I had to get stuck again. They were sympathetic about, but it is a time consuming thing, you have to pay parking to get in, take time off work. They had all the things in front of them but they just forgot, which is human but still it is one more thing.”

Bad communicators

“When we did IVF, meeting with embryologists was pretty good, they tried to explain what was going on with our embryos and they were pretty positive. After the IVF they had to do rescue

ICSI because only one egg fertilized out of 22. When trying to understand why that happened and trying to ask questions we had some difficulty reaching them. They were nice enough to call us back, but it was a frustrating conversation trying to get the answers because they were not understanding what we were asking. I also had a very frustrating experience with a lab tech. I had to do a hysterosalpingogram. There was this back and forth conversation with the doctor's office whether we were going to do just an HSG or a hysteroscopy. Finally it was decided I would do a HSG but by then I was already on my way out of town so I could not do it in the ideal window, the first 10 days of cycle, but my fertility specialist's office insured me it was fine because I was on the pill and so could do it anytime of the cycle. When I called the lab they told me that because they never do it outside the first 10 days I need a note from my doctor. I got that note but by then it was later in my cycle and I have driven all the way to town and the lab tech refused to do it because they said if I were pregnant they could be flushing a baby out of the uterus. That was very upsetting. I left in tears, called my doctor, he called them and then they got me in later that day. It was very upsetting dealing with them apparently this office was not used to do that, but they also freaked me. As a woman who is trying to conceive to be told that if you do this test you could flush a baby out of the uterus it was just very upsetting. That was the most upsetting day ever."

"I had a bad experience with lab techs here during our first IVF. There were all these issues about whether or not they were going to vitrify the embryos or they were going to slow freeze them. With freezing ice crystals can form and there is only a fifty percent survival rate of the embryos. If you vitrify, it is an instantaneous freezing, so there is not time for formation of ice crystals and there is a ninety percent survival rate. We really wanted to make sure that any embryos we had that were going to be frozen will be vitrified. We were told to talk to the lab techs about that. They were in a very big hurry and on the phone they told us "You did not have any extra, you did not have any embryos to freeze anyway." I just lost it. I started crying. I said "Oh my Gosh. You are telling me we did not have any embryos to freeze and you are being so cruel about it?" It was really bad."

“The embryologist, I guess we had a couple of discussions with them and they were nice, but they were as short. So I would say it is a very limited experience. I remember being in the room when they were implanting the embryo and I think those were the lab techs and with them the embryologist. They were nice, they did their job. So actually it was a very limited experience, but they were fine. I cannot speak to that too much. We did see an embryologist at the day of the retrieval that gave us a lot of information. She came through and told us how many eggs we got, what they were going to do, that sort of thing.”

Office Staff

The bigger the facility the less personable

“It is mixed. It really was different depending on the different places. When I decided to go just to the regular doctor to do some minimal intervention, it was one of the most popular obstetrician places in town, everyone was pregnant there and there was me trying to get to the other part of the journey. That did not feel too good and the office staff, I guess, they were just in pregnancy mode. So I felt bad for them. But my other, the fertility specialist, this particular Doctor place, it is so much smaller operation. So his office staffs wear so many hats. They are the nurses. They know you, so it is not really much of a distinction for them. It is good except for when there were pregnant office staff at the fertility clinic. That always would not be great.”

“They are young, do not always know what they are talking about, does not appear that maybe they understand the process all the time. Once gave us information or missed giving us information, so we were not able to get our injections because it was a Friday night, so it screwed up the process. Also, the setup of the office is kind of one long counter. There are three or four girls that might check you out. So there is no confidentiality. I work at a hospital, I am a social worker, that is a huge thing. I do not really care, I mean if everyone else is there, they have the same issues. But there is still some sense of you know... They are talking to another couple about the next steps in their process, the next appointment. I am thinking, “Oh they are doing that,” and I am thinking, “Gosh, I should not know that.” And then what if they are saying that about mine? And other people are thinking about... Again we are all here for the same reasons, so I do not really care, but it is still that privacy, some sense of privacy and safety there. I do not think because they are young.”

Not good nor bad

“They overall are very welcoming. They did a very good job of calling and making the appointments and letting you know the appointments. They would relay the messages to the doctors. Coming in, they greet you, write your name if you changed your insurance, have a seat. So there is not much interaction. They just make your appointments, do what you need to do. There really was not anything good or bad. They could make the appointments and connect you to other nurses or whoever. They have not been insensitive and they have not been super great either. I do not interact with them a whole lot other than checking in checking out. The accounting office would be great, but the girls at the desk were not great. It is kind of hard to say. Overall at the local clinic everyone is really nice. I had one situation right before my retrieval were I had pretty high stress and again I prompted them to draw progesterone level. Turns out my progesterone level was a little high. So I was at risk of ovulating on my own which would have been very bad before my retrieval. They called me after I had been there for an ultrasound to tell me to take this drug that inhibits ovulation. I ended up giving myself six shots in one day. It was just very stressful and part of it was because the office staff was not communicating very well with me. And when I finally picked up the drug from the office I had to deal with the receptionist who did not know what the hell was going on. It could be something they might work on. Communication and getting also the front office trained a little better since you know that is not their specialty. I have had good and I have had bad. I have had a financial coordinator person who was trying to give me advice such, “oh twins will be easy.” And I thought, “Oh you are the financial person, you really should not give any advice on medical stuff.” I did not say that, but I think she is not supposed to be talking about this kind of thing or how many embryos to put in, she is the financial person. Some of them were funny. They were helpful on the phone usually.”

The bills people

“In Minnesota with your taxes you can deduct semi-medical expenses and that is the only time I would ever call them. Just with the superfluous extra billing for no reason, and I would not

qualify them as pleasant to work with. For the fertility specialist I just felt that it was very cold, very businesslike. Upfront the first thing was “Ok this is the treatment that you are doing today and this is what you owe, and you need to pay that right now.” Then there was also some mix up about payments where I thought they were billing me for way more than I thought I needed to pay and I got very stressed about that. The office staff in the billing and insurance interface were always just so ambiguous, you do not know what you will be paying; they cannot tell you what you will be paying and that is very frustrating.”

The best customer service

“They are the best customer service you have ever dealt with in your life. It Is amazing. Office staff has been good too. I have not had any financial issues, they are not messing with billing or anything. They have been very informative. They have been very accurate. Then they are really cool especially in the fertility office. They are so sweet and so kind. When you go in there it is like, “Hey H.” So you feel like you have a relationship with them and so it is really nice. They were very positive and very sympathetic and whenever I got really frustrated they were good. Them and the nurses were the best at handling emotional aspects, whereas the doctor just focused on medicine. The office staff was really nice, that was something that my husband and I were talking about afterwards; everybody that worked there seemed to be on the same page and not just like that fake nice that sometimes you get at office. I felt they were genuinely interested in your success and in you getting pregnant. Definitely in the medical side like prescriptions they were always on top of everything and organized and I think that is really important in these situations. I remember being extremely impressed because as women you are involved with other medical people your whole life, but I was really impressed with this office, because I had never had this response and organization in the past. Fine and friendly. They are pretty great. They schedule things and give non-judging looks when they schedule your appointments. So, what more can you hope for?”

Diagnosis

Diagnosis describes the actual experience of undergoing diagnostic testing and various types of diagnosis for the Fertility Treatment Experience. The sub-affinity titles or various components chosen by the participants and their interview responses are listed in the following order.

- | | |
|---------------------------|---|
| ◆ Diagnostic Labs & Tests | ◆ Medical History (Medications, Trauma, |
| ◆ Ovulation | Disease, etc.) |
| ◆ Sperm | ◆ Unexplained Infertility |
| ◆ Genetic / Physiological | ◆ Doctors' Opinions |

Diagnostics Labs & Tests

No Testing needed here!

“I wanted to start that after six months, but I was only 33 at the time. So we ended up waiting a year before starting the diagnostics. That was when the first doctor I met with wanted to put me on Clomid without really running an HSG [test]. I had some cycle A3 labs done, but I feel like she just did not go over anything with me. Her answer was just going straight to Clomid and without really describing.”

“I did lab work twice and I did an HSG, I think I was about the extent to that. They were kind of the basic blood work and I went and had an HSG and then hysteroscopy.”

“I did blood tests, I did a couple of HSGs. The first time was scary just because not knowing what you are doing. For the first one I did the nurse was not very gentle and so that was a little painful, but the next one I did was fine.”

“I am disappointed that all of the work I did at the end was not done at the beginning or even offered. I just do not understand that even now actually after I went into this IVF cycle the doctor recommended that I get some more lab work done for some clotting factor that I never been tested for and it is a significant sort of clotting factor. If you could do that upfront, it would just make so much more sense. Like so many people have to ask for a new test for Beta-3 integrin. Most patients are not recommended to get it until several failures. It is a five hundred dollar test. Why do you want a bunch of fifteen thousand dollar failures before you get your five hundred dollar test? I feel they do not have a very good grasp on the monetary part and how valuable all this testing could be earlier on.”

“I have had to do almost none. The standard things they do that are gynecological appointments. My husband, and I was with him for a lot of it, had to do a couple of sperm samples and blood tests and urine analysis and all that. I know that was sort of uncomfortable for him, particularly like “Ok, we have to time this just right. Did I understand it is this morning or that morning? and what time? and where? and distance and I am I doing something that is screwing up the viability of this sample?” So that was a little rough.”

Lot of time and money for nothing

“That was just crazy I would say from 2009 to 2012 we were trying to figure it out, we thought we had a guru on we finally got, it looks like we were right, so from my diagnoses perspective we spent a lot of time and money trying to figure it out.”

“It was fine except for the doctor in the other city. We were told that was something extra that might give us some insights, it was cutting edge. But appointments had to be made a month in advance and then went and had to wait an hour and a half to see the doctor and then he screwed up the test. So it ate a lot of time and money for nothing. Not to mention that they have never been able to diagnose anything about my wife.”

“I had various hysteroscopy and sonohysterograms, just checking to see if the uterus is fine and everything so far there is no physical rip. There is nothing wrong with my uterus or my ovaries that would prevent me from getting pregnant.”

“I went to see my urologist because of our friends that were doing IVF went to see an urologist when his count was low, and he recommended that I go see him. He is a really great guy, but he would not give me a diagnosis for why everything is low. My testosterone was in the normal range. My estrogen was at the normal range. He did not want to do any kind of exploratory surgery, which I certainly appreciate. I was doing my appointments with him in tandem with my wife runs of IUI. When we decided to do IVF he said there was no point in me going any further because it does not really matter if my count is low because as the fertility doctor said if you have one sperm and one egg we can do ICSI. Well, he did not know they were doing ICSI, but I think the urology doctor knew that I had enough of a count to do just IVF, but he was not aware that I had antisperm-antibodies. So for the diagnostics and the tests they say that my wife has PCOS, but she has no other symptoms other than them just saying it. So I feel like we do not know. I feel they are running through some of the motions that they think that they should.”

“It was about three months of testing. It was very difficult. It was time consuming. It was the hoops we had to jump through before they could tell us whether or not they can help us. It was not easy. It was long; it felt like the months were passing. We wanted to see progress and we were busy with all these testing and everything was normal. I am like we just keep going. I am fine. Let’s just do this. It was just unnecessary component; unnecessary headache.”

“Lots of blood works. First time I had blood work done everything turned out normal except my thyroid; I was hypothyroid, so I had to start medication for that. I was not reluctant to do anything and everything that I could to figure out what was going on and why I could not get pregnant.”

“We did a lot of diagnostics, and that is probably one of the earliest really emotional times where you are going through this pain for uncomfortable procedures. Such as the dye to test your tubes.

It fills the uterus up. Many people had cramping with the test but that one did not give me any problems. But with the saline sonogram I fainted on the table. So that was a really bad experience. Everyone was really professional as far as what they were doing. But for me personally it was really difficult.”

“The first things they did was to check my husband’s semen and check that I was ovulating so they just do ultrasounds and blood work to see my progesterone. It felt like I spent a lot of time doing that at my original OB/GYN’s office and it was not making any progress. They also sent me for an HSG but it was not conclusive. Then at my specialist’s they redid the HSG and were able to see that one tube is constricted but still open enough that an egg could get through. They also did a laparoscopy and were able to force fluid through. So, you are starting to go through all these tests and it is a lot more invasive than you are used to with any other medical procedures. Just like having the ultrasounds for the first time and then you get used to it cause you are doing it all the time, but an HSG is more invasive and it just gets more invasive as you go.”

There could be a lot more explanation

“You feel like you are thrown into all these diagnostics and tests. You are thrown into them and looking back really early on because nothing was covered, [not] even the diagnostics tests, you know, they are not explaining how expensive this is going to be before you go into it and how expensive it is prior to even getting to the treatment portion. Yes it just needs a lot of more explanation around it. They just throw in that you need this blood test and you need this scan. They say “this came back normal, this did not.” But it is a whole new world with new language and you do not know anything. You are forced into it and think there could be a lot more explanation.”

“One that stands out in my mind is when I first started going to that lady doctor. She was not really an R.E. but thought herself as a fertility specialist, she had me do a mucus test and she really got my hopes up. She said “I like it when I know the answer to the problem.” She immediately drew the conclusion that I did not have the right amount of mucus so that made it

difficult for my husband's sperm to travel and so if we did IUIs it would work. That test stands out in my mind and then the salpingogram when they came out back with this whole idea that I had scarring. I remember, the lab person, she was not a doctor, she was a Tech, I remember her and I remember the doctor both kind of – it is something that you pick up and it is so subtle - but they seemed judgmental and it was because I had an abortion. I know that because it was something that they both separately said and it seemed like they were being judgmental about it. Those are the 2 that I remember and I have negative memories about.”

“We had to interpret all our results because doctors do not really tell you a lot. They either talk down to you, or they just give you a piece of paper and say, “There is this and this is going on” and it is words you have never encountered before. For me not so much, but for my husband was a huge ordeal to get the sperm test done because he had to take off work, there is a very limited window to take it downtown. We really have got to plan it and do logistics and that is not fun.”

“I had to fudge it to get my doctor to even do tests, because they want to wait a really long time, and then they botched one test and I had to go back in. Even when I was getting my results, I never felt that anyone explained it really well. I ended up taking it to other people who were non-traditional medicine and get them to explain it a little better and doing my own research. They say it is normal. What does that mean normal?”

They are not necessarily fun to go through

“There were so many emotions at that time. I was anxious to look at the results, so I did not pay a lot of attention, I did not have a negative experience, I just wanted to get it done, get it over with, and figure out what the problem was.”

“I do not think there was a lot of testing because they did just the initial phase of testing, which was basic blood test only and then his sperm count. It was convenient but stressful in the sense that you are terrified of every test and what it is going to mean and what is it going to say.”

“They are not necessarily fun to go through. They did the HSG when they inject the dye and that is a little uncomfortable and painful. My doctor’s office, who would order that, said things were fine but they were sending them to the fertility doctor anyway. They called and said, “Well no, things are not fine. I do not know why they told you that.” So it is misinformation, which was frustrating, but I do not know that that made it necessarily bad. It is frustrating to go through, but I do not know the experience itself was bad.”

Ovulation

Trying to figure out on my own

“That always seemed kind of frustrating because my cycles were irregular, and so ovulation was never nearly predictable. I tried going by what the book said like looking for cervical fluids and temperature. But my temperatures were all over the place, and I was not using any ovulation predictor kits just because I did not want to go there just yet and seemed like another thing to do. I thought that maybe I could figure things out without bringing in something else.”

“She never had a regular cycle, so that was confusing at first for us to figure out. “What is going on here? Are you pregnant?” We thought we were having miscarriages at first, but in reality her period did not come every four weeks as usual, so it did not affect me physically, but mentally “Oh my God, could you be pregnant?”- No. “Could you be pregnant? No”. I would say emotionally it was more negative but physically it did not affect me.”

“I have just done the ovulation predictor kit. That is the only thing I have done. I have had many sonograms to check for cysts but not specifically for ovulation because I have not done monitored cycle yet. To the ovulation stick was a negative experience because no one wants to be doing that and it was annoying to have to worry about what time you are waking up and to have you drink enough water. Have you drunk too much water? Like is this the right time to do? Is that really a pink line or is that not? So I did not find the ovulation predictor kits to be pretty much fun.”

“I wish that it had been checked earlier. I was on my own. I was doing all kinds of my own metrics to figure that out. I think we should have more quickly gone to the sonograms.”

“I had always had a very regular cycle. I charted it and I charted my temps and so it was always assumed that I was ovulating normally because all that was pretty normal”

“It was self-done; I was able to ovulate on my own and I could track it at home.”

“I did charting for ten years before we started trying. So we did not do anything but share those records and they were fine with them.”

“We did the ovulation predictor kit. So that was really hard because you have to pee on the stick to know when you are ovulating. It is kind of stressful”

They have never tested me

“It changes every month. Right now I just check my basal body type. I use those ovulation predictor kits, which do not really help me because for some reasons has to do with the thyroid, and my temperature never spikes until like four days after I get a happy face. So those do not really help me. They have never tested me to make sure that I ovulated, which kind of annoys me because I feel that should be the first stop to see if I ovulated. The infertility guy just immediately wanted to put me on shots. They did not even test that.”

“Not many medical test. It has just been a lot of timely waiting and seeing what happens with my body. So that is frustrating. I have not had to do lots of ovulation tests per se.”

Once I started treatments, they would check

“The first doctor, the bad one, she was having me take my temperature and keep charts. Then the R.E. did not think charts were necessary and he mostly checked that with sonograms, or maybe even blood test. I know I tried the kits that you take at home. I did not always have good luck with those, I do not know if there were not sensitive enough but I was ovulating so that part was not the problem.”

“That was horrible because I do not ovulate normal. It was frustrating on my part. Ovulation was hard. When we did the IUI cycles, the doctor would do an ultrasound to make sure I ovulated and I would do the over the counter tests for seven days and it will always show that I have ovulated. I would end up using at least two kits because I would always ovulate later. So it is just frustrating. Not a great experience.”

“I used a predictor kit at home. And then once I started IUI they would check with the blood work and with the sonogram to make sure I ovulated.”

“[Before] We did it on our own. We did ovulation prediction kits, it did the job but not much fun. Have to do some sonograms I did not enjoy that; I thought it was pretty uncomfortable. Just awkward to do, plus expensive, very expensive”

“I think initially of not knowing when I was ovulating, before I even sought any kind of help I invested in those basic kits, then the digital expensive kit, then finally going to doctor. So initially they obviously diagnosed me not necessarily with an infertility diagnosis, it was just in terms of an irregular ovulation and they would also allow me to do sonograms closer to the time that you were ovulating to investigate.”

“I did blood work, which was fine. I did home kits, but I do not like doing it, but at the same time it gives me hope when I get that smiling face. It is working, I am ovulating.”

“I had to monitor at home and then once I got a certain result at home I had to go in for a sonogram to see what was going on. That was very stressful. Because I work full time too, I see patients too as I am in the dental field, it was really difficult. If I got a positive reading, I had to go to the doctor the next day and I had patients to reschedule and this was just stressful. I met a lot of women who were able to just be at home or had office jobs and could run out, which is great but it was a little stressful for me, but I made it work. My employer was fine with it, but still it is a little stressful.”

“I have been charting my cycles at home so I was sure I was ovulating, but it was not regular so to check for ovulation they were doing the ultrasounds and the blood work.”

Ovulate with extra drugs

“They have always been able to get my wife to ovulate with extra drugs. She did shots for hormones, and I would have to give her sometimes shots daily or whatever. The overall experience was [negative]”

“I never really got an explanation. Once I pushed for the drugs to help me with the ovulation, it was clear that according to them I was ovulating, but there was still a lot of confusion on what was going on and I would take it to the alternative medicine folks, which would do a much better job at explaining everything. I was using the OB kits and those are very easy to use, but it was never clear if those tests could be a false positive aside from going in and getting an ultrasound done. It was very confusing on whether ovulation was the problem or not.”

“I have never done it, there was not that much testing going on around it. I did it when I was on the drugs. So we took ovulation tests during that time to make sure but my ovulation has always had to be induced.”

Sperm

A little challenging to get him to do that

“Yes, my husband had his semen analysis that was a little challenging to get him to do that. But he did. And they did not really go over the analysis. I guess it came back fine.”

“It was funny the way he talked about the first time he went to the lab. He had to go to this one specific lab and do it there. It is just a regular lab; kids and people are there for their blood draws. So he goes to the bathroom, they do not have even a special room, and then hears somebody calling his name, and he can hear all the kids outside screaming or whatever they are doing, and he hears someone calling him again, the way he tells it is just hilarious. I am sure it was not a good sample.”

“They will tell you, “Ok, you can do this home. You just have to be here within thirty minutes to one hour.” Depending on what time of the day, what day it is, and where it is in town, that could be kind of a challenge. So that was not good and they could say, “Oh you could do it here at the office” but that was difficult to do. Here in the US, when we did IVF, they had a separate room and they would have aides, like videos or magazines and stuff like that, and it would be a dark room screen room. When we did IVF overseas, it was a room adjacent to the hallway where everybody was meeting and I had no idea, anybody could come through that door.”

“Thankfully we did not have to do any extra testing. It was fine. We usually were able to bring it in the office. Half the time he was able to take it and half the time he had to do it there. For IUI he could take it. For IVF or testing at the clinic or work up, he had to do it there. You know they do not like it but...”

“Pretty negative because you have all the hassle to get it done, and of course how my husband feels about it and it is not anything you can fix, he is doing everything he can.”

“They did a sperm count. It is all done at once; you do not need to go twice, they read it after they do the initial plunge, so that is not a pain skill, this is just an experiential skill. It was not easy to do. They did not actually chase me with a needle but it was close.”

“He did not enjoy doing it, but it was pretty straight forward, because all he had to do was just collect and drop off. He would do it at home. I think once or twice he did it there.”

“Because, I do not enjoy doing that because my husband did want to masturbate, he wanted me to. I would have to do that, I had to cup it and I would be so nervous to not spill it. This is like gold! Then I would be so anxious and freaked out driving to the clinic with it tucked underneath a sweat-shirt trying to keep it warm.”

“There were a couple of times we could do at home and bring it, but it had to be within thirty minutes. So we had to do when the traffic was really low and to make sure that we can make it.”

“It is so complicated and you have to do a certain number of days without intercourse and my partner had a real hard time with the whole process. It was very difficult for him, and the staff did not really try to be accommodating, so just get him to have to do the test was really difficult. At the end I think it was more stress related. The morphology was strange and he had a white blood cell count that was high. He took two tests and the first test was low sperm count but then the second it was not; which it did not make any sense to anyone. So, It was kind of ruling out things because we had two conflicting tests and we did not really know what that meant. He did not support the idea, he was very much against it, it was something personal. They suggested to do a third test, of course they are going to say to do one more test, but at ninety bucks a pop, and he by then it was such of a hassle to get in for both of these tests, so we ruled it out.”

“I would say convenience wise was convenient but in terms of stressful, Yeah! I remember being hard on him to go and for both of us all that time period was scary, what was going to happen.”

“It was just very *very* tiring. There is not a whole lot that I could do except not have sex for a certain amount of time so that he could get an adequate sample, and I do not want to hover over his shoulder. But at the same time it is like are you doing it right? Are you handling it right? Are you contaminating it with anything? Are you keeping it warm? And what is going on? I feel better if I have some control and this is one thing that is completely 100% out of my control. I have no control on this situation. That is very uncomfortable. I did not like seeing him feel uncomfortable, that kills me. Seeing him hurting and uncomfortable.”

“He could do it at home and just bring it to them. For him, it was probably negative experience because he felt pressured to do it. But he was really lucky he did not have to do it at the clinic, almost all my friends’ husbands had to do it onsite. So for him it was easy in the grand scheme of things yes. For me, I only had a negative experience with the nurse when she was telling me instructions for him on how to bring it and how rude she was about that.”

One doctor is not the same as another doctor. Plain Confusing

“You think the sperm analysis is the same everywhere, but with one place it was always totally normal and almost like stellar. But the fertility doctor did an analysis he said there was a motility issue that he felt could be easily related to bacteria, and also said that was a little bit low. So not everyone is equal and that is hard because his counts were off the charts and so I feel like all the early ones we had could be a little low on this or that. I feel it is such a hard field because it is developing so quickly and one doctor is not the same as another doctor.”

“Yes, obviously my husband did that portion, but his came back as kind of a borderline, it was in a gray area, it looked good, but there were a few bad ones. It always came back that way, really never looked that bad, but when we got to the IVF portion they ended up having to do ICSI. And so looking back on it I wonder why everyone said it is not that bad; it is borderline, even the doctor we loved said I would be surprised if we needed to do ICSI and then we ended up having it done. That confuses me.”

Another blow to us... that test should be done the very first day you walk in, not years later

“I had to do a lot of semen analysis through different doctors. It was not till recently with the local clinic that we found out he has a low count and nobody ever told us why until we went to the local clinic where he did the sperm and body test because they required you do it before IVF. He had a positive antibody test, meaning he has antibodies against his own sperms. That is probably one of the reasons that he has a low sperm count. That was another blow to us to find out we both have issues. We did not find out that until really late in the process. So then you wonder how come nobody else did this test, and why do we bother with all this other crap if we really needed IVF. We asked the fertility doctor and he said a lot of doctors do not do the antibody test, it is not until you get to IVF that they do something like that. It makes you think that the OBGYN office is sort of limited, and you start regretting why did I go to an OB/GYN that does fertility? Why did I not just go to a reproductive endocrinologist? So yes, you look back and you think why did not you guys dig deeper? Why did I even bother with IUI if his count is this low? We did three IUIs and they always told us, “Yes, this is good.” even if it is not. We did not know what is a good count, what is a bad count, now I know the process, but at the time we did not know any better.”

“With the urologist it was fairly positive, but then when we did the antisperm-antibody test with the fertility office, almost two years after my first sperm test with another doctor, it was a pretty negative experience for me because I was so angry that I had been done all these IUIs, which essentially do not stand a chance of working because of what I have going on. I was pretty pissed about that. Every sample I have given I did at my home, except the day of the retrieval I had to give a sample at the office and that was fine. We have friends that are going through it also. So we are able to joke and we actually send photos of the dirty magazines to each other as a joke. So we are trying to have fun with it. But that testing for the antisperm-antibodies is something that should be done the very first day you walk in. I cannot understand why I was never tested for. I do not even know if insurance covered it. I would doubt it, but I would still pay for it out of pocket even if it was a thousand dollars, which it is probably not, it is probably in the two

hundred dollars range, but if it was a thousand dollars upfront to get tested on that to then save on those four-five IUIs that we did, I would save a lot.”

“At first they only did a count and then when we got to a new doctor they wanted to do an analysis and they realized there was also an issue with sperm. So the first doctor we went was just focusing on me and not on my husband. With the second one we found that he had antibodies we were upset. So it was negative because we did not really find out until about two years after we had gone through some IUI treatments. It was a waste of time.”

“[Tested] Only during the course of IUIs. He has a child from his first marriage, he is almost seventeen. So they assumed that it was not an issue. It turns out, he went to a different doctor recently, his testosterone is very low. He was frustrated that if they had suggested that or... If that is the issue then we could have resolved that a couple of years ago. My doctor really was only focused on me, which is not necessarily the case. When they would give him his report from the IUI, the first one she said, “Well it is not great, but it is ok” and he said, “What does that mean?” and “I do not know,” that is the term she used “I do not know.” I asked, “Can I have a copy of that so I can compare?” I think they are surprised when people pay attention to their own medical care because nobody does, I guess. I work in a hospital and I have some knowledge, I want to have copies of results, so that I know what is going on. You know the terminologies sometimes, and they kind of are, “Oh well, she knows what she is talking about. “Last time you said this and you remember last time this was not great.” “Oh, that is right. This looks good.” “You did not even remember that last time was great. So let us compare the two.” So I guess it is more of the doctor.”

When you are diagnosed low it makes you... it brings about a certain low self-esteem

“Obviously every fertility process requires a separate sperm donation from me. I went through my own experience where the diagnosis was very low sperm count and that leads to further medical treatment as well. So that provided me with a bit of a roller coaster atmosphere as well.

The other thing that I would say about the sperm is when you are diagnosed low it makes you... it brings about a certain low self-esteem.”

“They tested my sperm and they told me it was on the borderline of normal and hearing that was like “Oh, that is embarrassing” but I could not do anything about it, so I would say I was more surprised. As a guy it is either going to be all or nothing: you are either able to make babies or not because something that happened you are the 1% and that is not fair, so that was surprising. We knew it could work but we did not know if it could work with the both of us having issues.”

At that point I had gone through so much and it was his time

“I was really happy that my husband had to go through something because everything has been on my end. Everything has been like you will have to get naked and do something awkward and have the doctor look at you. So I was really happy that my husband had to finally participate in doing this and so it was positive for me. He would mind a lot but I do not have sympathy for him at all. Usually I am nice to him and like “Oh poor baby your day at work.” but I do not even want to hear it. Not a word.”

“My husband had cancer, so they froze some semen and then they made him do a test several years after he was done with chemo to make sure things were moving. When I started seeing the doctor about the infertility, before they unfroze it, they had re-do the test and all was good. It went fine for him, the tests were not too involved. For me it was frustrating because I wish they would check more cause all they checked for him is if they are moving or there so many active. Is not there more you can test? Why cannot they test more to check that everything is working with him, they are doing so many tests on me.”

“That part was easy for me because that was the only thing my husband had to do. I remember thinking “I have to do all these stuff and all you have to do is just one thing.” I know we had some stress because they wanted my husband to do the sample at home and then race it to them.

It had to be within an hour but it was during traffic hours and we are on the other side of town, so there was some stress involved in it. Of course, you are also hoping the numbers are good and that we are not going to have an additional problem to the already female factor. There were few times with IUIs where his numbers were not that good but overall was good so it was not the source of the stress. I do not want to minimize it because I know it was stressful for him, but for me it was not that bad”

“My husband had to go and have a sperm test just once. He had to do a deposit once and of course he has super millions sperms that were healthy and everything. I am sure he would tell the experience was probably not as good, but it all worked out. He was able to do it at home and he had to get it into the office within an hour. I was not present, I just said, “This is what you have to do and this is where you have to take it.” I am sure it was stressful for him, but at that point I had gone through so much and it was his time.”

Genetic/Physiological

Testing Cost and Insurance rules: a big challenge

“Previously I had tried to get tested for MTH MR gene just because it runs in my family. Years before trying to get pregnant I was told that my platelets were fine, so I did not pursue that. Years later I saw another doctor who said “Well, we can actually test you for the gene.” I thought “you do not want to do that, insurance is going to label you as somebody who has genetic problems.” So I did not. I actually thought that was kind of screwy. What if I had [that] and I want to know? So, I shelled that for a while until I started in this experience, and I heard more and more people saying check for that gene.”

“I think the biggest part of this is not knowing what is genetic and what is physiological and not understanding where or if you can really have an impact on it. If something is genetic, you have very little opportunity on having impact on that particular issue. In this case it is fertility, it is sperm low count, it is all those things. Not knowing and not understanding what sort of impacts you cannot help in fixing the problems that are there rather than just trying to conceive. So this side of experience is not really understanding and not knowing. I think we did some tests to figure out, I do not know what they are called, but to figure out the genetic piece of it and whether there were any genetic abnormalities. I do recall some were much more expensive than others. So we may have passed on one because the overall benefit did not match the cost of it as part of the number.”

“We did some blood testing for sickle cell anemia, but we did not do anything like that until we went to Czech Republic where we did an immune panel and a blood-clotting panel. I did find out that I have two genetics blood clotting disorders, which is interesting. We did not do any of that here. I had friends who had to beg for that testing and I know in US it is very expensive, thousands of dollars. We paid out of pocket for it in Europe, it was three hundred dollars. So, it is crazy.”

Testing is done rarely and only after few failures

“They did Karyotyping on the third IVF cycle and it was a new clinic”

“I researched it a lot and I met with a genetic counselor here. By the end, as I was getting older and using the surrogate and all we were investing in it, I ended up getting tested for everything; both of us. Just because we are going through all these expenses, the surrogate, we need to know if we have any problems.”

“After I had a miscarriage I was telling the doctor “Maybe we should do this, we should check that.” He was very convinced that it was the age of my eggs that was causing the problem and the testing might not really be helpful. So he thought it was unnecessarily and they did not do anything really specific to that.”

“I do not remember doing this before, now when we got pregnant we did obviously the genetic stuff for that, but as far as I do not remember doing it...”

“We did not do any of that. I think they had hopes that had I more eggs left, so that after the IVF cycle they could have done something.”

“We did not have to go through it, but I may be going through it now. I had twelve blasts that survived freezing. We will put back three and if these three do not take I will probably go ahead and have the other nine tested, PGD tested. But we have not done that yet.”

“[For] Genetics that there were some screenings done. Physiologically with the sperm examination”

Medical History

Going back was really difficult

“That I did have to go back was really difficult. In my teenage years I was wild. I started experimenting early with sex and alcohol. I did get pregnant twice and had two abortions when I was 14 and 16. I keep thinking if I had these two children probably I would not be married to my husband. Things worked out the way they were supposed to, even though I do have a lot of regrets with those decisions.”

“It turns out his medical history had very little to do, but you feel you are judging everything. I had so much as far back as we have been able to trace on both sides. Five generations of women on my side, no one has been able to have a live baby past the age of thirty. My great grandmother died with a calcified fetus inside her. My mom had five miscarriages between me and my sister. They all hit menopause early, early thirties is when they started getting partial of full hysterectomies. I always had this awareness of “it does not necessarily mean that you have an early expiration date, but chances are” you know. So, there is a sort of pressure and having to dig up all of that, all over again every time.”

“It did not really come up for us because I had not really had any history. My mother has short-term memory issues. I remember trying to ask her about her history and how it might have impacted me, but she just did not have any details to tell me, so it is kind of a mystery. But I know that it was five years between her having my brother and me. So five years is a little longer than most people especially at the time she was having children. So I asked were you trying all those five years? She said she was. So that indicates something to me that was probably undetected.”

Just a bunch of questionnaires

“It is hard to get the information because you do not really know what people’s history was. Filled out a bunch of questionnaires, we did not go much further. I mean the interesting thing for me was that all the information that we gave them did not ever amount to anything. It was a lot of filling out of questions. It was annoying every time you go to a new doctor you have to redo all that. So it was just kind of irritating thing and it is time consuming.”

“We had to fill up some forms for a start if we knew any infertility in our history, but not anything too in-depth. I remember we had to do a standard procedure like, some blood test and just general stuff.”

“We had to do an extensive written history, I would not say it was easy. My parents were deceased and so I had to ask my sister questions. So, it was time consuming.”

“There were parts that were difficult. It was a lot of paper work and a lot of testing and a lot of digging stuff up. But it was just unnecessary headache again and there was not anything.”

They completely put it off

“Just paper work. I told them my mom was exposed to this DES drug. They are like, “Oh Your uterus is kind of small but it is fine. They completely put it off.”

“I do not really think that either doctor went into a lot of that as an interview process, it was more just going by the labs. There was not much of any questions that they really took into account other than just the basic tests I did. So there was not any kind of background. They did not seem to ask too many questions about that. It was interesting I had spent all this time doing charts and brought them in to show and they were not that interested. I do not think they asked a whole lot about my history. It did not feel very involved like that was not important.”

“I do not really remember doing a whole lot of this. When my husband found out about the sperm, he started googling and got in a big rabbit hole on why he would have antibodies and he

does not have any infections and this and that. But doctors have never really asked. They just take the diagnostics and go with it. They do not care about why. We have not had an answer about that.”

“They did not talk a lot about that. In my family everyone is super fertile, so it did not make sense to me that I would have problems, when everybody in my family had no problems.”

“It was basic information that I provided, fill out a survey or questionnaire. There was a very little work up done in regards to genealogical or genetic, even factors that might have influenced sperm health there were not really gone into it. They were positive about it because they were trying in many ways to facilitate a customer.”

Unexplained Infertility

A cheap way of saying “We do not know.”

“Well, that is pretty much what we were going through. I guess it was an ovulatory disorder just because my ovulation was not predictable. But at the same time that is not really a diagnosis because what is causing that? I was trying to make sense of it, I guess it was hormonal disorder, that is what they were saying “oh you know Clomid might help with that” but you are not really getting at the root cause of it.”

“I think that is the case. Many years ago on low sperm the doctor felt that he knew why and I went through the surgery and none of that worked. The doctor, in trying to understand the low sperm count, could not understand why the original surgery did not work and what the problem is going forward. That is how it remained for the rest of our time. So overall that is unexplained infertility. It was very frustrating for me that the doctors could not understand and again that he made me go through surgery on something that had not bearing whatsoever and had not effect.”

“It is a lot of crap. I feel like I am not having an answer. I feel that there is a reason for everything and they just do not want to dig deep enough to figure it out”

“They labeled me with that too. I do not know how they got to it, but when I asked “Why I am not getting pregnant? What is going on?” They answered, “It is unexplained.” I thought it was a cheap way of saying “We do not know.” So when you look at the papers they put PCOS and unexplained infertility.”

“You feel so confused and wonder what you could do or what you could fix and you feel you are running out of time because you do not know what is wrong.”

“That unknown feeling, if it was sperm count or low motility factor or something like that, then we would go, “Ok, that is it. That is probably it right there,” but the fact that we were able to get pregnant, you do not know if it was that the egg was not just viable because of age. The doctor expressed that too, saying “Hypothetically saying it was probably egg quality” but he really did not know for sure. So that was frustrating.”

If there is a problem, we want to fix it

“We always had and still have unexplained infertility, we do not really have a diagnosis. We know there are issues, but we do not have a clear idea. It is pretty frustrating not knowing what is going on. We did four years of treatment before we come to the conclusion that I can get pregnant but I cannot keep a pregnancy. If we have known from the beginning, we would have done things a lot differently. There is a process and they go through their checklist, you try one thing and if that does not work you go to the next thing. You try this first, then you try this, then you try that. It takes you forever to get to that end point. I think the doctors are doing what they can. I think it is the medical sciences in there. Once they concluded I cannot carry a pregnancy, there is nothing they can do about it, they just do not know what else to do.”

“We had unexplained infertility. We kept doing different types of testing and kept doing IVFs and they just did not know why it did not work because we had really quality embryos. We did three IVFs, my first IVF was when I was thirty four, the last one when I was thirty seven. I had two chemical pregnancies very earlier on. I had a lot embryo transfers. Probably transferred at total of eleven or twelve embryos. A lot. So they just did not know and it is funny because in the beginning I was really glad. I did not want to hear that something was wrong with me nor that something was wrong with my husband’s sperms. I thought that he would feel the blame was on his shoulder. If something was diagnosed with one of us, I would have rather be me than him, if that makes sense. I would have taken the news better than he would have, if that makes sense. So in the beginning unexplained infertility was kind of a relief, it is like nothing is wrong, but after so many years it is like, “No something is wrong. They just do not have the technology yet to know what is it that is wrong.”

“At the end of the day you want to know what is going on.”

“Well, I feel nowadays, they should be able to explain just about everything because where we are in a state of with technology and the way things work in the medical world.”

“The doctor always thought it was age related for me. One thing that happened to me and maybe this is a part of it is I have been going to these treatments for so long and then all of a sudden, my uterine lining went out. It had not been a problem and it always measured thick enough and after several IVF it just went ‘kaput’ and the 4th IVF had to be canceled. They had to freeze the embryos because we needed to wait for my lining to be better and it was a whole year where we had bad lining. The doctor thought maybe all these medications and treatments had stressed it. So we are taking a break and keep checking on it periodically also tried to revise my diet a little bit and I went to acupuncture even though I am not sure it helped but I was going because I thought I had to do something, if nothing else, for relaxing. I just did that for a year, the doctor even had me try vaginal Viagra. He was calling his old professors that he trained under to consult about this problem he had not seen before, it is very rare, there are people who had poor lining but not that suddenly goes bad. That I guess would be unexplained.”

“We tried two IVFs; it did not work. It was unexplained. We do not know what it is. I am not sure the doctor ever announced that I had that condition, but to me it is unexplained infertility.”

“[For] five years there were doctors not telling me what exactly was going on, but I did not know that I was infertile because they never told me that because I was so young, I just kept on getting written off.”

“That is what they told us. It has been very frustrating because it goes back to the medical model, if there is a problem, we want to fix it, and if there is no problem, well then what can we do? You know it is out of our hands so there is no fix. There is no solution for that and so that has been very frustrating. The doctor does not talk about it a lot. “Keep your finger’s crossed this is

the month.” Ok, it was not our month “Well, fingers crossed. You know next month.” Let us talk about why this might be happening, or what else we can do, or else we can look at. I feel very little attention was devoted to the topic itself. It is only more research that I have done on my own just do know how common this is and what have other people done, what are some things I might bring up to the doctor to suggest we try. That is been very frustrating that they are not offering a lot of discussion and/or solutions or options maybe. My husband feels like, “Well, there are very few things in science that we do not know anymore. They have answers for a lot of things now, so why is there no answer? Is it that they are lazy and they do not really want to look into it?” They just want your money to keep you. You do not know so you keep coming back and they are just trying to get your money.”

Everything works so great

“It was always unexplained and I feel my doctors never labeled me. He labeled me as a great IVF candidate. He never said we are totally unexplained. It is sort of “everything works so great. IVF will totally work for you. I feel like that is the biggest problem with medical field.”

“At start they said I had very low ovarian reserve. I was diagnosed with both unexplained and old eggs. I remember seeing both on my documentations. I did IVFs in here and it did not work. There just were not any indicators on why it was not. It was horrible being unexplained. And the whole time I told them my mom was exposed to this drug. They are like, “Oh, your uterus is kind of small but it is fine”

“Yeah unexplained is pretty much what it was. All the labs came back negative, everything was fine and that is basically what he said it was just unexplained, it could be a male or a female factor, a combination, timing. There was not any physiological issue that he could come up with. That was really stressful, it should seem hopeful but it was like “What is wrong?” for me it was stressful but for my husband as soon as he found out that his boys could swim he was “Ok, I am good. It is not my fault!” [laughs]”

“That was our diagnosis. They kept saying that one tube was constricted but it was still open and based on that I was not considering it a tube problem although just to be safe I insisted on doing extra ultrasounds every month to make sure I was ovulating on the other side, but it did not help it still was not working. So that did not explain the cause, then we did a laparoscopy and found two little tiny bits of endometriosis, they got rid of that, but that did not seem to help either. When we got to IVF, she kept saying “the eggs look good, the sperm looks good.” After the IVF and the eggs did not fertilize no one could tell us why that happened, nor they said there was a problem with the eggs or there was a problem with the sperm. They just did not know. And so yes, it is still very frustrating being unexplained and not knowing what is going on with you.”

“That is what I have. Because everything keeps showing up normal on my tests and I had all these surgeries I wonder “What am I not doing?” I also did have an eating disorder when I was younger that lasted for a long time and that is where my thyroid issue probably came from. It reached a point where I had to get treatment for it at a residential treatment center when I was 19. I had bulimia and anorexia for about five years, I hardly ate anything, and when I did, it was anything fat free and low calorie. I was obsessed with nutrition labels. I was very obsessive compulsive, always weighing myself and I had to be a size zero. I did not get my periods for a time because of the way I was treating my body. So there was a lot of guilt and shame from that too thinking that maybe that has something to do with my hormones because the only thing that they have found out is that I ovulate later in my cycle day 18, 19, 20, and 21 instead of ovulating on the 13th, 14th, 15th day, which they say is normal and not consider that to be an ovulation disorder.”

Probability & The magical number

“For years even before I had gone to the reproductive specialist that was the initial diagnosis, I was thirty five at the time. Then the fertility specialist mentioned diminishing ovarian reserve and that is why he basically said to me flat out “I do not know if there is another possibility to go through IVF again.” But we did not want to have any regrets of not trying. So unexplained infertility was as we were going through the initial phase.”

“They could never tell there was a reason why it never worked, a big black hole there. But here is my lay, because I am a kind of a pragmatist - having looked at the statistics - it is entirely conceivable and in fact one might hold even expect that our result was as it was. Granted we had tried it multiple times, so if we have a 50% chance and you try multiple times, one would think that you would roll a dice “sevens” but it does not work like that. That is probability, that is not statistics. So in many ways our infertility was explained, either works or it does not. I do not dwell, because there is never an exacting explanation. While many might need to hear “This is what is wrong and it is not fixable or it is fixable” and when they do not know what is going on that seem the part that consumes people most, not me.”

“I knew the results were just the hormones levels as a thirty-seven year old woman at the time I was textbook. My levels were low and my whole issue was egg quality, which was low because of my age. The devastation of the phone call, I did not understand it at first until I really was able to grasp it and see what was going on because I just thought, “Ok, these are the levels and how do I get pregnant and have a baby?” I did not know it would be so damaging, but it is what it is and it takes a long time to accept it. I did not at first.”

“They said I got too old. You know, my numbers seemed OK compared to my resolve friends. They just said “you are too old. Your eggs are probably bad.”

Doctors' Opinion

I would tell him that concern he would usually talk me out of it

“I feel like they just did not take things seriously. They just wanted to either go right to Clomid or keep saying just do not worry about it, just that whole dismissive thing.”

“I have a girlfriend who went through all this telling me that doctors always blame the female factor. It is your eggs, but could be a male factor too. We never did extensive testing on my husband, just more on me and I think I was sort of torn. When he would explain it to me I understood why he thought it was female factor but then sometimes I would have in the back of my head my friend telling me “You know, these male doctors have a bias and you should insist that your husband get all the testing. You should hear that story where people have gone down this track all this time and then all of a sudden after years they find out it was the male factor all along.” That would be one of the only things I was frustrated with. I was not being really pushy; he would always say “We can try anything you want,” but when I would tell him that concern he would usually talk me out of it. I do not think that it was male factor at all but I always wonder.”

“Doctors just called and said I was unexplained, and when I asked them about the abortions, the eating disorder, the thyroid, they said that it probably did not have to do with it. In one way it makes me feel relieved, but on the other way it make think they are either trying to make me feel better or they are not giving it enough credit.”

“Well, with the doctor who diagnosed my husband, you could talk very strong personal opinions on how we should do things. I felt there was some pressure there to go his way and explore those options and that is not really the right thing for us.”

They cannot really tell you why, but you A great IVF Candidate

“This one I had a lot of hard feelings I guess. The doctors did not accurately describe what the potentials were and what the reality was. And then my doctor not understanding what the low sperm count issues were.”

“We basically eliminated ourselves out of the process entirely, which means there were never any opinions other than “that did not work.” And that is not an opinion that is a statement and a fact. The doctors never had any opinions that were helpful. They were able to present to us alternatives and options that we could try, but their opinion, the medical opinion part of it, it seemed like it was not there. I do not think it is necessarily failing with the doctor’s part, I think it is just where the science is right now and they cannot tell you. They can tell you they think an egg is bad because they look at the picture of it and it does not look like some other eggs. But they cannot really tell you why it is that way or even if it is that great.”

“I personally feel people’s opinions are their opinions, everybody is going to have one and it is going to be different than somebody else’s and you can only go of what your data is showing you and what the professionals could do this ten thousand times more than me do. So we took the opinions of the physicians in Minnesota and it is like rolling a set of dice and saying you need two twos to get pregnant and it does not always happen and while it is frustrating I do not know if they missed my wife’s endometriosis, I do not even know it was present when we went through the IUIs. I do not feel there is a day where I felt we got really screwed and he bought a BMW with our money, but then it was like “They may not have been there, perhaps the testing has changed over the last three years.” So it is their opinions, you as the patient have to make a decision, they provided them it is not like they said “What do you want to do?”

“I was very frustrated with my wife’s doctors talking with her about with this sort of unexplained PCOS. They did not make any sense to me because I felt they should be able to give us more information around why she has that or how they know she has it. They just say you have it and then do not explain anything beyond that.”

“It is hard when you get back that kind of news. I can remember the exact moment when I found out about, I was a wreck. They gave it to me in numbers and I had to go on the computer and look up what that number meant; how bad is it and what does it mean; because they gave us numbers and then they gave us, “That is unlikely” but unlikely does not mean anything when you are going through that.”

“Well, it was frustrating that they could not tell us why you have this, but they could tell us that it did not matter what exactly the cause is here and even if you are unexplained, you can do the IUIs, you can do IVF. My fertility specialist’s opinion was very helpful, while my original doctor did not know and I felt they were guessing and trying things.”

“I did not necessarily agree with his diagnose. The labs said I have low eggs, not super low but kind of low, I did not agree with his opinion on where we should proceed with treatment, but I do not thing If I were in his position I would made a different call. IVF has a very high success so I see where he was coming from but it is just not for me.”

Different opinions

“I get different opinions everywhere I go. That is frustrating and confusing. I am a nurse, so I feel I am more knowledgeable than most going through this process. But I am not a fertility nurse. I do not know anything about fertility. It is very confusing to see so many different opinions on how I should be treated.”

“Just depends on the doctor. I thinking getting multiple opinions is important. You need to seek out the right doctor to get the opinion. if it is the right doctor then great, but otherwise I do not really need your standard opinion. I could google it.”

“Most of them were wrong. I could probably have more, I could not have afforded it. Who knows? I could have had twins or a couple of kids if they had diagnosed me. You know if their opinion had been correct in the first place. Sure, and they were not.”

“Going back to when I was first diagnosed in 2008, just finding what was wrong with me was a relief. We had been going for five years without getting any answers, so getting an answer was a positive experience, knowing that there is something wrong with me and I was not crazy and we could deal with.”

Easy opinions

“I am thinking of doctor “Mr. this is going to be easy.”

“I look back and I even wonder if I really had PCOS or if that was just the popular diagnosis at the time or the easiest to pinpoint because I had a few cysts. But was that really it or was it not? And they did not do Metformin at the time. It was not until later on that I was on Metformin. But yes, I did not have any of the major symptoms you hear about. So I will always question that. And I question why we did IUIs so many times for so much money. They do not take cost into the equation at all, like how much money we could spend doing three of these versus a better chance at IVF and be half the cost. So his opinion was pretty easy. So he did not offer very many opinions.”

“I remember the day my doctors told me to get a second opinion with another doctor at her clinic. That doctor was pushing egg donor saying that it is better than adoption. He used those words and I got so mad at him. So we got into this argument back and forth about all the pros and cons between egg donation and adoption. He really killed me when he said that egg donation is cheaper. I said, “What are you taking about? It is twenty to thirty thousand for the eggs and then you are going to do infertility IVF cycle on top of that. There is no way it is cheaper than adoption.” And he said, “if you got an egg from your niece” “Well, my niece is nine years old. So I am not getting an egg from my niece.” That was a really bad conversation, I remember asking if we should use the frozen embryos for surrogacy. He said no and I should go straight to egg donation. But our surrogate actually did get pregnant. She miscarried after eight weeks. But to me he was too opinionated.”

“I feel the OB/GYN was over optimistic. There are so many unknowns. It is just really hard. Doctors have opinions, but I think they do not know. So for me it feels not so great. But at the same time, I feel that the second doctor, tried to be very honest and tried to be very caring with his opinions, but the OB/GYN, I feel her opinions were kind of unfounded. I wish she had done a little bit more; been a little bit more upfront.”

“He did not do all the tests. He had one month to look at, but he just looked at my follicles on day two and that was it, and said I have unexplained infertility. How can he even know that I ovulate every month, if he did a test to see if I ovulated. I am mad about it.”

“I thought the doctors were difficult to work with, with the exception of working with the second fertility doctor here in the beginning. I asked her, “There is so many people I know who are too old and their eggs have gone bad” and she is like “I am not concerned about that with you. You do not have a problem.” Then we did two IVFs, one month after the next. We did one and went right into the second one and then we were shocked when we are planning a third and she was like “No, you are too old, your eggs are bad.” “But you just told us that was not a concern for you at all.”

I never second-guessed them

“I feel he was fairly hopeful about it and just still a matter of fact, “This is what we are going to try, this is the plan. I never, I do not think I second-guessed anybody. I have mostly been able to trust what they say about my condition. I feel comforted that it is PCOS because that is so common, they deal with it so incredibly often. It is not like “everything is in place. I do not know what is going on.” So I feel they have been able to know what the problem is most of the time. Well I felt that the doctor stays ahead of the game. He gave us diagnosis as it was but I think the solutions were a little bit on the cutting edge, which was good. Actually what you want is somebody who is not afraid to take a little risk, but who is willing to do the research. What I loved about him, even as he gave his diagnosis and we talked about all the different options that

he seemed to be well informed about. He suggested to try things in some other places where doctors were actually trying those, “You know we are not doing it right here yet but if you want to do it, let us give it a go.”

Fertility Treatments & Process

Fertility Treatments & Process describes the various types of treatments that may be part of the Fertility Treatment Experience. The sub-affinity titles or various components as indicated by the participants and their interview responses are listed in the following order.

- ◆ Treatment Labs & Tests
- ◆ Treatment Preparation & Scheduling
- ◆ Medication
- ◆ Diet
- ◆ Rest
- ◆ Surgery
- ◆ Assisted Reproductive Technology (ART)
- ◆ Alternative Medicine

Treatment Labs & Tests

The men perspective

“I would say as a husband, as a man, it is negative because you see the woman going through it all. The testing for me was very simple, you either go into the bathroom and provide your sample, or you provide your blood; for a woman is much more intense and I felt awful that she had to go through it and there was nothing that I could do to take away that pain and that is sad.”

“All I can vividly remember is the embryologist and after they have extracted the eggs and they go after the process, that is actually an exciting feeling that you know the baby is being created. So that is a good experience. I am sure not all labs and tests were exciting and fun, but I do not remember anything negative in the treating process about labs and tests.”

“It was only peripherally entertained by me. That was her, that was all her, that was her baby so to speak. I was supportive. I wanted to be there as much as I could, but I could tell from the feedback of how she presented it, she wanted more and I failed to bring my full presence to

whatever I could have helped her with. At the time I did not know how, I did not have the tools; I could see the need but I could not get there and I will tell you the truth, my wife would start weeping and the first thing I get is this expression (annoyed expression) and that is really not helping for a relationship. So that translated into maybe being a little ambivalent.”

A necessary evil

“It is all necessary to me. I just liked to be doing something. I felt more in control while going through treatment just because I knew I was trying something. I was not just having sex. I guess personally I liked doing it, but it was very stressful trying to arrange around work and then find something to tell my boss. But I liked knowing that I was kind of doing something.”

“Well, the IVF experience was very short. The majority of my memories come from IUIs and having to check your fallopian tubes and stuff like that. Having to schedule time for that part of the process was more of an inconvenience but yet exciting because I wanted to get to the diagnosis part more than anything.”

“That part was not that bad. You know, you are getting lots of blood draws and you are getting that kind of stuff but I did not think that part was too bad.”

“It is a burden, but at the same time when I was doing labs and tests, I had little bit of hope, because it made me feel I was doing something for the progress. But it was definitely annoying have to leave work and make arrangements.”

“They were uncomfortable. Especially waiting in the waiting room so long. You end up going to the bathroom beforehand but then you are waiting so long that your bladder fills up again. So it is like “ok what now? And then they would come and say “Sorry we made you wait. And now your bladder is full and here comes the vaginal ultrasound.” “ah come on people”

“... getting the sperm it is really complicated. We had to do it several times taking it in and it is a kind of ordeal every time and getting blood draw sucks. We were north and there is only one

place you can take his sperm, it is not downtown, it is only a twenty minutes drive with traffic. But, there is only an hour window, so he has to collect the sperm, control the temperature of it, get it to this lab in traffic in the time window. Meanwhile he is missing work, so he has to call his boss and ask for time off and he does not really want to talk about why, and then he has got to get it there, hope it is still good and the results are still accurate – because he had to drive for thirty forty minutes at this point.”

“I did a lot of blood tests and I did a couple of HSGs. I had to go for a DNC and come back a couple of months later to do a hysteroscopy. It was just frustrating when you have to. I already did this. What else have I done?”

“It was somehow frustrating, part of doing the IUI is there were all these doctors’ appointments, coming in twice during the month to do ultrasounds one at the beginning, one in the middle and then you come back for the IUI itself. So there were a lot of doctors’ [appointments] and that was a little frustrating especially when it was not working. You feel ‘why I am I doing all this?’ There is a lot of extra blood work associated with doing the IVF, but I just got used to all that.”

“Oh my gosh, if you go through IVF the stimulation really stinks. You have to do blood draws every three days, you have to do ultrasound every three days. You just feel like you have been poked and prodded, having to go through that is not fun.”

“We did a few IUIs and so with that there is not a lot of blood draws and obviously the sperm stuff. With the IVF there was a lot of labs because they check constantly the levels. I hated that. I hate that a lot.”

“We have been through this for six years with no child, so it has not been great. We have done three IVFs that failed, we are going through that again right now, but we are doing an egg donor.”

“It is not fun to be wounded and the way they have to poke you and squish things around. It is not fun.”

“Labs and tests are pretty straightforward. We did the basic. We did the basic vaginal sonogram to check the ovarian reserve. We checked extra ovarian FSH, progesterone, all the checks to establish the baseline. Then of course it was the ton of blood work every other day when you are in the process of going through. They check the ovary to see how the follicles are doing. It was pretty straightforward kind of drive. They tried to make it as comfortable as possible. What I loved about the fertility doctor was that he has the online portal. You could go in there as well and see your progress every single day online. I thought that was helpful.”

“That whole time period was just really stressful and really hard and every test was a big deal and scary but it was not because of the doctors, it was because of what we were going through.”

“It is a lot to keep track of. It is a lot of appointments. You are missing time at work. You are driving to and from places. I lived my life in two week increments and that makes life pass by really quickly and you miss to hear it now because you are only looking ahead to the next two weeks. I feel the last couple of years have been a blur that have passed by, I do not know where they went. I lived in two week increments.”

Treatment Preparation & Scheduling

I had to be on top of my game

“I feel I had to be on top of that because you need to see so many and you see how crowded it is. When I was doing Clomid, I had to really have a sense of my cycle and they would tell me “oh the ultrasound technician is only here on these days” and I had to figure out how that would fit in [my schedule] and if it was not right then I would be missing an opportunity to see the ovaries at the time when we needed to see them. But that was not at the fertility clinic, once I was at the fertility clinic I was able to come in whenever.”

“Scheduling was annoying in terms of my sensitivity and my anxiety with proceeding with treatments. I feel I always had to negotiate with the nurses to start when I wanted to start. I do not think they fully explained the process to me to be able to figure out how to do things and when I could start. I feel they were holding back information. I would say “I wanna start now” and they say, “No you cannot start for 2 weeks.” They would explain just the first part and not what comes after or give you a picture of how your body works. With more experience I got it, the more I understood the process the more I would negotiate with the nurses and be like “If I do this can I start here?” That should be coming from them “This is what you need to go through. This is when it should happen but this is what we can do.” I feel they were never in as much hurry as I was and they never really got that. They are like “Oh yeah we will wait for the lab tests and then we will do this” and I would say “can I be doing this while we are waiting for that?”

“It depended on the doctor, with the OB/GYN was positive, they were very organized. With another fertility doctor that I tried between the first failed in-vitro and before we started the donor process I could not even get him to call me back... when I started getting those negative experience I moved on to somebody else because it was too much stress.”

“That was tough. It was difficult. We tried to make a calendar to show all the steps and when we do what, when we are coming in for ultrasounds and stuff. I do not know why they are not more organized and why they cannot just put it in a calendar. Just seems like we had to pull teeth to get answers from them for when we are coming in and it was always difficult. There will be situations where I need to get in that day to have an ultrasound and it was hard to get through to them and then they could not fit me in until maybe the next day and I was like but what if it is to late then? It was of a lot of juggling. It was very high stress, this could make the difference between our path going with this or going with this. It is all the weight of the world on your shoulders. It is phone call after phone call and checking the schedule. I think that was more difficult with the clinic here because with the other one out of town I was just going every two weeks. They would just come in and go “oh this is going on. Come back in a couple of weeks.” But with the clinic here I was on a protocol. I had to juggle everything.”

It totally controls your life

“This is the one that is very regimented and this includes the shots we are taking during the IVF process. The preparation of the shots during the IVF process and scheduling is very regimented and your entire life is dictated by the grand scheme; the grand schedule, but as well daily schedules. So micro schedules as well as macro schedules. You cannot plan a vacation around a certain time, you could not fly or do certain things. That is a very all-encompassing process and it totally controls your life.”

“It takes over your life. There’s a bit of excitement in it as well but leans towards negative”

“It is hard to deal with. You think you have it pinned down and then it changes. We just moved here and that is why I decided not to get a new job because we were going to be doing this. The money would really be helpful, but I cannot imagine trying to do this in Colorado while being here and having a new job. I just could not imagine my employer would really be open to that.”

“All those thing suck [sic]. It is a lot of waiting, a lot of stressing out while you wait and my body is particularly frustrating me because it does not respond well. I have to take a lot of drugs to get stimulated. Right now we are waiting to do our very first IVF transfer and I just found out that I have to bump it a week because my uterus is not responding to the drugs. It is trial and error process that takes forever. So it stinks trying to coordinate it and trying to do it around trip or events in your life. It is almost like you have to put your life on hold because everything depends on this fertility crap.”

“There are so many doctors’ appointments, you are always going in, and they tell you would be uncomfortable. I remember our friends having birthday parties that I could not attend because I was in pain.”

This is one of the most challenging part

“That was awful just because my wife was crazy, work was nuts, I was always able to go, but it is difficult to get away. I have a very flexible work schedule so I was able. I do not know how people who have normal jobs where they have to go to an office every day, could do it. It took away from life, it took her time, ten whole hours a week that she would have to go.”

“I would say the scheduling is hard even for me but especially for him. He has to ask off work and not really explain, so when you tell, your boss “I have to go to the doctor” and you obviously do not have a cold or anything like, they are aware that you have something going on but they do not know what it is and you do not want to say “I have a problem with my sperm count” So, the scheduling is pretty awful.”

“I feel that the whole process of infertility is scheduling [laughs] both with the doctor and the kits. I feel like there is a lot of that and it is stressful.”

“Having to juggle job and things of that nature and fitting it into your work schedule.”

“The prep for the IUI was fair up till I got a positive on my home test and then figured what to do and go in the next day. If that happened during a workday suddenly I have to take off. I was not telling work where I was going, just, “I am not coming in tomorrow morning.” But it was fairly fast. The scheduling for the IVF was the big one. We had to schedule everything. There was a lot of taking off, but once they got me on a schedule it was to expect that were going to be all these appointments coming in all these times and they did not tell you what was coming up. It was just a lot of, a lot of visits.”

“There Is a lot of stress related specially because I did not know I was doing all these stuff, all the checks, and you suddenly need to leave, you have a lot of appointments and things like that. That part was not terrible but it was not great.”

“I just remember it to be kind of overwhelming, just the amount of information, “Ok, you have to take this at this time. You have to take this at this time.” I am talking about my wife, but I am there to help remember or help her or whatever. That was just overwhelming, all the things she was supposed to remember to do on top of everything you are also supposed to do with your regular life, it just drains you.”

“Because I am a graduate student, my schedule was pretty flexible. So I had the benefit of that. I would say nobody likes to have to do that kind of crazy scheduling and preparation.”

“Having to make arrangements with my work because everything does evolve around the doctor’s schedule, when they are available. Of course your body’s schedule somewhat too, but you also have to work with a very busy doctor. So trying to get in at the time and having to make arrangements with my work, around important meetings or having to disclose what is going on with my boss, that is how it can become uncomfortable.”

“It is time consuming and there is a lot that I have to do – give myself shots, patches, it sucks! But it is worth it, if it works.”

“Although it took a long time. It is the only complaint but that is just human. From my perspective it was easy, but mine is not the most important experience.”

“It is hard to schedule some of the treatments because they depend on your body and when you get stuff done. It has not been happening nearly as quickly as I would like because I do not get cycles regularly. We have to wait for them this time. We have to take progesterone. I wish that it would happen faster and would be easier to schedule but I think that is just sort of how it is.”

Like air traffic control

“For the most recent IVF, that was fantastic. I thought it went back to having one nurse. She was in-charge of everything. We always said it was like air traffic control, she was so good at preparing us and letting us know our schedule. We had this master calendar that they got prepared for us and there was always an on-call nurse on Saturday. They were awesome, she was great. I thought they did that really well for that portion.”

“I think they were really good. They were flexible as your body would allow it to be. Once you get to the cycle, you are a slave of your body. Whatever the body says, that is what goes. If it is like you have to take a shot as on this day, take a shot on that day, we are retrieving on that day. I think they were really good, really accommodating. As a matter of fact, I think we went through my egg retrieval on Sunday; so they were doing whatever your body says, that is what would go. They have a great scheduling system and when you go in it gives you a treatment plan. So everything is online. You know on this day you take this, this and this, and you have this shot on this day. You have appointments here every day. So everything is completely lined up. They do a really great job of getting you ready for that.”

Medication

It is painful, you are spending all this money, and it is an IF, but definitely a necessary evil

“I hated every minute of it because they were all shots.”

“When you are doing the shots, we have been over places, we have done shots in a parking garage and we have done shots in public bathrooms. It is absurd. And you know they have to be refrigerated and so you are bringing a cooler. It is absurd what becomes normal, or the fact that you cannot just go to a friend’s party without them or if he was going to be out of town, who was going to give me my shots? If I needed the big one or the tiny or do I *fuck up* for doing it myself. So it is like what is your travel schedule then calling your good friend and ask, “Are you able to come over at 07:36 tomorrow?” so it is just absurd.”

“Medication is not fun at all. It is really expensive and you feel like crap. I remember going back to the treatment preparation and scheduling they have us get our medications all at once. It was everything from the birth control before you start the IVF all the way through to the pain medication after the egg retrieval and all the hormones that you might need if you get pregnant. I remember my husband picked it up and he came home with two shopping bags full and it freaked me out. I was like “this is a lot of medication we are putting into my body.” And the amount of money we spent on it was astronomical. Then you started taking the medications, they are not fun to take and you are feeling just miserable. I was lucky that at work they knew I was going through this and they were able to understand if I was not feeling well or I did not want to schedule meetings. I always had a backup. My stomach was really upset, it is painful and at the whole time you are spending all this money and it is an IF it is going to work. It is just a gamble.”

“It was very easy to order online; no problems there. The doctor gave us a tutorial. We had a classroom with other couples to learn how to use all of it. I did the shots myself. That was hard.

Shots in the beginning were hard because it is the first time you are doing them. I wanted to do them. There is actually one you do intramuscular in the behind, for those I was very *very very* nervous the first time my husband did it on me. That was hard. During our third IVF he had to go out of town for a week. I just did by myself. It was really empowering.”

“I had Lupron and it was not until the fourth or fifth IUI that the OB/GYN recommended doing a sonogram. After looking at the sonogram, I started Clomid. For the IVF, I did the antagonist treatment both times with the injections. I had no problem jabbing myself with needles. Despite my fear of needles, for me it was just part of what I had to do and I just dealt with it. The hard one was the really long thick needle that we had to do in the thigh for the frozen transfer, we had to do that for about two weeks every day and that was extremely unpleasant. One time my husband in the last minute went to a concert and I had to do it myself and that was really hard. But, I did it, after I got the courage I just jabbed it into my body. It was not pleasant. I just knew I had to do that.”

“Being on the Gonal-F injections for so long and then with the donor process the estrogen injections on the bottom were awful for me. I had a reaction, I had to go to the doctor, I could not sit, I had to walk around with a pillow and I was on estro for a long time too. So the medications I did not enjoy, both from an emotional stand point of views making you a little bit off and physically, the effects.”

“The medication is horrible, sometimes it makes me feel good because of the extra hormones. I was on Lupron and I just got off from that a few days ago. I did not sleep well for a week, I used to wake up sweating. It is not fun.”

“There were some really awful emotional side effects and hormone swings. At one point I was doing the Chinese herbs on top of all. It was just an overwhelming amount of pills. I tried Femara and then Clomid; and then with my acupuncturist he was working on the key clearing.”

“I understand you have to take the medicine. You have to do it, it is a requirement in order to get to an embryo. It gets you to a fetus and hopefully to a baby at some point. A piece I did not understand when I first went was that they do the retrieval, then they watch the eggs and then in five days they transfer the eggs back in. Initially I did not quite get that. I thought there was going to be a window to get some of the medicine out of your system. Because I had no idea, I was thinking how does a baby survive under all these stuff? But I guess they know what they are doing. The medications were difficult. The shots were grueling and I am now still doing shots, still doing this cycle and have bumps and lumps and bruises. I am ice packing them and you numb them but they are still there. So, the medications are tough but they are definitely a necessary evil.”

“I never had severe side effects. The worse medication I took were the intramuscular injections, those are painful. I did some vaginal suppository, which are awkward but not painful. The shorter needles were never a problem. The hormones were never a problem. Some people say the medicines make them crazy or anxious; I never had problems with that. In terms of the timing it took a little preparation, I had to bring stuff to work or if I was travelling make sure I kept it refrigerated. In terms of getting them, a lot are mail ordered so at times if it is a Friday you had to make sure that you call before 5’oclock and then you are not getting them it till Monday.”

“I think that was fine. I did Gonal-F. They gave me a lot of stimulation. I did not have problems with the shots and my good nurse showed us how do to all of that, how to mix everything because we had dry and wet vials that we had to mix. Taking all that medication was difficult because I had to juggle it.”

“There was a lot of resistance at first to taking these meds because I thought something must be really wrong with me if I am having to take these heavy duty pills every single day. Right now I take eight pills in three different installments throughout the day and it makes me feel like a cancer patient, or someone who is gravely ill, I have to stop what I am doing so often and take all these things and balance them out. I really do feel like I am sick because I have so many

medications. On the other hand I have not experienced a lot of side effects and they seem to be working for me as far as doing what they are supposed to.”

“They gave me progesterone to help with the luteal phase defect. I do not like that medicine. And they did not test it. They did not test my progesterone level. They just gave me medicine. That is annoying.”

Hormones are dangerous business

“Initially I had to take the pills, it is a five days course to take it at the same time every day. They say it can make you feel real icky, I did not see any side effects except that the pill tasted horrible and then a couple of weeks later you have to go in for an ultrasound to see how the follicles are developing. Although it worked for us I did not like taking the medication, it was abnormal. You think, “What is this doing to my body? Is this a good idea?”

“I am not a needle person, so my husband did the shots for me daily, if not twice a day. They were several, sometimes two or three administered at one time. It did not bother other than in terms of how my body reacted to it and the way I felt, I was not myself. It was a lot of medication to deal with. You have to take the medication with you, transport them, keep cool, time it right, getting up in the morning and just somehow fit them in to your schedule. So that more than anything is very stressful.”

“When I did IUI the doctor doubled my dosage of Clomid. He did not mention that to me, but I just wanted to get pregnant, I did not care. And oh my gosh, I thought I was going to kill my husband; I hated him. Never in my life did I think I would be someone who got a divorce and I was seriously driving to work thinking that I was going to have to get a divorce. I hated him. I did not associate it with the medicine.”

“For my husband they did a round of Clomid, which was interesting because it has different side effects than putting him on artificial testosterone to try to stimulate sperm production. He went

through a couple courses of that before they did another sperm test and found out it was working. It was frustrating, trying to figure out the right dose because it was like half a pill every day or one pill every other day. “Are we keeping track of that? Are you taking it at the right time of the day?” I took the birth control pill for eight years, so that was something that I was familiar with but my husband was like, “What is this?” Then all the side effects of being on hormones. You think about women going through infertility treatments, same happens, hormones are hormones. They are dangerous business. He got really aggressive, angry, passive aggressive, and frustrated. He did not see any changes in his behavior, but I saw a big change. That actually caused a lot of problems. When he got diagnosed he had to deal with a lot of feelings of his sex drive being tied up in the idea of his virility. So it kind of tanked. Even though his testosterone was going up, the Clomid made his sex drive to tank, and he was very aggressive. With the low sex drive when he could not work himself up to it, he was not necessarily excited about it. I have a past history of sexual abuse, so he triggered me for the first time in sex. That interfered with our intimacy and sex life and it was just this compounding problem. Once we finally decided, “No it is not helping, there is no way you are making sperms. Get off the drugs,” things slowly started to improve. It got to normal. It was like, well let us tear everything down to its foundation and re-learn each other sexually all over again because obviously for over a year my excitement about it was we could be getting pregnant, and when that was taken away, it was like, “Oh that is kind of a buzz kill.”

Husbands helped with shots

“I have not had a lot of problems with medication. I do the smaller ones myself, my husband does all the intramuscular ones, he has been great doing the shots.”

“I did not take any medication, but I did have to give my wife several dozens of shots. That was not fun. I did not understand how much of that I would be doing and these big needles and being uncertain about sticking some of the needles. Initially we had the nurses draw on her where I should do it in black mark and when they stated to fade we drew them back in again. So I would have a better idea, but every now and then she would bruise and I felt pretty bad about that. I was

never super comfortable with it. It is hard and you need to get the needle it in all the way. So that was not fun.”

“For me it was frustrating because she was having to do a lot and I could not really be there. These were shots or pills she was having to take, it was frustrating for me because I thought, “I wish I could be doing, I wish I could take this for you.” Because she would have bruises on her abdomen or bruises on her behind. The other thing is I had to learn how to give a shot to somebody. They would tell you on the videos, “You need a sharp, jabbing motion.” I was like, “That sounds horrific.” Just inflicting pain on my wife, I did not enjoy this. As far as side effects, not too much on that but overall it was hard for me because I would have liked to be able to take some of the shots or some of the pain and I could not do it.”

“My full exposure to medication was whatever was on the counter top and what I am injecting her with. She just said, “This is what you are going to be doing.” And I said, “Ok” I will wrap my mind around it and I was glad for it honestly because it was a way that I could express being there for her, and so we built it up kind to be a big deal. That was my interface with the medication that I think it was profound.”

“That was the hardest part; my husband would give me the injections every night. You do so much and I felt like it was such an intense experience. We did three injections at night, plus the progesterone inserts... and you have to take them with you when you go around.”

Expensive and challenging to get

“I hated it, very expensive, how it will get in at certain times and worrying if it will arrive on time. Lots of medication; needs be refrigerated and mailed to us. Medication cost, I remember an episode after having a treatment and we did not have the right medication and you always think whether that was what caused the loss or not. So yes I have no good thoughts about medication particularly with IVF.”

“I did Clomid and Femara and they did not actually bother me too much. The meds for the IVF were not that bad; they were expensive and that was the issue for me. I did not like having to give myself shots but it was not so bad either. After IVF there were a couple of meds that were kind of annoying.”

“It was a lot to keep up with. I do not have positive feelings about the medication. I had to order it from out of state and sometimes from out of the country. I think one of the doctors even used some medication from out of the country. Sometimes you need to start the medication right away and it is not going to get to you in time because a pharmacy out of state is compounding it for you or you have a cancelled cycle and the medication you bought here in the States has a really short expiration date and wonder “Why did you give me medication with this short timing and not give me a refund. When I buy something I expect the expiration date to be a year from now and it was just a few months. I have had some bad experience with the medication.”

“The medication started with Clomid and Femara did not have any adverse side effects. Then it was costly when it got down to the injectables.”

Not bad if orders are organized

“Of all the stuff and all the complicated parts of infertility, I would say that was either neutral or positive because I used Freedom pharmacy in Massachusetts, they were really helpful. They would always ship on time and they would help me figure out how much I needed. Yes, I would say of all the things it was not that bad.”

“Right now I am on estrogen and I feel like it is messing up my stomach. It is making me gaining weight. None of the drugs that you take during the IVF stimulation are very fun because you are giving yourself at least two shots a day. Now I am just on oral and vaginal estrogen. I have taken progesterone, I have taken LH, FSH. These are, all shots. I have done the stimulation and we have four frozen embryos. So I am done with that. I have tried all drugs. So that is a very negative experience just because what you put your body, you have to give it to yourself, and

your world revolves around taking drugs. Getting the drugs from the pharmacy has been positive. With the OBGYN's office, kind of sucked because I was using this ivfmeds.com and they are overseas, and they were always on back order. So that kind of stunk. Now I use Freedom Pharmacy and also Avella, a specialty that is compounding pharmacies, and that has been very positive."

"The medication is kind of crazy. But for the most part everything went smoothly. I had what I needed, when I needed it. There was one time when they gave me medication but they did not give me syringes and I had to run to CVS to get the syringes. I never did any ordering. It was always through the doctor. I did Clomid, Femara, some injectables, Provera. Sometimes he gave samples. I do not know if he does that anymore but at the time women no longer cycling gave him back the medicine and he gave me free samples. That was really nice. Other times I just had to go downtown. There was a place across from where we took a walk that had the injectable medication. So that was really convenient. Even though it went smoothly it is not good. It still *sucks*. I never had too strong reactions to it. I would feel blotted and stuff but did not make me too upset."

Diet

He did not tell me. It came from me

“I changed my diet pretty quickly because one of the things that I had suspected from reading in some books was that one of the reasons I might have irregular cycles was maybe some polycystic ovarian stuff going on. Then right before I got married, I started changing my diet because I wanted to fit in the wedding dress. Then my father had a heart attack and diabetes and all these heart diseases. So all these led me to a really drastic diet change, which as I was reading in the books on fertility diets it all seemed to be part of the suggestions anyway, like reducing carbs and sugars and we were not eating a lot of meat anyway. So I was trying to substitute it with beans. I had had some high cholesterol in the past, so I stopped eating as much dairy. I just would want to embrace it anyway because I felt a lot of this is in my control, so I can do that and I am going to get healthy. So I pretty much embraced the diet. I would get upset though or I would feel like if I was on vacation if I was going off the diet.”

“That was self-done when I went to alternative doctors. My acupuncturist would recommend certain food that would make you more fertile, just making sure that I was not crossing any boundaries with me taking some herbs while on the medications. Also finding out if it is true that actually changing my diet was going to do things.”

“I started before trying to get pregnant to cleaning my diet really well. I have gone through a whole detox protocol, identified some food allergies, tried to get them out of my diet. It was very helpful in supporting me because I was already eating healthy and to continuing that even when things got stressful probably helped a lot.”

“No. Nothing. Other than what I was already doing. We eat pretty healthy anyway. I do not know that we made any changes.”

I wish doctors would tell you more about diet

“I did not have to do anything. I do not remember a whole lot about diet. I remember staying away from alcohol, which is not a big issue. But I do not have a whole lot of recollection of dietary changes. I could not have caffeine. I think I limited chocolate. I watched what I ate but I did not do anything dramatic. One of my meds I cannot have dairy with it and so I changed what I ate for breakfast but then I decided to take it a different time of day.”

“No doctor has ever told me to change my diet. We have asked several times if there is something in the diet that would make this better for us and everyone has said, “No, do not worry about the diet.” Recently, about a month ago, I went gluten-free just because at this point you are doing anything to get pregnant. I do not need to be gluten-free, but I have read some information and a friend of mine said that she did some research and found that it has positive effect on your ability to get pregnant through IVF. I wish doctors would tell you more about diet.”

“The urologist had me limit alcohol intake. I do not drink too much as it is, but it was one of those things where if you do drink or socialize with friends to limit yourself to two drinks a day.”

“I am vegetarian so I always thought in the back of my mind “Is this related to my diet?” because you will have people tell you “You should eat this or that or the other.” One thing I do not like to eat are eggs, it is not about being a vegetarian, I just do not like eggs. Even the acupuncturist would have liked me to eat meat and fish but I would not do all of that. The diet was more of a stress or worry like I am doing all this other stuff, this is one more thing, maybe if I would do this. Matter of fact, this part is maybe a little bit funny and it applies to alternative medicine with the acupuncture: I have been a vegetarian since I was a teenager and this acupuncturist, she really wanted me to eat meat, really wanted me to eat eggs. I compromise I would eat the eggs but she had these herbal remedies or I do not know if she calls them herbal but different kinds of herbs that she takes. So I was joking with a friend and I said “Who would have ever though that I would break my being a vegetarian after all this years by taking pills that are basically gelatin made from donkey’s skin and sheep’s placenta.” It is a testament as to how far you are willing to

go “Okay, I think this sounds crazy but I will try it.” The doctor did not worry about it. He really did not think diet was the problem. He did not really put tons of stock into the acupuncture even though he seemed encouraging when the lining went ‘kaput’ to go to the acupuncturist. I think maybe because he knows it has a connection to helping you relax but he did not thought it was a terrible idea, he was not trying to say it would work either, he was kind of on the fence. He definitely did not tell me “Let Us look at your diet, what could you change.” The acupuncturist did and she even wanted me to have really high amounts of B vitamins and eggs and higher protein and those crazy herbs. One of her specialty is working with infertility and so she was very good and a lovely person.”

“At that time, no. Now yes, I think that is why I got pregnant. Doctors only gave me basic directions like do not drink caffeine, but I have never drunk caffeine. I am not a caffeine person. Once in a while I have a coke, but I am not a caffeine person. When they went down the list “do you do this?” No “Do you do this?” No. “Do you Smoke?” No. I felt like I ate fairly healthy, being vegetarian and I do not eat out as much. So they did not really reduce this or that. He did not tell me. It came from me.”

“They asked to take certain things out and shape up your diet. I am a pretty healthy eater anyway, but it was not a bad experience at all. Probably the wine is the worst thing. They did not put me on a strict diet.”

Diet is a nightmare

“I am trying really hard to eat well but it is not always easy.”

“Diet is a nightmare. I can barely eat anything anywhere. I went gluten-free five or six years ago and then for this IVF cycle I was on a really restricted diet that was high protein and low carbs and anti-inflammatory which is no dairy and eggs. I am sort of still on that right now as I am trying to go into the pregnancy, I am supposed to be eating lots of proteins and all these other things. I have been doing it now for five years and my diet still becomes more and more

restrictive. It is a pain in the ass for my husband. Our kitchen is transformed slowly into a gluten-free kitchen and I do not buy things I cannot eat. It is hard. I think that is the hardest part of it and I cannot wait to be done with this era of my life so I can eat whatever I want even if it makes me sick so that I do not have to worry about it affecting anyone else. That will be really nice.”

“That was hard. In the beginning I tried to be really good about my diet, thinking that eating salads all the time would help me get pregnant and after you have been going through for years you kind of give up on that. It is like is this really making a difference?”

“There was so much that I could not control that was one thing that I really wanted to control. I was like “we need to eat better, let me help you” and that was like hitting my head against the wall. I could not do it. I could not convince her to change. If I would try to get her to change, it would have just been awful so I would eventually desist.”

“When I was trying to get pregnant - before we knew about infertility issues, I was working very hard to get down to a lower weight just to make it easier to conceive, and obviously the diet is awful. My husband had to stop drinking and he was not super happy about that.”

“I tried to stay healthy anyway. So from that perspective, it was not a weight issue or what I was eating or anything. I started looking at alternatives that might help in terms of natural and organic intake but it was not a drastic change for me. I probably tried it for maybe a day or two and then moved on. I could not stick to a program in that sense. But in terms of how I ate and keeping myself healthy, then yes, I think that was typical.”

“I have been told to be on the PCOS diet and “oh God I need vegetables” and all that stuff you are supposed to be doing. But I have not been able to stick with it and I feel frustrated with myself because I know if I were able to control my weight better then I may not even need all of these medications because losing weight is the best treatment for PCOS. I feel frustrated with myself that I cannot seem to get it together. I do not know why. I go to therapy and that is something we explore in therapy but it just comes down to if the food is available I will eat it. I

do wonder if some of my medications are messing with that. I have always had problems with it, but it just seems to be more intense now. Before, I thought I should eat better, but it did not really bother me. I do not mind being overweight. I still feel beautiful. I still feel sexy. I still have a good sex life. It does not bother me socially. It has now just because I would like to have children. I see people who are bigger than me who are having children and this is unfair. Anyway, I have not been able to do anything. I feel very powerless when it comes to that.”

“When I did acupuncture they mentioned something about changing your diet and I was reluctant to that. They said something about dairy and they recommended changing to goat milk from regular milk. So I did that. Somebody also said, “well if you really want go gluten-free.” I just rejected the advice for the most part. Other than I had to quit caffeine, that was from the regular doctors and I was working towards that anyway, but that was hard still. Especially for the IVF, they are very strict. I did not eat chocolate, not even any decaf. That was a rough adjustment period and afterwards when it had not worked, I thought I did all that for nothing. So, any dietary changes I had to make were not pleasant.”

“I like coffee. I read conflicting studies on caffeine and coffee. It was frustrating because I was changing my lifestyle; to me that was a big deal cutting out coffee and wine and that kind of thing. I felt that was huge, for me that was just really difficult. I felt frustrated that I could not enjoy something I normally do. I feel that gave me undue stress. So I actually think it was worse to diet and cut myself from things I enjoyed; because it made me feel angry. I used to go to poker night with friends and I would not drink any alcohol because in a week I was going to do the IUI, but I would not know if it really mattered to withhold. So it was frustrating. I really missed my coffee and I missed my wine and beer and I hated having to change my life.”

“We put on an alkalizing diet because he tends to run a high PH thinking that that would be a thing. He was not happy about that but it turned out to have no effect. He had a very negative experience tweaking his diet to try to up his sperm count or health.”

“I drink wine and, of all the things, I was not going to. I know a lot of women change their diets. That was one thing I did not stress about. I did not make a lot of changes or stress myself out.”

“My acupuncturist had me do a cleanse. So I did like a ten weeks class, it was hard to do it. It was interesting because I became vegetarian for five months after the cleanse.”

“She was trying to take a very holistic view point according to whatever she was reading in whatever newspaper - not a book, because it would change periodically, so yeah I am good with beets, but still it involves a little change from the regular,”

Rest

Hard to rest during treatments

“I found it difficult to get good rest. Maybe being infertile at the time was causing some stress. I do not know about as a direct result of shots or drugs or something like that, but as far as the whole process, I did not get much rest at that time.”

“I could not sleep at all. They advise you to get as much rest as you can but the process is stressful and it interferes with your sleep. There were a lot of sleepless nights during that time.”

“I feel like my rest was disrupted just with all the charting, having to take the temperature. For a couple of years there I did not want my husband to know I was taking it. I was taking it in hiding which is just absurd and I think it thwarted my data because I would creep into the bathroom and you are supposed to take it without any movement and upon first waking. So my rest was, I think it was messed up.”

“When you are under stress it is not easy to sit and rest, but I was still able to get sleep.”

“It is really hard to rest during the process. I never got a side bed rest. They never recommended that but I had a hard time just sleeping in general I think hormones shifts and stress.”

“There were times that I was not sleeping very well. I think that was all mental.”

“You know we ended up doing a mind body seminar. It is all about the mind body connection. I was able to learn to meditate, listen to relaxation tapes at night, relax or rest. So that had a positive impact.”

“This is why I love the acupuncturist, they targeted different things, like digestion or rest. I remember I told them one time, “I am not sleeping good. I am sleeping and waking in the middle of the night and I am up for a couple of hours and I go back to sleep.” So she put these little things right on my chin. I walked out of there and I was a little yawning, but did not think much of it. When I got home it was maybe seven o’clock in the evening, I fell asleep on my couch and I woke up from the deepest sleep I have been in a long time and it was one or two o’clock, so I got undressed and went to bed, and I just slept. Every week I would go in, she would do this little thing and it did really help my sleep. So she would focus in on areas I was struggling with.”

It affects your plans

“I would say the only thing I remember in terms of rest would be post implantation and I mentioned not being able to go on vacation and that sort of thing because immediately after the implantation we had to be pretty immobile. So that is about the only recollection I have in terms of rest in regard to the treatment.”

“Yes, you definitely have to rest. The only advantage of going through this for five years is that by the time we got to IVF you knew what we are going into. We really treated it like an investment and we planned a lot. We had to make sure that nothing was on the calendar for those two months and housework was done. We had freezer meals ready, so I did not have to cook. We really prepared ahead so I had lot of rest but we were ready for it. So it was not a stressful thing.”

“It is hard not to be able to be very active when you are going through all these cycles. It is a hard thing to manage and it affects what you can do and what your plans might be with your friends.”

“Because I am typically very active, I play a lot of sports, during this process it was difficult for me to take it easy in terms of activity level. I was thinking, “should I be going out to go play while I am taking the treatments or after the procedure after they have done the insemination?” You know, those are the kind of things that would go through my mind in terms of rest.”

That was not really part of my treatment

“I did not do a whole lot of day rest and my doctor did not make me do a whole lot. I had to rest for a day after the IVF, but they did not require me to do a whole lot and I was glad it was easiest for me to get back to my normal schedule of doing other things rather having it constantly on my mind.”

“We had plenty of that. Rest was not an issue.”

“The acupuncturist was trying to tell me “Do not over-exert yourself.” I play soccer, or I did play soccer several times a week and it was like “You might be doing too much” but to be honest I ignored her on that.”

“That was not really part of my treatment. I did not really change much. I did not rest much I just kept doing what I was doing, but I should have rested. They never really said I got to rest.”

Surgery

Very difficult emotionally

“It was during [treatments] because after two IUIs failed I did the laparoscopy. Then he wanted to check for any scar and any stuff”

“That was a bad time. Because we had two IUIs and they did not work and then the surgery. This was after two and a half; maybe three years. Now it is just like what now? We are going to go more serious or take a break? That was a bad time.”

“Surgeries I remember were always surrounding just the negative implication. It is the removal of the fetus. My own personal surgery, which resulted in no change whatsoever. So most of my recollection of surgeries was bad; the circumstances were bad. I do not have bad recollection of the actual surgery, but it is the emotional circumstances, the why you are having the surgery and the outcomes and that I have to experience all that. Oh, Miscarriages. Miscarriages, there was one miscarriage we went to the hospital and they removed the fetus and that was very painful. Any loss like that is very painful. Particularly after you spend some time on a low or high where you feel this might succeed.”

“I had surgery for an ectopic pregnancy. The actual surgery itself was fine. I did not have any problems with that. It was very immediate. They got me in as quickly as they could, considering it was life threatening. They were great and did what they needed to do. Of course then you get the emotional factor but that is the most difficult part of it. Just having to deal with that thinking how could this happen to me. It is my faith more than anything dealing with that side of it and understanding why. It is what it is.”

“As part of the fertility treatment and process, the only surgery would be the hysteroscopy. That was successfully accomplished but very negative emotionally.”

“The egg retrieval, really stressful living up to it because you do three or four weeks of stimulation. Right before it was really stressful because of my ovulation fiasco but the day of it and the days after were fine. The nursing staff was amazing, the best nurse I have had yet, she was so informative and answered all my questions. The surgery went really well. I mean everything about that process was good.”

“No other than the actual egg retrieval. Yeah it was scary. Psychologically.”

Really difficult physically

“It was tough physically. Surgery was really difficult physically, for the recovery of the endometriosis. The egg retrieval was not as bad but still just the bed rest afterwards and you are feeling all these things and you do not know what is from the medication, what is from the surgery, what is normal, what is not normal. It is kind of your whole body is out of work.”

“I had lots of surgeries before and then I had one just before this IVF, and that was several months of recovery before I was allowed to do this IVF. I had two laparoscopies before this, I had one ectopic pregnancy and I had a laparoscopy to remove that. That was when they found out that I had some Endometriosis, otherwise they would not have known that. So that was useful I guess. Overall, all my surgery experiences were good.”

“I had the laparoscopy and that went fine. For the IVF where they take the eggs out that one was pretty easy, the easiest anesthesia wise. When I had the hysteroscopy I was sick afterwards because of the anesthesia.”

“Yes, miscarriages and then hysteroscopy also, so kind of expensive, time off from work. The hysteroscopy was very painful. There was some scar tissue, so they did the surgery to remove scar tissue but then they put a balloon shunt in there for two weeks, which was extremely painful. They said, “Nobody has pain with that.” Well, “It hurts to sit down and it hurts to stand,

I am very uncomfortable.” “We can take it off early, but you may go backwards” and, “Well I do not want to do that.” So that was very not fun. It kind of impaired life and we had to go out of town for a weekend. You know it kind of seeps over. It is not like it is here and it is done. It continued for two weeks at Christmas.”

Scary egg retrievals

“I had the three Hysteroscopies and that was just frustrating because I needed to have polyps removed quick. As far as the surgery, it was not a bad surgery; it was not difficult to recovery. When I miscarried, I did not have to do the DNC, I did the medication because my doctor said anything you do to the uterus can possibly cause scarring so to protect my fertility chances he recommended the medication. With the egg retrieval there is always stress involved because you are worrying about the fertility report, how many are going to make it to the end, the process, and how many to be implanted. The surgeries went well, the IVFs pretty much always went well in the sense of the procedure. The only thing that went wrong one time during the retrieval my blood pressure went crazy down and I was out of it in the doctor’s office and it panicked my husband and it panicked the doctor and the nurse. I do not know if they hit a nerve or they did something, but it was really weird, you feel like you are having an out of body experience where you can tell people are coming around and you are trying to wake up, but your blood pressure is too low to respond. That freaked everybody out including me later.”

“We did a few egg retrievals. I remember one egg retrieval, I remember it was very scary, she basically fainted. Her blood pressure dropped. I forgot what it is called but some sort of medical condition. Basically her brain gets overloaded. That was scary because I was not there, I was at the office, it was a helpless feeling.”

“Just the egg removal. That was good aside from two negative things. We had one nurse, shot blood all over the wall, got my vein. It was everywhere. Aside from that one experience I had one nurse ask us what I considered an inappropriate question. Aside from those two things, the surgery was always the best experience for me because I did not have to think about anything. I

did not have to worry about anything. They drugged me. I went to sleep. It was the most relaxing part of any treatment. It was just going under for the surgery. I do not know if anybody I know felt that way, but I felt that way.”

It is Not a big deal

“The nice thing about the surgery is that it does not hurt, it always happened when we needed it to happen. I had a couple of surgeries, nothing invasive. Just the DNC and hysteroscopy. Pretty sure it is all I did, and it is with anesthesia in the hospital but it is out-patient. It is frustrating just because you take the whole day off work and it costs money. These surgeries are fine.”

“Well, for IVF they extracted the eggs and then the laparoscopic surgery. It was not too bad. It was easy. It was not bad. Extractions were not bad.”

“I had six. The process of having surgery is not good, but as far as the scheduling and getting taken care of everything [was positive]. It is never fun to have surgery.”

“I had to do the laparoscopy and also had to have a polyp down my uterus [removed], but it was not a big deal.”

“Both the egg retrieval and the implantation were good moments of bonding, because when she is in pain I can comfort her. Honestly, there were some schedule conflicts and again I think I could have been there for her more often, but I do not know if she is either pragmatical or just fooling me but I took advantage of it because I have a busy schedule too and so she would go to contend with those on her own. The doctors were actually surprised that I was not there for I think it was the egg retrieval; one of them is more invasive than the other. Well, no... Maybe I did not leave her hanging. I know she was in that chair a couple of times, where maybe I could have been there for my sweetie. Yes, I drove her home a bunch.”

Assisted Reproductive Technology (ART)

The cost and more...

“No, we did not do that and we did not do the forced ovulation, I wanted to go as minimally invasive as possible to start off and to be honest, mostly financially as well. So, I just did the ovulation predictor kit and then that was it.”

“We have been talking IVF and are we were going to get a loan. We got approved but not for the full amount. It was just going to be so stressful being out that much money and not having any kind of savings left. And so we decided to wait and see if his numbers would get better. Then we did an IUI, and we were set to do another IUI this past October. My numbers were good, the doctor was a little bit concerned because of my age and so he had me do some blood work to make sure that my estrogen levels and some other levels were right. They are way better than we ever expected. We were so excited and the day of my procedure instead of taking me to the procedure room they take me to a conference room and told us that my husband’s numbers were even worse, they just got worse even though we thought the exact opposite would happen. So, that is where we are. I do not know if I will be able to afford IVF. I was excited when I saw one of your emails where you mentioned the grants, The grants? I was surprised. I mentioned it to my husband, he looked it up and we are applying.”

“Because of the outcome, it is not cutting edge technology, it is not the best that medical science can bring to bear. They have genetic typing and they can do fine tuning of the procedure other than the one we bought into; yeah I bet it was the best we could afford, it is good for those who can afford it.”

“We have not since none of the issues have been with him and since we know I cannot get pregnant. The doctor says that maybe there is a five percent chance increase in doing the IUIs with the injectable cycles. So we just do not know if that is worthwhile. Also this is sort of a

more minor thing that my husbands' parents are Catholics, and there is a lot of issues that come along with that, the church rulings and things like that. We are not catholic but it still raises a whole lot of issues. We were at my in-laws' house recently and I picked up a book that just happen to have some information about in vitro. This particular book said that in vitro is an outrage against that child as if the child had been created via rape. That upset me a lot and asked his mom if that was what she believed in. She said yes. Even that is less of a concern for us because we would probably not tell them, I would hate for my child's grandparents to think that if they were created via IVF. I do not think it makes a difference how the child gets there, I think the child is just as legitimate a child whether they come to the family through adoption or IVF or birth. But I would hate that anybody would think that about my child. I would rather adopt rather than have a child that people are thinking about."

IUIs did not work, we lost time and money

"I did three IUIs and three IVFs. IVF sucks. It is terrible. It is very stressful. You have to be very committed. It has to be the number one thing on your plate while you are going through it. The IUIs were not too bad other than we lost those four months and the money."

"IUIs we did seven. It was completely unfulfilling. I do not feel the doctor was very good. We went straight to IVF once we got to the second doctor because that is what his recommendation was based on where we were in our lives. At that point we were already frustrated and felt the time was ticking and I felt the IVFs gave us more hope. I felt we had better doctor, so that experience was much better. We did four, maybe five. We did at least once a year for 2009, 2010 until this past year. We got pregnant one time and then we had a miscarriage. Then we could not do it for at least another two or three months because we had to get back on the cycle."

"I feel the IUIs were a waste of time especially since they did not test me. Every time we did a round of IUI and it would not work they would change everything they were doing and say, "We could do this, we could also do that, we should also do this on top of this." Sometimes we were going to say, "Why do not we pretend we have done ten and none of them worked. Then what

were we going to do? Let us do that now.” I was so pissed that I demanded we have a regular appointment with the doctor before we start a cycle, because we were only seeing the PA. I said, “Look, you guys are adding new medication and information every time we do one of this. I want all the information right now. You have diagnosed her with PCOS, and she cannot be the first person that you have diagnosed, so let us do everything upfront.” He said, “If next IUI does not work, we will do some exploratory surgery.” I said, “That is exactly what I am talking about. That is one more thing that you are trying to add on after another does not work.” He did not have any way to explain why they do that. So, that was frustrating. I feel it is better with IVF. We are lucky in the sense that we have four frozen embryos and I am trying to be more positive about the whole thing. I feel the fertility specialists still do not give you all the information. We were just having an appointment and they said that we owed another eight hundred dollars for something; where was that coming from? That is new information, but for the most part, they have been informative with us. I feel that is been more positive than dealing with just the OB/GYN doing the IUI.”

“We did two IUIs and they did not work. I had to take time off and my husband did as well in the morning because he had to be there.”

“I feel like the IUIs are a waste of time, I did six. I did two with my old doctor before she quit and then I switched doctor and we did two more. [Then] we did two IVFs and I got pregnant both times, but miscarried. Then my doctor suggested to look at the sperm, that is when we did the sperm test. There is an anomaly, it is not a definitive anomaly. Clearly something is wrong but it’s not ruling out pregnancy all together. So while we were waiting for the sperm test that takes 6 weeks, we did 2 donor’s IUI because it was cheap. I never got pregnant from the IUIs, only the IVFs. I could get pregnant but not stay pregnant. We would not know if it is a sperm issue or a genetic issue. All the genetic tests came back normal. You never really know what going on.”

“Other than the IUIs, the IVF technology works. It did not work for me necessarily. I got pregnant every time through IVF”

“I did thirteen IUI’s, then we did one IVF with my eggs and then the donor IVF. One negative was a ripped egg coming out but other than that we did not have any issues.”

“They did not work. Trying for six years off and on doing treatments and it fails. Then there might be six months to a year before we decide to move on to something else. I feel the IUIs were a waste of time, but I do not feel like the IVF were a waste of time, we tried at least.”

“We did one IUI. My doctor told me that it was not going to work but I insisted on trying it, so we went through one round and of course it was unsuccessful. Just going into it knowing that we had a really small chance put a dark cloud over the whole thing. The process was easy.”

“We did two rounds of IVF and she produced many many eggs and we had maybe one, one time, and two the other time. They implanted all of them and they did not work. We did not end up with any extra embryos. We never made it to day five testing because we did not have enough, there was no extra material to work with. None of the IUIs worked. While we were doing the IUIs I think I ended up getting my wife pregnant through natural conception. When we did IVF using my sperm and donor egg, we got again one embryo and that did not work out. Then we did IVF with the donor egg- donor sperm and my wife carried the egg and that did not work either.”

Fascinating procedures

“The thing that stands out most to me on that is the ICSI process. I think all of the processes were fascinating and it is amazing that they can do it. I remember asking the doctor lots of questions about how that can be done. I was fascinated by it and thought it was very interesting”

“For me, it was just part of the process, you have to do it if you want to get pregnant, if you have infertility issues you have to go through it. I was not excited to go in there and see them, see the IUI procedure. From the process perspective, it is a miracle that they could do it.”

Nobody knew why it was not working

“Overall IVF experience was pretty good because again we were lucky we had good numbers. Everything looked good. We had good egg retrievals. My two cycles that were at my local clinic in California, one had like a pretty low rate that made it from fertilization to blast, but the other cycle was pretty good. I had two transfers from the first fresh IVF cycle and I had four transfers from the second IVF cycle. So overall on average those seemed like good cycles and again nobody knew why it was not working.”

“You just get your hopes up that it is going to work and then after so many you do not have your hopes up. As you are going through the motions you are thinking “What else am I going to do? Maybe it will work.” The worst IVF that I had was one where we actually had 5 perfect embryos and that was a really big deal. The doctor was very optimistic and of course we were too. His recommendation was to put in all 5 and none of them took. Of course I regretted it and I wondered if the doctor should have checked that I had polyps again. In a sense kind of wanting to blame him. In retrospect thinking “Oh, if only we had checked that, we would have frozen them or not put in 5” and “Oh my gosh, that may have been our best chance to ever make this work and we blew it.”

“I always produced a good number of eggs and only once we had to canceled a cycle because of the lining. They ended up doing a frozen cycle and we waited a year. When the lining finally gave us a good month, we implanted those but it did not work out. Then you think “Okay, that was our last chance to have children with my own eggs... then I am going to hope to move onto donor eggs if my lining will cooperate.” As far as the assisted reproductive technology, my feelings about that are that you feel optimistic but at the same time you feel like a guinea pig and these people do not have the stuff figured out very well. For example, the doctor was calling his professors about the vaginal Viagra. It was like throwing it up against the wall and see what works. You are thinking “if I was born 10 years later or trying this 10 years from now, they might have figured out” When you think about the fact that you could not have children it is life-altering, it is kind of hard.”

Doing trial and error on thousands of dollars

“My experience with IUIs was very negative. It was painful and I think they are stupid. Every single time I would do one I would have less follicles growing. When we started the IUIs I was maybe 35, I went straight to injections. So that was good at least we did not lose much time. I did four. Because of the DES exposure, my uterus is small and the cervix is messed up. It is really short and stenotic and closed. So when I did the first IUI, I had severe cramping. It was horrible, very horrible, traumatic. They did not say what to do or not to do, so I took Advil and we went in the next day and because I did that none of my follicles had ruptured. But, they did the insemination and we hoped that maybe the sperm got there the right time but it probably did not. We did four of those and I never had a pregnancy. After four we moved to IVF (did four IVFs, two with my body and two with a surrogate). [First one] he did the regular protocol that I do not think a lot of doctors use now. He did the long Lupron protocol, so I hardly stimulated and we had it canceled. That was super traumatic. It was not even my doctor; it was on a weekend with another doctor. That was frustrating because at that point I was 36 and if you are over 35 they should not even use that protocol. A lot of times they just do the same and you do not want to practice with 15 thousand dollars, you know? Some places give you a break, but not this one. I used \$5,000 worth of medication and had to do another, a total joke, just a waste. That is when I got mad at them and went to another doctor in another city. I heard a lot about the doctor, everybody had twins. I had a pretty good cycle there, twelve to thirteen follicles growing, I think I got eleven eggs. We transferred three but it did not work. Then, I came back to my previous doctor because I could not be out of town again for another IVF. I did another one in here and it did not work, and there just were not any indicators on why it was not. Four or five months later we got back into the game and we did another IVF, it was a terrible cycle because I went through it with a cyst. Everything was all different sizes and really messed up. We ended up with 2 embryos frozen, and we found our surrogate. It did not work. We came back to the clinic when I was forty I did one fresh cycle with our surrogate and one worked. That was the worst, the embryos were terrible. They were day three embryos, only four cells, and they are supposed to be eight. I never had a fourth cell. So they are like, “let is just put them back in the environment

they want to be in, you never know, we have seen four cells work before.” I thought for sure would not and one did.”

“It was not good or bad. It was just what it is. You would have to go through it and you did it. We did the Clomid; Clomid did not work. We got up to the highest dosage and then we went to IUIs, and because I do not have a cycle naturally, we went to IUIs with the shots. We did Gonal-F. It was a very expensive IUI and looking back on it again it is like we probably should have just jumped to IVF but we did not know. So we did three IUIs and at that point he suggested IVF and we had burned through sixty thousand dollars. We were young and so I was burnt out and we just took a break.”

“Going through IUIs is exciting because you have hope, you want it to work. At the time it was something that we thought we need to try and hoping that this could ultimately lead to my end results. I had a great experience with it in terms of the process, I think more of the difficulties was in feeling bad for my husband and anything in having to do in terms of delivering the brown bag. Then being there an hour or two afterwards and timing it between my job. So, those were the only stressful sides of it. Going through the IVF is definitely a little bit more stressful just because you are taking a big risk. There are big financial obligations and there is no guarantee. So, in that sense it was more stressful going through that process. IVF was definitely much more difficult process involved. The medication was way more intense through the IVF.”

It is not something you would wish on anyone

“It been has not good by any means. You do not think it is going to work, it is scary, it is expensive. If I take out the end, it is terrible.”

“It was very hard to do. It is not something you would wish on anyone; pretty difficult going through the process. We did four IUIs but not positive. Going through the IUIs was a very emotional experience, you are kind of hopeful and waiting and when it does not work, you know. Physically it was fine; more emotional. For the IVF, the first one did not work that was definitely

the hardest because we made so many great embryos and our doctor was really excited. It looked like it was going to work sort of on papers. That first time was hard. I only wanted to do two IVF but she had us involved in a research study, so our third one was free; the clinic covered everything.”

“We did IUIs, IVF, and frozen transfers afterwards. Some of my IUI experiences were bad because the OB/GYN was not very good. It was a lot more painful than I thought it was going to be. I think they are not as experienced with it. I was bleeding and having this sharp pain and I felt alone because they did not suggest ahead of time to have my husband there. I was sitting in this room for 15 - 20 minutes by myself in the dark and it hurt. At the specialist it was fine, it just was not working. The IVF worked, so that was good, but it was very frustrating going through. There was so much involved with the IVF process with all the doctors’ opinions, the testing, the meds at precise timing. Then missing work and also you have this two-week wait when you are not allowed to do anything. You are not supposed to lift anything. I have to decline trips at work but I could not tell them why.”

“Going through it was a little frustrating because my body does not respond unless it is very stimulated, I take a lot of drugs. I took Femara and nothing happened, then I took three days of injectables and it did not do anything. I had to immediately move to all injectables. So starting on day three of my cycle, I was giving myself shots. With the OBGYN you only get one or two ultrasounds per cycle, that was frustrating because that was like trial and error thing. The IVF is not very fun. It has been very very tough but we are sitting here with four frozen embryos. So that is a good outcome but getting there was not a positive experience”

“The first IVF felt really frustrating because when we came for the embryo transfer, which is nerve-racking, they scheduled two people at the same time. We had to wait in the lobby for about three hours and that is really frustrating because there is a time you do the shots, so you have to get in, plus I was nervous about what is going on. I wish they had told us, “Oh my gosh, we have another couple going through it. Why do not you come back in three hours?” But instead we just waited. It was very difficult. I still did not blame the doctor, but I was angry that they did not tell

me. It was unfortunate and nothing like that happened the second time, but it did really add a ton of anxiety and stress, and that was too bad. I kind of wondered for a long time. Is that why it did not work?”

“It was about five IUIs. Going through that was pretty straight forward, they did not bother me as much. The IVF was rough because physically it took a toll on me. It was really hard because I was very over-stimulated. I was very tender because of the over stimulations. There were a lot of compounding factors, but I did not understand at that time and I do not think they did either nor cared to. The first IVF was crap. The second one went quite well. It was smooth. Everything went well, it did not take but the process was smooth. Prep was smooth and the transfer was smooth.”

“I did not get pregnant, so that sucked. It was expensive and not fun at all and one of the nurses was pregnant and it was not helping, I was glad she was there but...”

Alternative Medicine

Acupuncture helping in regulating cycles

“I think it was maybe 2010, a little over a year after we tried, that I started going to acupuncture. The treatments have helped regulate my cycles as far as providing blood to the area, and also helping me with my rest and my stress. Then the community and the knowledge; she just does not do acupuncture, she had me on all kinds of herbal medicine, I was brewing tea from the acupuncture clinic. She helped me find a Maya abdominal masseuse to work on my uterus because in the process of doing all these ultrasounds they found out that I had retroverted uterus, my uterus is tilt a little bit. Western medicine does not think anything of, but if you read about it in other cultures, they talk how maybe a strenuous lifestyle and all this lifting. So the uterus is a little out of line and I ended up wondering what caused that. Maybe there is pressure on my blood vessels that is causing it, you never know. So I ended up going to a chiropractor as well because I thought maybe I am having some alignment issues. I also did fertility yoga which was great. First I bought DVDs, so I was doing them in the house because I had done searches for fertility yoga and nothing came up. Then I tried again and suddenly there was, this woman lives here, who does fertility yoga. It ends up being more like support groups. She does not do strenuous yoga, she does this very short routine, which is meant to promote blood flow and relaxation. It is a handful of women in the room sharing where they are at with their cycles. She has a series right now going on and so she did a retreat where we all went to a nice place and wrote and talked and shared.”

“I love it. I love going and I love how it feels afterwards. I have actually noticed some changes from it. My ovulation day has changed to five days earlier and I can feel it warming me. It is kind of weird but I take the herbs and when I take them I feel heat on my thyroid. I like it a lot”

“I have tried herbs, just biotechs to regulate my ovulation so that it is not so late, and also I have done acupuncture.”

Does it work?

“I think there were questions about it, whether it worked, whether it did not work, what are they, what is available? I do not know if we ever had those questions answered and I am not even sure how many we asked formally to somebody else or even looked it up ourselves.”

“I have not done anything with alternative medicine. It is fine if that is what you want to do but I do not think of it as scientific, as legitimate, as proven as the actual medicine. When people say, “oh you should try acupuncture,” it just makes me angry because I feel my problem is past the point of acupuncture being the thing that can solve it. I think that if acupuncture worked there would be scientific studies. The fact that there is not means that it may work sometimes for some people. There is no point for you to try it because you do not know if that is going to be useful. So, no. I have not done any alternative medication. I am sort of been resisting as a matter of principle.”

“That is not applicable for me. My wife has been doing occasional acupuncture. I think it works. I have not done anything. I would love to do it. I do video production on the side and I worked on a video with a friend of mine for an acupuncture facility here and part of the deal was five free treatments so I am still needing to sign up for that.”

“She did some acupuncture and I think she did some yoga too or things to help her relax. I remember her doing the acupuncture and she is a vegetarian, and they would give her some weird diets. Some of the diets included eating something that had animal. Never really crossed my mind to do them myself. If they’d tell me, “Hey! There are some theories out here that those may be helpful for this” and at that time I probably would have done anything.”

“Yeah, she did. She had in fact, but I would have to defer again to say it took effect in the long run, it provided her comfort but it was not altogether effective.”

It gives you power over something

“I have gone to maybe five different acupuncturists and had sort of different experiences with all of them but overall it has been really helpful.”

“I did not take any herbs, but I did acupuncture and I really loved it. The therapist is amazing. I went to her for infertility, I have been to her for back pain, and I induced lactation. She helped me with milk coming in and stuff like that. She is a bethsemina it is wonderful. I could always tell her what is going on, I would cry, she is a really good part of my team. Not just an acupuncturist and she specializes a lot with infertility.”

“I have been doing acupuncture for a long time. It has been great. I really like acupuncture especially recently because I found a provider I really like. I see students because I am cheap, I do not want to pay a bunch of money because I go every week. I have been doing it for a long time; I try to do it once a week or once every other week. It is been really good. You have to kind of buy into it. There is a little bit of voodoo involved but the last two treatments have been awesome. I have done meditation and I do yoga and that is all great too. I really have tried to do things to better my mindset because I felt I was in a really negative head space and I wanted to go into the IVF transfer with more positive outlook and try to use the power of positive thinking. So I have been seeing a therapists too. I tried to do meditation, I do not do it every day. I try to take yoga. I kind of pick a different kind of fitness class, I like this studio down town and they do the *yo-strong*. I just try to pick something once a week as far as yoga.”

“I tried acupuncture for the second IVF. I really love my acupuncturist. She is amazing. I felt such a good connection with her. I felt that she really cared. I could not afford to do acupuncture for the frozen treatment, but, for the longest time, I wanted to go back just to see her.”

“I did acupuncture, fertility yoga and herbs recommended by my acupuncturist. She is very big in the fertility stuff. So she had a workshop. I did a few fertility series with her right before the

frozen transfer. I love her. I have been going to her for years and years and years. Wonderful woman.”

“My doctor referred me to an acupuncturist, she helped put together the diet and we did acupuncture, we had herbs and all those other things. This is why I love the acupuncturist, they targeted different things, like digestion or rest.”

“I did acupuncture for a couple of months and I got pregnant, but it was unsuccessful and I just stopped. She recommended some herbs that I take, it was fertility tea that I started to drink. It was really relaxing and it worked, so I was happy about that.”

“I did acupuncture when we were doing the IUIs. We obviously did not get pregnant but I cannot tell you if it did not help or did help. It was something we tried; it is obviously an added expense. We did some fertility yoga. We did some meditations. I would say positive just for the relaxation and it gives you power over something. It feels like you are doing something as opposed to just the medical staff. What I did is called Power Yoga. We bought a DVD online that I could do at home that was specific for fertility, but I liked the regular yoga.”

“I did acupuncture because I heard that it would help. It made me feel more in control like I was doing something other than just taking the medications.”

Not for everybody

“It was not part of my treatment. I did go to acupuncture once, this was before I even went to see the fertility specialist, just to see if it would help and I hated the experience. I almost could not walk the next day, I sometimes have back issues anyway and I do not know if it was just lying on my back for so long, but I felt seized up and I could not even walk the next day. I went to the student clinic and I thought “Maybe he just put the needle in the wrong spot!” That was not good.”

“I did acupuncture and I hated it. I am not into needles, they do not make me comfortable and having to relax full of needles, and then herbs continued to make my hormones swing all over the place. I finally ended up stopping all acupuncture and switching to massage just to handle the stress.”

Just to lessen stress, it is like cheaper therapy

“I did acupuncture for maybe three months. I think more than anything it was just to lessen stress; like more of a calming and not knowing if would help. So obviously it was not successful but that was prior to me finding out what my true diagnosis was, before I was diagnosed with the diminishing ovarian reserve.”

“I tried acupuncture and yoga but it was not really fertility. It was more relaxation. It is possible that it prolongs some of my pregnancies. After doing it, I felt it was more a mental thing than anything else. I feel it was cheap therapy because I did get something out of it and it was not as expensive as going through a therapist.”

“It was just something that you had to take time every day to do. So it was hard getting there. But, I felt good coming out of the appointments.”

“I enjoyed the acupuncture; it actually helped me relax quite a bit. I think it helped me out through the very long term of Gonal-F. The acupuncturist kept me sane, she was also almost like a therapist during that time; she was very good with it and she dealt specifically with fertility patients.”

“I did acupuncture, it was relaxing, but the cost adds up. Given that I am still paying all the regular doctors I tried it one month while I was doing the hysteroscopy and did a cycle. When I did the transfer and it did not work, I quit because I felt I have spent enough extra money on this and it did not seem to help. They feel you should do it longer to get the most out of it, and I had a really sweet acupuncturist, she gave me suggestions. I was talking to her about being frustrated

with having to miss the support group at my RE's office, she spent time looking up for other suggested counselors and she found the support group. She was really sweet, really helpful in that respect, but I do not think the actual acupuncture worked for me."

"I did acupuncture and I took some herbs that tasted horrible. The acupuncture was relaxing, but I do not know if it would have worked or not."

"We did acupuncture. I did a few times, went to a lady for fertility massage a few times. I think in Mexico they have these ladies who do Mayan abdominal massage. It is like regulating the blood flow and sometimes your uterus is more tilted and they are kind of readjusting it back into place. It is a very concentrated massage on the abdominal area and sometimes in your lymph nodes, in your groin. They did not do anything, but they were relaxing and I have never done either one of those. I have never had a massage before that. I have never done acupuncture. The experiences were fine, but I do not know if that is kind of my thing. They are cheaper than IUIs and whatnot but they are still relatively expensive and so drinking the Chinese herbs every day"

Cost/Finances

Cost/Finances describes the different types of expense incurred during the Fertility Treatment Experience. The sub-affinity titles or various components as indicated by the participants and their interview responses are listed in the following order.

- ◆ Insurance
- ◆ Medical Bills
- ◆ Medication Cost
- ◆ Out of Pocket Expenses
- ◆ Loans
- ◆ Sacrifice
- ◆ Missed Work

Insurance

We will diagnose you, but will not do a thing to stop this

“Insurance paid for the diagnostics, but because the diagnostics did not illuminate anything for me, it is not like we could stop paying for stuff or whatever. It did not go very far. Paid for some labs. It did pay for some of the laparoscopies but we did pay a lot of it. I did not have insurance for the IUIs or the medications. Acupuncture is not paid for.”

“My insurance did not cover much. That was very frustrating. It covered diagnostic, and it would cover test or ultrasounds when I was not actually doing an IUI or an IVF. It covered the surgery, I am glad that it covered that, but it did not cover much.”

“It did cover my blood work that was pretty significant, but, it did not cover the IUI or the IVF. It helped out though. I will admit, it definitely did help me out. A lot of the visits were covered, but things like the sonograms were not. It was kind of frustrating. I wish insurance did cover this a little bit more.”

“Oh, we are broke. We are so broke. They covered labs and blood drawing and stuff like that.”

“It would be great if they covered anything at all. “We will diagnose you, but will not do a thing to stop this.” This is very frustrating and it is all so bloody expensive. We did get a, “Is this a pre-existing condition?” “No, we got diagnosed. It was not pre-existing” and we had to do all that paper work. Insurance really sucks. Then the same thing for when insurance paid for my counseling appointment to deal with the fall out of the infertility diagnosis. After a certain point, they are like “we need continuation of coverage forms. We need this and this and that.” It was like, “Great, add on more pressure when I am already strained. That is fantastic, thanks.”

“We had some insurance for the blood work. I do not remember how much or what it paid for the hysterosalpingogram. For the treatments we did not have any insurance at all. That was all out of pocket. A very negative experience because of the exorbitant cost and the impact that it had on our lifestyle.”

The insurance was pretty ambiguous and It was hard to figure out what was covered

“Our insurance definitely was a very negative experience. It was hard to get through, hard to figure out what was covered; really difficult. I remember I just broke down on the phone one time. I told my husband “I cannot do the insurance any more. You have to figure it out.” That was definitely challenging.”

“The insurance was pretty ambiguous and so I was not on top of where the money would be coming from or going to and that is a big negative. They paid for a bit, there were some negotiations. Yeah, some of the diagnostics they pay in the beginning but once you go into the treatments... It took interface and time to spend on the phone, so it was not only to the front office of the doctor, and that was my question, “Why do I have to do the work?” That is not what I do for a living. Leave the work to the professionals, but in this case I had to interface with both

the office staff of the clinic as well as the insurance company and then get those people talking, which is far beyond what me as a consumer should have to handle.”

“There is absolutely nothing good to say about insurance. My example I would say it is not knowing what is going to be covered under insurance or not. There were positives, there were certain treatments after you get through with, you will go up to the office staff to pay and they would say that this treatment was covered and that treatment was not, but a large majority of them were not covered. I do remember lots of discussions trying to figure out prior, what is covered and what is not. And it is a very difficult, impossible process to know what you are going to need first of all and what is going to be covered.”

“I hate insurance companies, they are difficult to deal with. You feel like you never understand it. Every time you get a different person it is a different explanation. I still do not understand five years later. It was almost a relief when we did the IVF and they said absolutely nothing is covered. We did not even deal with them. It was almost easier to just pay everything out of pocket and not have to deal with them at all. But you still do because sometimes the blood work is covered. It is like there is a grey zone. Some stuff is covered, some stuff is not. It depends on how it is coded. It seems you need to know the secret password in order to understand it. You could hire someone to do that for you and it would be a full time forty hours a week job to just do the insurance.”

“A lot of things were not covered or you would think they would be covered but they would be rejected after being told that they would be covered, and then you would have to fight. Well, granted we were getting this through the view point of the providers. So they would say, “Well, we put this in and this has been accepted in the past. Right now they rejected it.” All our view points were through their view points, so it may not be accurate. I feel we need definite overhaul of the way we do medical insurance in this country.”

Having a child is not a necessity

“Having a child is not a necessity so insurance does not cover any of it. It covered the diagnosis. It covered 80% of the hysteroscopy and that stuff, which still left us with several thousand dollars. If you are doing just clomid and natural cycle, it will cover the ultrasounds for that. But as soon as you do clomid and an IUI it is almost a thousand dollars on that. So insurance stinks. “

“It is frustrating they do not cover it and I do not know why they would not cover something of this nature. I feel folks that have to go through IVF are people that have been married for a number of years. I would imagine they are typically older. They are probably a little more well-rounded because they have the financial means to even pay for it. Why would not you want people like that to be able to procreate; make more successful people in the world because that stimulates better business in the future versus, other people that can get pregnant and do not have the... You know what I mean? It is hard to explain it without getting super negative on certain individuals. I would like to know the insurance companies’ reasoning for not doing that. Not being able to have a child is not seen as a medical condition, which is funny because if we had a child that will be one more person we are paying insurance for. So that is more money in their pocket. Right now the birth rates are way down from what they were even twenty-five years ago, you would think that these companies would want more children in the world because that is more people keeping the economy going.”

“They did not pay for anything. They would pay for labs or if I had a positive pregnancy test, they will pay for some stuff but in terms of fertility treatments, my insurance was worthless. I had a terrible feeling about that and having gone overseas where these other countries see infertility as a medical problem, not like an elective thing, not like cosmetic surgery, they see it as something that is a medical problem that you could try to treat on top of the fact that they have socialized medicine and the price of the medication is not driven by so much greed. So yeah, I have bad feelings towards the insurance.”

“That is probably the most disappointing thing for me. I work for the city. We have an amazing benefit package, the city is very progressive for the most part. We provide services for domestic partnership, we provide insurance for pets. All kinds of different things are available, so very

progressive. But when it came to fertility treatment, it was lacking as a nice way to put it. They provide for diagnosis, the hysteroscopy and those things are covered and so you can figure out what is wrong with you, but when it comes to getting treatment for it they do not cover anything until you get pregnant and then it is covered like a normal pregnancy. What kind of sense does this make? You know the state of Texas has a law that states that you have to offer fertility insurance. When I called them about it they were like, “Yes it was offered and we declined it.” Even the monies that I put aside on my own, we have the flex spending account, they did not let me use that for fertility treatment. That is coming straight from my paycheck and yet they would not allow me to use that for fertility treatment. We ended up doing some really fancy coding so that I could use that money to help me do my IVF cycle.”

“I think it is stinks that insurance does not cover fertility, especially if you have a medical diagnosis.”

“Insurance never covered anything. They did the diagnostics and then after that they did not cover anything. But then I went on my employers plan before coming here I learned the United Health care plan that had two thousand dollars of initial infertility coverage and overall the plan, it is a PPO. I am amazed that they cover things, but sometimes they do not. Some meds are really expensive and they are not covered, like the IVF meds were not covered. But lots of little ones that I always had to pay for in the past now were covered. It sucks that it is not all covered because I definitely feel that this is all medically necessary. I wish there was a mandate everywhere that you had to have coverage because I know that people in Massachusetts are fully covered for a certain amount of infertility and as a result people there get many IVF cycles fully covered.”

“Our insurance never covered it, we knew that it would not. We just called to double check and sometimes things were covered.”

“While my insurance covers maternity it does not cover any kind of fertility. Obviously the well woman exam is covered my husband could go to the urologist, but once we see a fertility specialist, then we are getting outside of the realm of our insurance coverage.”

“Insurance does not cover, at least my job does not provide any kind of insurance which I cannot believe that there is no. Yet they provide some type of financial incentive towards adoption, which does not make sense to me why they would not through the health benefit side of it.”

“Just the IUI is five hundred dollars. The medicines too, I had some donated to me and so I was able to use that three times. Clomid is not covered, I have a program we pay fifteen dollars and we use it for generics, it was cheaper to use it than my insurance. The insurance does not cover it at all, nor the appointments. We needed to go to so many appointments. They ended up not being two hundred dollars like the lady told me. We have been talking IVF and are we were going to get a loan. We got approved but not for the full amount. And it was just going to be so stressful being out that much money and not having any kind of savings left. And so we decided to wait and did an IUI instead. So, that is where we are. I do not know if I will be able to afford IVF.”

“They do not cover infertility, but because my periods were a little irregular my doctor visits were covered. That is only because my doctor is creative, “Technically this is a problem.” So that is the only thing that my insurance covers.”

“I have absolutely no fertility coverage, it is all out of pocket. Some diagnostics has been covered. Now that I am doing IVF, I pay out of pocket for everything. When I was back three years ago with my OB/ GYN, the ultrasounds and things like that were covered. But as soon as it moved to fertility I pay. I am close to \$ 20,000 I would say all together. Far more than they tell you it is going to be for sure.”

“We were hoping to get more help, but the insurance covered basically nothing, so we did not have any coverage. We had insurance but it did not cover any of the infertility expenses.”

“I do not have any type of coverage, not even for diagnostic. Everything is out of pocket.”

“They covered the diagnostics, his test and my test which I felt was a fraction of what the actually cost was, which all together was about seventeen thousand dollars out of pocket. It is ridiculous. There should be a better way to pay for it and it is crazy to me that insurance does not help at all.”

“I went into it hoping they would cover things up to a point and they did. Also I was able to ask my doctor, my primary OB, I asked her to put another diagnosis and she did, she put irregular periods or something like that. But as soon as I did see the specialist, I went in with my eyes wide open, there were not any surprises. I knew that initially some of the labs would be covered and they were, but after that it was not. I knew what was going on, and I knew what they would have covered and what they would not. It is what it is.”

“In general our insurance was terrible because they would cover fertility treatments but because of my blood work levels, if you have a certain blood level it is vetoed. I appealed it, I wrote letters to my insurance company, I had my doctors write letters, I appealed it and it still got denied. If my levels were in their range they would have covered 90%. I am not going to bore you with the numbers; let us just say if your fertility hormone level is under 20 they will not cover you, but if it is 20 or over, and you cannot get it redone, you cannot test it again in six months; they take that first one and they just hold on to it.”

Some insurances pay for treatments

“When we first started my husband’s insurance covered the IUIs, all the sonograms, and the procedures. We just paid for the meds. So that helped a lot. Then he switched jobs to a company that covered 2 IVFs. We had twenty (20) thousand in IVF covered and ten (10) thousand in meds. Hardly no one covers anything now, so we were really lucky that a lot of that was covered in the beginning. It was a lot of paper work, and some appeals and keeping up with it. But

overall, we were very very lucky. Now nothing is covered. On my last IVF we somehow got something covered, just the part that was on my body.”

“I have pretty good insurance coverage and I recognize that it is better than what other people have. It is not the best insurance, but they paid for a lot. They covered fifteen (15) thousand in treatments and seventy five hundred (7,500) in meds. I have United Health Care, but a lot of it was negotiated by your employer. It is nice to have that coverage. It gets you through the beginning part and you have to evaluate how much money you are willing to spend. I do not think I had to fight them or anything. I had one bill come recently that we had genetic testing done and I never had to pay anything before. So I called insurance and they said to call the lab and so I called the lab and they told me to call United Health Care and so I just threw my hands and paid the bill.”

“My wife had good insurance through her employer. He was very clear from the get go what they would cover and they covered what they were supposed to. I think we ended up getting more out of our insurance than I expected. It lasted longer than we thought it would. It covered the first IVF entirely and then some of the second one. So we were fortunate to have the insurance that she has. It made big difference in being able to do some of the stuff that we did.”

“I have good insurance, United Health Care through my work. We had not to pay a lot out of our pocket. I always had that coverage. You just get it automatically with the plan I have. We are on the last one, I only have nineteen thousand left. They covered IUI and IVF. I feel very blessed because I know people who had to pay. It is hard and we are blessed so I feel we have to try until the insurance covers it.”

“Insurance has covered more than I thought it would. It even covered the sperm analysis and it has covered all of mine. I was really worried about being really expensive and it has not been very so far because I have just been doing Metformin and things of that sort. This month is the first we are doing a large cycle with injectables. My husband works for a small company and they just have really good insurance. And I have been so grateful. It has not covered absolutely

everything of course, but the co pays are really low and it is nice to not feel it is out of your control.”

“I was pleasantly surprised by what they would cover and how much of it they could cover. Of course we tried donor sperm and they do not cover that, but the majority of the drugs were very affordable. The doctors’ visits once I did not have to come in every time and cut it down, so it was not too bad.”

Medical Bills

You have to be ready to write a check for how much they tell you

“It is expensive and we had to pay for the whole thing out of pocket. The American costs were much higher than those overseas. Then again just the whole insurance process not knowing what your bill is going to be at the end of the day. You just have to be ready to write a check for how much they tell you.”

“We feel very fortunate that we even had the money to do any of the stuff we have done because I easily could not have had that money so we just would not be here.”

“It is expensive I do not even know how to get in more detail about that. I think we probably spent sixty grand (60,000) and we are not even thirty yet. It is a miracle we had the money to do it. It is expensive, but if you want a kid you have got to pay for it. We did it and you have got to pay what they charge.”

“We did get a lot of bills. We are fortunate we were able to pay for everything out of pocket. We did not have the financial burden that some other people do. So it was not hard for us. I mean it is a lot of money, but it was not hard for us to pay for it. It is not the thing you want to pay.”

“It is not very transparent, there is no way to get comparative analysis on any kind of medical treatment, you have to stick with what is in your network. I could go on and on about how awful that process is.”

“We are still dealing with it, we are still getting bills and one blood work worth is thirty five dollars which is about what you expect even though it is covered, but the next one was three hundred and fifty five (350) dollars, and it was for the exact same test and it is because they did not run it the correct way. But if you were not smart and thinking through we might have just

paid that three hundred and fifty five dollars. I hate to think of people that just write checks and do not think. So I hate it.”

“It was more expensive, of course it is always more than you expect it to be. At the time my husband was still in school, so not only was he not working at all but we also had tuition for him. We were only with my paycheck for at least two years and we were just paycheck to paycheck, so every additional bill we had to weigh it out and make sure that we could pay it.”

“We have had a lot of them. It is frustrating to feel we are paying all this money and you have nothing tangible in return”

Knowing cost since the beginning lowers stress

“I think everyone was pretty upfront about how much things would cost. I do not think bills are ever an issue.”

“At least the RE was upfront with what I was going to have to pay as opposed to weird situations with my OB/GYN’s office. When they did the IUI, they did not even check. They said “well, maybe it will cover maybe it will not. We just do them.” I was more stressed out waiting to find out how much I was going to have to pay, that just knowing right up front. The RE’s office would tell you, you have to pay this much, you pay it and you are done with it, instead of worrying about how much it is going to be.”

“It is an expensive process, but I was expecting it to be expensive. I did not have any surprises. It was exactly what I expected.”

“Luckily we paid the one lump sum, we knew ahead of time how much it would cost and that is all we paid. He did not have options for packages. We did a lot of research too. We took a trip to India before we did this treatment to find out how much it costs over there, what the options were for going there. It was only four thousand dollars for everything there, but the

inconvenience of going there and getting it done. We were afraid, so we paid to get it here; but here you have no options, we had to pay before the treatment, you do pay all of it.”

“I did not have any bad experience with that just because we knew the cost associated to it. The IUI was covered because I guess the way they coded it. So it was good until we got to the IVF side. That is when nothing was paid for. No sonogram. Nothing.”

Pay as you go lowers stress

“We have not had too big bills because we usually pay everything that day and that helps keep it manageable. There is not a big surprise bill later.”

“We have not borrowed. I am trying to pay out of pockets, [try] not incur more but we will, you know, we are considering doing IVF.”

“We paid out of pocket as we went through stuff then of course the surgery.”

Financial help lowers stress

“It is hard to say. We paid, who knows how much, for IUI, but once we got into the IVF realm, we have had financial help from my parents and my wife’s mother. That has been a big help. We have sort of split the cost up in thirds, so that has been helpful. But because we do not have kids we save money and we do not really spend a whole lot. It has not been too terrible, but also we are only talking about one round of IVF. I do not know how it would be if this round did not work.”

“We were very fortunate to not have those stacking up. We paid tons of money. Sometimes I try to think how much money and it is scary to try to put it together. The IVFs are about 15,000. The IUIs, I bet by the time we were done we probably paid 15,000 for all of those together. Then the surgeries, the insurance covers the hysteroscopy, but I still have to pay a certain amount on

those. Then if you think of everything that is on top of all of this other stuff for sure at least \$100,000. We are fortunate that my parents helped us with some of it. They do not have any grandkids and even if we never asked they helped us. So we did not deal with the entire expense but it was still a lot.”

“High, costly. Sometimes the doctors will work with you if you have already gone through one IVF. We would get a better deal as we got into the third or fourth one or they would give us a discount on the drugs they provide or something like that. They would try to help us out. I would say we built up a relationship with him and he probably felt guilty. Yes, you know we had given him a lot of money over the past two to four years.”

“The fertility specialist was less expensive than the doctor [at the big clinic]. I knew getting into this what it would cost, around fifteen thousand for the first IVF and around eight to ten for the second one, which is probably about four or five thousand less than the big clinic. Also we did not have to go off site and ship the sperm. So we did all of that for less money and they gave us a break on the second one. We also were pretty proactive in asking if they had extra samples for medication. We managed, of course it was a lot of money, but we expected that and they did try to work with us.”

“We had the cash we set aside and it was a lot of money but it did not drive us into bankruptcy. It was a huge amount of dough. It actually was money that needed to be spent as another way of looking at it. It was money that it was necessarily spent to get us where we are. But it is a boat”

Medication Cost

You are having to pay for them whether or not they are expensive

“We were blown away of the cost of medication. It was very very expensive. I was taking a thousand dollars a day on the second cycle. So that was for twelve days, \$12,000 gone. That was rough.”

“A lot of these tie in together with insurance, which medications were covered by insurance and which were not. So you were having a lot of that same uncertainty. And again having to pay for them whether or not they are expensive.”

“I bought the progesterone and Femara and is eighty dollars, just for that.”

“It is very expensive and I needed a lot. I guess \$10,000 of our meds was covered, so about an IVF and half was covered under insurance. It helped. I needed the kitchen sink protocol. My friends and I joke about that. I needed the max you could take per day, it always was like \$6,000.”

“It is so expensive. It is outrageous how much some of these drugs cost.”

“It is very very ridiculously expensive. It is absurd how expensive it is. I could not imagine that it actually cost that much to do it. Even ultrasounds were like five hundred dollars apiece and it is like that machine has been paid off for years you know. By God the fertility doctor knew we are paying everything out of pocket and we are struggling and he cut it in half for us. He did half the cost just by telling the billing place. But he knows it does not cost him anything, that is just so absurd.”

“We had some expensive medicines that she had to get and through specialized pharmacies. Getting them was something my wife did, but I think with some of those specialty pharmacies there was little more coordination on the phone. Also our doctor here helped us out to some extent with samples. I do not know if they gave us unused medication from other patients, but they were able to help us out especially when we emptied one prescription but only just needed enough to carry us through a little bit longer, whereas if we had ordered more medicine, we would have been left with whole another set of it. They were very good at helping out with that.”

“Most of that was fine until we got to the IVF and that is when it was crazy expensive. That was three thousand dollars’ worth of medicines.”

“It feeds into my bad feelings about the insurance not covering things. I always joke but I am not really joking that medicine is liquid gold. If people knew this tiny vial of medicine is \$6,000, it is outrageous. It skews your perspective too. I have a friend; she had gone through some of these. She wanted to have an IUI but then she cannot afford it this month. I think “An IUI? It Is like nothing because I am dealing with IVF, so I was kind of “It Is nothing, you, pull it together.” Yeah, you lose perspective and you start to think people are crazy when they say “Oh, this is going to be expensive, it is a few hundred dollars.” You think “A few hundred dollars? That is nothing compared to what I had to pay.” Anytime I had an IVF cycle, my doctor had me on the highest dose of injectables and that is when it gets so pricey.”

“Yeah probably half the cost of it was the medication. That is crazy! Things like those progesterone inserts, which are pills, were five dollars apiece and they were, “You might need more or you might not need more” and then when you need more it is like a three hundred dollars bill. It was horrible.”

“Most of that was fine until we got to the IVF and that is when it was crazy expensive. That was three thousand dollars’ worth of medicines.”

It is affordable with insurance

“It is affordable with insurance. This stuff my husband is taking is not specially expensive.”

“Insurance covered it, I think they said they would cover up to four or five treatments of it, which was great. I think like I paid five dollars.”

“All the medications that I have been on so far besides Clomid, which is not very expensive, have been covered by insurance. Metformin is covered because it is a diabetic medication. Now we are about to get into the injectables and I know those are not. I am a little bit scared and I do not know how much those are going to be. I really need to call the office and ask but I am a little bit afraid to, I am sort of having some denial about that. So far leaving out the injectables they have been much more affordable than I thought.”

“Clomid is not cheap. It is not covered. They do not cover any fertility drugs. Luckily our pharmacy has a cost program, so it was like fifty bucks a month instead of the two hundred or whatever it is without any cover.”

“Once insurance stopped covering it got expensive. The doctor’s office would give me samples, that was nice. So I was able to save money to the generosity they offered. Medication cost if insurance covers it is fine if they do not it is not.”

Shopping around

“It is so expensive. I have been doing overseas from the Netherlands. With the OBGYN’s office was better when I shopped around other places, but they were always out of stock. That was kind of annoying. Freedom pharmacy has been really good but again it is really expensive. Like for IVF, the initial order was \$3,000, we were spending more because I had to get more drugs. I have had to buy extra drugs you know. So that has been expensive. Every IUI because of the amount of drugs I needed was about \$12,000 and we did that three times. So it has been costly. It is very very expensive.”

“Well, that was definitely extremely expensive, that was the majority of the IVF, the cost was just insurmountable. I always tried to find out where the lowest cost was for the injections. In that sense, it was more of a nightmare because I would take the initiative to try and figure out that on my own whereas directly through the actual infertility specialist that recommends where you go buy them. I started looking on the internet to find out what other options that I had. I found out that you could go overseas and purchase the same type of medications at a reduced rate. So there is a little bit of savings but it was trying to time it. So, I did find alternative places where the cost was low, but you had to time it to where when you are receiving your medication they did not expire, or that they would be good because they would be kept cold. So in that sense it took a lot. It was draining. So for patients like me who had taken the highest dose, that was probably about fifty percent of what the cost would have been. The IVF alone was about \$12,000 and the drugs were thirteen to fifteen and that is not including the sonograms.”

“My wife pretty much did most of that or she would work with the offices or she would talk to the women on the infertility forums on what they did. So I think she may have found better places to get the drugs and cheaper ways.”

“I went with a European distributor. It was online. I found it myself. “Make me fertile”, that is the name and it is out of Israel.”

“The IVF drugs were pretty expensive, We got them from off shore, from Israel I believe because it is cost savings.”

“I figured out certain medications are allowed by insurance. Walgreens has that online Walgreens’ specialty pharmacy as if you order stuff from them it is covered by insurance. Then freedom fertility pharmacy, they were helpful. The medication was not covered, but it was helpful to get the discounts that I was able to find through the doctor’s office and on my own. Because my friend is a pharmacist, she was able to tell me like call CBS, call this place and see what they can do for you.”

Out of Pocket Expenses

Above and beyond doctors bill

“Driving, taking time off from work, I have sick time, but it all costs, it means that I cannot stay home with my baby whenever I finally have one.”

“Well, it is expensive to buy the food, and the yoga, and all the various therapies. Oh yes and acupuncture is so expensive.”

“Fear about out of pocket expenses is a big deal, because you just do not know about it. As you go through the process you really do not have any way of knowing how much is that costing you. You could be looking at 20,000 or 50,000 dollars if it takes, maybe you only need one course but if you need five maybe five does not even work, so I would say intimidation of it is more than the actual experience.”

“What was really bothering me and my husband was thinking of the money that we had spent after having our first daughter to get a second. Thankfully we are pregnant now, so it worked out, but thinking we wasted her college education. I could see that would lead to a lot of issues in people’s relationship, we fortunately were able to talk about and pull back, but the whole financial aspect is another reason that adds more stress when you are already stressed out.”

“Yes with the surrogate. I mean we had to pay her, we had to pay an agency, we had to pay a lawyer. It was insane. I did one IVF in another city, I did a work up in Colorado and IVF in Colorado. And yes, a lot of travels, lots of hotel costs. Yes, it was a lot.”

“I even did alternative medicine, acupuncture. God we spent like \$10,000 on acupuncture.”

“With the alternative medicine part, is extra for sure, but I have not minded as much because I get so much out of it. I do not really think about that usually, but you kind of think like, “Gosh. I wish I was not doing this.” But, I get out of it what I put into it so I feel it is worthwhile.”

“That would be all the medical bills. Besides medication and medical bills, they had to ICSI because the sperm when they are extracted, they have no tail. So you had to incur the extra expense. There is always the cost of transportation.”

“Well, if you count plane tickets. The first donor that we agreed with lived in Florida, so there was a lot of logistics in dealing with that. He flew it to us. It was still like three hundred dollars plane ticket for sperm with thousands of men throwing away perfectly good sperm every day.”

“We went to Europe too and that was included in the overall. You have to pay for the travel, but the cost of flying, the treatment, the hotel. It was about half the cost of the procedure here in the States. It is five or ten grand and that includes plane travel, and also includes the donor and everything. Here the donor agency will charge you; I do not know what they will charge, but it was a lot. That just blew my mind away. I remember our doctor here was giving us the best he could give us and it was still twice as much as going overseas. That exceeded my expectations.”

“Just travelling back and forth from doctors’ offices, and the extra things during the meeting when you are going through all of this. It is crazy. It is little things like, “Oh I need more syringes.” I do not think out of pocket expense is a lot, but it adds up because you end up spending a lot of time and gas going back and forth.”

“We were driving back and forth to a nearby city for that year which is hard. I took a lot of time off of work for all of this and kept it all hidden and somehow managed to live this double life.”

“Insurance covered some things but most of it was out of pocket. I think probably the biggest thing was the difference in cost between America and foreign countries. So as we would like to go to a more expensive infertility process the fact that you have to go overseas to do some of

these things or you are driven there to save some money, it is challenging. But again it's all out of pocket. You have to go into it willing to spend whatever it's going to take and you know that certain things are going to be covered with insurance, but most of it is going to be out of pocket. But there is nothing good about writing the checks out"

"Yes all, all my medical, the medical travel, all the acupuncture, all the doctors that I see. Twice in a row now I have met my out of pocket max and for the doctor it is like "ok, well let's pay twenty five thousand right now."

"The amount of time you are driving to the clinic you need even paying for the parking. I mean just the cost of driving down town and then parking and then it is lunch break so you end up eating lunch out. And then you try to think every step, the acupuncture, trying to eat better, and it is everything. Absolutely everything is out of pocket expense."

"By that time since I was seeing a fertility specialist, the insurance did not cover anything, once the diagnosis of infertility was made was all out of pocket."

"All the stuff for IVF and the meds were out of pocket. So out of pocket this year alone we have had twenty thousand dollars, just stuff that we had to pay not counting anything that the insurance covered. I liked knowing upfront how much we were paying, so that was good. But it was just very stressful even going in for things that were partly covered. Figuring out how much do I have to pay, how much is insurance going to pay for the laparoscopy or hysteroscopy."

"My husband and I, we had the luxury of being able to afford it, but nobody wants to spend that kind of money on something that you are not guaranteed. You want to get to the end results and you will do anything to get there no matter what it takes. We were at a stage where we could afford to do it and so when it came to out of pocket expenses, we tried everything we could to minimize it as, researching for cheaper medication and such."

“We could afford it. I am happy for that. We took number of days off of work both of us. We travelled to Georgia twice. We travelled to Houston twice. We travelled to Dallas twice. And then we have hired surrogates.”

“That is one of the things I am thinking about going in May with Resolve to lobby and talk to Capitol Hill about the bills they are going to, they already passed the adoption tax credit so hopefully they will pass the infertility tax credit as well. So all out of pocket expenses definitely were very high. Fortunately we were able to pay for but they were still negative experience to have to pay and at least not get some insurance support.”

“It is expensive but it is something that we want, so we are willing to pay for it. We both drive old cars that have been paid off to pay for this kind of thing.”

Loans

Seeking loans to pay for IVF

“We have been talking IVF and are we were going to get a loan. We got approved but not for the full amount. It was just going to be so stressful being out that much money and not having any kind of savings left. And so we decided to wait and see if his numbers would get better. So, I do not know if I will be able to afford IVF. I was excited when I saw one of your emails where you mentioned the grants, The grants? I was surprised. I mentioned it to my husband, he looked it up and we are applying.”

“We got a loan from my dad. I had to borrow money from him and pay him back. But he was able to help us.”

“We only had to take out one loan, we are doing right now and it was worth it.”

“We did not. I definitely researched them a lot but we did not take any loans. I think if we did IVF. I was going to do loans for IVF.”

Got some help

“Thankfully, my parents helped us once we go to the end. We have been very lucky with family. My mom and my husband’s parents have helped us significantly with the cost of IVF. So we have not done any loans.”

“We did not take loans, but our parents helped us out and we are lucky there. Now granted, we probably, we could have done it, both of us are working so that helps. Both of us have good jobs. Our parents have some money, they are not rich, but it helps. My heart really goes out to people who do not have those means or who are basically sacrificing everything. I am glad our

sacrifices were... we did not do any trips, we did not do anything fun for three to four years. We cut back. We made sacrifices there, but it was not like, "Ok we cannot eat this. We cannot do that." Our sacrifices were different. But then I just stepped back and I was like, "There are people who will basically having to sacrifice a lot more than this." So it is hard not to be kind of selfish about it, but... And when I hear about the thing overseas, that would still be expensive for a lot of people, but the fact that you can do it for half the cost, I would take loans to do that."

We used up our savings

"We did not use any loans. So we used up our savings. We did not want to go that route. So we just dug out of savings. We scrambled up our money. We were blessed as we had saved money beforehand, so we did not have to take out any loans. We have been saving a lot these years and we essentially put all our savings into this."

"We got a grant for part of our IVF, which was pretty cool and then our parents have plenty of money. For the grant part, you write into the fertility organization, you explain your story about the finances that you had to undertake the emotional cost of everything you share a story, and if you can sell it to enough people it works. We were offered two but we passed on one because we had already started the IVF and I told the lady from the second grant that "we were lucky to get money we did not think we would get, I understand it may not work, but if it does your money is going to be able to help somebody else." She did not necessarily understand that but here we are, so obviously it worked for us and I hope it worked for them. Plus we have parents that do not even think and write us checks to help us with that IVF piece. We paid for all the IUI with our money"

Sacrifice

We gave up everything we could give up - we had nothing more to give up

“For years our life just changed. Everything shut down. We were living a double life. I would go to work and people passed me on the hall and they go “Hey, how are you doing?” it took all the energy I could possibly master to just lie, “Good, how are you?” It was so difficult. Every day, I would come home from work and after having pretended to be happy all day, I would just lose it. Every single night I would come home from work and cry for a couple of hours and my husband would say, “We got to stop doing this. I cannot have you crying all the time.” It got to the point where I did not grocery shop because I did not want to go to the store where there were children. I would not go to restaurants ever because there were families there. We would watch TV, but only if my husband was actively holding the remote, and if a commercial that came on had a family, kids, anything, he would instantly change the channel. When I was out in public, if there were families or kids anywhere, I would consciously not look at them. I refuse to let my eyes connect with that person because I do not want to fill hate. I do not want to feel misunderstood. I do not want to feel different. I put all that on sacrifice because we sacrificed our social life, we lost touch with all of our friends. The few friends that we told what was going on, they just did not get it. They did not care. They were just like “Oh you will have a baby eventually.” And it is like “You do not understand what this is doing to us. It is killing us.” It would make me furious when people go, “Hey, how are you doing?” when they knew we had just done IVF and it had failed. How could you ask me that? Our world is shattered. We do not know how we are going to go on. We do not know how, even if we found the emotional strength to go on, how we would pay for it. We are lost and angry and sad and you are just casually saying, how are you? It was maddening. We just stopped talking to people because we did not want to get that kind of treatment. I feel we sacrificed everything. We gave up everything we could give up. There was nothing left to give up except our love for God. Beside of that, we had nothing more to give up. We gave everything we had.”

“Huge sacrifice of time not only in the day to day and going through the process entirely, planning routine around the treatments and the process, not going on certain vacations, not being able to go on airplanes on certain times and having to plan your entire life around the IVF and IUI process. Sacrifice is really a whole more. Not only the scheduling part of it but also not knowing what is coming next. Can you start a career, do you look for career or is your entire planning and thought process surrounding having a child. So sacrificing those thoughts of getting another house, moving away, changing careers, those sorts of things. Things that you cannot really think about. And have to forgo thinking about.”

“All kinds of sacrifices. It looks like we just moved in. It is taken a long time to get to this point. Because of the infertility you tend to not only lose money but you tend to lose desire to make your area around you a home because you are so focused on this. We do not have a sofa, we sat on a futon for years. We do not need this. We do not have that, and it is ok, because you want this one goal to come through and unfortunately it takes a lot of money. It took us a long time to even get the walls done and we did it ourselves. Just buying a sofa, that was a huge thing for us. Just trying to build up savings. Because we got married later in life in our thirties, we thought, we move into our home and start a family sooner than later. We had some savings and all that is gone and once it is gone it takes a long time to put it back. So it has been hard financially. That is why it looks bare, but it all comes with time. It just takes a little bit of patience.”

“Huge monetary sacrifices. I feel like our work has probably benefitted from infertility because in some ways we focused on our work for five more years than we might not have otherwise. So if we had a kid eight years ago, I would not be where I am professionally today. So that is sort of interesting. In some ways I think that is what helps keep the balance, at least I had that to put myself into. But sacrifices, I feel it is more than just the time and energy and decade. That is all gone. It is not just financial it is just life. You could not go on vacations because you did not know what you were going to be doing three months from now. I feel like the only upside to infertility is growth, like personal empathy growth. Yes, you just have a lot more experience with trauma.”

“Negative because of the rigidity around time like maybe not planning certain vacations or figuring out when to visit people or not to visit and maybe social gatherings. I felt uncomfortable with friends if I was having a pretty hard time and did not feel understood or I could share.”

“My husband changing jobs, he almost took a step back for us to get that insurance. So he made a lot of career sacrifices. He could not take the vacations he wanted and every time you spend money you feel guilty about it because you should save it for another fertility treatment. It reached a point where it was so hard and so depressing that we could not even help each other. I could barely get out of bed in the morning, I went to therapy and to acupuncture and it was so hard for him. I had nothing to give. So that was hard.”

“There is a lot that is involved in terms of the process itself. Making these decisions based on my faith, you go back and forth all day and debate when you are catholic. But you have to do what you have to do. There is also time from your job, having to work around that. Then for me it is also trying to stay inactive, having to rest and I was battling that a lot in terms of sacrificing my activity level, which to me is important.”

“If you are spending so much on this, you are not doing the fun stuff, fun trips or other spending. You sacrifice time too. But we had a limit. We kept going further, but we set a certain point, where we decide it is not worth it to keep going. Like we decided we do one IVF and if we had any frozen then we go with that. We did not want to go beyond a certain point financially, I do not want bankrupt ourselves. Not to say that it was our very last shot that worked and it was weird. We had three embryos and the very last embryo worked, a couple did not unfreeze. We were wondering if that did not work or if I was going to lose it, would we go back and try again? So yes, there was certainly a lot of financial and emotional stress that all went into it.”

“We want a baby so bad whatever it takes that you sacrifice everything. Even planning vacations, “Where I am I going to be in my cycle at that point, what are we trying to do at Christmas time?” Coming back short from long weekends because we have to be at the doctor’s.”

“We sacrificed a lot. He is just now looking to buy a car; his car is from 1996 and it has been in bad shape but we have been like, “We are not buying a car until we get this figured out.” We would not go on any vacations. We finally took a vacation when we went overseas to do this process but for 5 years we would not go on vacation. I know there is people much worst off financially, do not get me wrong but it was still a lot. A lot of things put on hold, we cannot do this because of this, we cannot afford to spend that money because we may need that money. But we did not have the stress of the medical bills piling up. We would either have the money saved or my parents, helped us. We are very fortunate about that. At the same time I cannot say it is a positive experience. My husband has a lot of frustration because he would see our friends go on vacation or get a new car. They do different things and he would be very frustrated by that because he felt we worked so hard and why is this happening to us and that kind of thing.”

“Personal sacrifice, I would say we probably did a lot of that. We built a house and there were some things that we wanted to do once it was done on our own, but we still had not done because we put the money towards a baby, a non-existent baby. Like vacations, fun things that we would have normally done we stretched money to pay all these things out of pocket. It is expensive, which also compounds to stress because you are not taking care of yourself emotionally either. So the self-care goes to the side because you are so focused on these two week increments, and money, and how we are going to pay for it. Not a lot of vacation, or time off even. I do not want to take a day off because when I am going to sit at home and think about things. So you just keep working but it is sort of counterproductive. You need that vacation, but I cannot relax.”

This is \$100,000 dollar baby

“We made a lot of sacrifices. It was our savings and thinking back of how much of our money we have used and even now that we are pregnant, things that we would have used that money for. We have friends that are currently pregnant, they just have sex and they get pregnant, and then they just can buy baby stuff. This is a hundred thousand dollar baby and we do not have that

money to spend on a stroller or for nursery furniture. Whatever we would use for the baby, we sacrificed way long ago. It is all worth it, but it is a huge sacrifice.”

“We are up to six figures between surgeries, fertility, and everything. Thinking that money could be going towards college education, or savings, or retirement. We worked so hard to save it, since we ultimately ended up with children we look out at it and say, ok, it is not a big deal now, but at the time when you are going through it and it keeps failing it is just a sacrifice in general. Also, I sacrificed my body. I still deal with the sex drive, I do not know if it is because of all the hormones that I have been on, and I am at a very high cancer risk now, because of all the fertility treatments I have undergone. Basically now I am looking at having a child and then getting a full hystorectomy because of having family history of cancer and increase of it. So, I feel I sacrificed a lot for my body, it was worth it, I am going to have my children, but the sacrifice was huge. Than going to the process of emotional stress of thinking and hearing drug addicts getting pregnant so easily an being able to give birth and here I am, a functioning member of society that does not have any addictions, I am healthy and I am having to put my body through all this hell. From my husband’s side just seeing me enduring that and to see my body get through the surgeries and everything, so there is a whole lot of sacrifice involved.”

“At the time it is insane, you cannot save your money for anything other than fertility stuff but now coming out on the other side and if it goes well in the next few months we will have a wonderful baby girl at the end of all, but you look back at it, you are like “Whoa! Money is money” you save it and what you save it for, it is not for things that you absolutely need to. That is the sacrifice that we had to make to have our kid. Hard to go through at the time, but once you are successful it is like going to school a pain in the butt but when you are done you with it you feel great.”

“We tried to keep things in perspective, and we knew that our relationship was more important than the whole journey and that had been not being able to conceive we still would have been ok. Financially it was a little bit of a sacrifice but overall I think we tried to keep those priorities.”

“I feel I have not had to make too many sacrifices. It is definitely an emotional process, but as far as sacrificing other things, I do not know. We do not make a whole lot of money, but we do well enough to live in this house in a decent neighborhood. And you have a TV and all that, but I do not need to have five TVs. You know what I mean? Well, I would like to have a house closer to downtown, but we bought this house last May when we were going through IUIs, and we definitely sacrificed on location and cost of the house because of our fertility budget that we were working with. We made a sacrifice, but it was still positive because we both knew this is what we want to do. We are fairly content with other things and the only other sacrifice would be other savings. But we tend to do a great job of saving as it is.”

I sacrificed relationships

“It was not a financial sacrifice because we chose for it not to be. Our marriage probably took a hit for those two years but we came out ok.”

“Monetary wise, we cut back. I have a lot of savings, so we used our savings. I think we are fortunate enough to have money to pay for things. We were not making deep sacrifices, we still went on vacations. I cut back on personal shopping. I definitely sacrificed a lot of friendships, just isolated myself and I think I did it more than my husband did, and it sacrificed our social life, which I think he had a hard time more than I did.”

“We have sacrificed years and our emotional well-being and our relationships with other people, not being completely sacrificed, but we have pushed away from a lot of people because of this process.”

“I had a friend that I know since we were twelve, she did not get my infertility. She got pregnant before she got married and she just did not understand what I was going through. So I realized who my true friends are.”

“Definitely financial sacrifice and then emotional, just relationships with others that are pregnant or were pregnant during the time, and friendships that were stressed because of me not interested at things that I used to be interested at.”

“For one, I felt I was doing it on my own in many ways because my husband was not very concerned about the outcome back then. He has two kids. He was doing it for me. What was really difficult was that I felt I had to sacrifice a lot, like quality of my work. My husband expected me to still be a good family member participant. It was really stressful. He has a very negative relationship with the bio mom of my stepdaughters and I remember during one of the IVFs, was right after the transfer, she was once again threatening to sue him and we were dealing with legal stuff. It was a huge mess. The oldest was refusing to go to her mom. It was really frustrating because I wanted some calm in my life and I wanted to be selfish for once. I wanted to have my own time to go through this and hope that it would work. I was dealing with so much drama in my environment. The day before my egg retrieval; my oldest stepdaughter got into a golf car accident. I was carrying her into the emergency room with blood everywhere. These were the kinds of things that were going on in my life when I should have been resting. I should have been taking care of myself. In the first IVF we moved during the treatments, it was just too much stress in my life. My project on campus was not going well. So I feel I am very bitter about sacrifice because I feel I am the only one that was willing to do it. My husband, I do not think he did it. I do not think he worked hard to try make my life more comfortable at that time. I do not think he sacrificed enough for me at that period. I needed more and I just do not feel I got it.”

“My partner and I have separated since this. It really took a toll on us and he was not taking it as seriously as I wanted him to. He certainly was not ready to jump into a fertility treatment so it was a pretty big sacrifice.”

“There were a lot of sacrifices that had to be made in order for me to go through the IVF cycle. However, they were what I want to do. I could not think of a better way to spend that money. Even when my ex and I would have conversations, we lived in a home, and I would say “we are paying \$60,000 a year for this house and it is just a house. It does nothing, at the end of the day it is going to crumble, it is just a house.” I said it and yet it seems too big of a sacrifice to pay

\$25,000 for IVF and it was kind of hard for us to get on the same page. It was a sacrifice but to me it was probably a positive sacrifice. It was the most important sacrifice I have made.”

We lost that sense of normalcy

“I just feel like we lost that sense of normalcy in a way, you expect your life to take a certain track and then it does not, and feels awful. We had waited until he had a job and finally he was settled and I was settled and everything felt like this was the right time, now we will make good parents and then we could not... and I felt the worse.”

“Of course there are sacrifices that you might just normally consider making in that process, both in time and emotional sacrifice. You were prying into some deep seeded impulses when you try to technologically finagle a baby, which should be done through a moment of passion and a grasp of partnership, instead is left in the hands of people with tubes and needles; and that is a major undertaking psychologically so it was a huge sacrifice.”

“I am a chef by trade. Eating all of the unpasteurized cheeses, the wine and all of these things you cannot have anything if you are pregnant or if you are trying to get pregnant. We took a trip to Seattle right after I got diagnosed and that was great because I ate all the unpasteurized cheese, drunk all of the wine, went on all the brewery tours and had all the sushi ever because it was the first time to have, for a year that I have been able to do it. That was such a big part of my identity, that foody world. It is frustrating when, “No I am not drinking when everyone else is and I am still not pregnant.” It is not like I have a baby to solace me when everybody else is having a good time or enjoying their meals with whatever. I do not mind doing it if I was having a baby, but the more months that cracked on, it is like, “Ok, I am doing all of these right things. I am not having coffee, I am not doing anything. Where is my baby?”

Missed Work

I Quit my job

“One year into [treatments] we realized this is a problem, and before switching to my new job, I decided to take some time off because everyone said “oh maybe if you relax.” So I took about six months off between my two jobs and it did not help obviously, did not get pregnant in that time. But that was why I made that choice so that was sort of lost work.”

“The hard part for me is the missed income because right now I am not working on purpose. And Not working is fine and wonderful, but not having the income associated with that for a whole year is going to have long-term effect. I am really going to wish I had that money next year.”

“January of last year I quit my clock-in job specifically because I wanted to improve my chances of having a baby. I quit my job and became self-employed to improve my chances of fertility and to make space in my life to get pregnant because the first time I got pregnant I had HG (Hyperemesis gravidarum) and I puked twenty four hours a day. So yes, I quit my job to do this. My husband missed a little bit of work when our donor was in town just trying to make everything work. I am glad that I made the choice because my health has never been better since I stopped working in the public sector around all the people with the germs.”

I Used a lot of my vacation time

“I was able to work it in my scheduling, I did not have to take days off work”

“No because I have vacation time, so I can just take vacations.”

“I missed a lot of work. My boss was very understanding but the way my vacation days work is that I have PTO vacations so you got no sick days. I ate up a bunch of my vacation days for anything.”

“I missed a lot of work; I work for the city, so I had a lot of paid time, I did not lose money from the missed work, but I did use up a lot of my time just going through the cycle. It was appointments. It was the time off for the hysteroscopy. It was time off during the two weeks wait. Time off to just get your head about yourself to relax a little bit. But it was mostly just those appointments. You know just trying... you are doing this every day... everyday appointments. I tried to schedule them around lunch time but that just did not work.”

I tried to plan the treatment

“I would have to miss work to go. I was teaching at the time, so it was not easy to be out of the classroom. They were able to get substitutes, but it is very noticeable you are not there. The kids are freaking out. It is like this domino effect and I never missed work. The other thing that we did was we tried to plan things in the summer. And that got old very quickly because you cannot plan it. So I hated it... And my husband who is also a teacher still was really “on let’s do things in the summer” and he just would not understand that it did not work that way. So stuck.”

“I scheduled the IVF so that I would do it over summer because I am a teacher. I was really lucky that I had that option because otherwise during the school year is really inflexible, you cannot leave and just go. I was lucky that I would not have to miss work.”

“It was very inconvenient to leave the office and do what I needed to do.”

“I worked full time last year. I am a schoolteacher and I was working with Headstart. I enjoyed that, but it was getting hard. I went through my miscarriage when I was still working and I did not tell anybody because it was so early. It started on a Friday when I was already going home, so I did not have to miss any school. I did not tell people, and I felt like I was lying a lot about

stuff. I felt I did not have time for appointments. So this year I took a job working two days a week. And that is been much more manageable. I am grateful that we have been able to do that. So I have not missed any work.”

I do not want them to know: You cannot afford losing liability

“We both have paid terms off so it is not even costing. It is more what is that you do at your job. You cannot afford losing liability in this job market. To me that is worse than the actual how to take the time off. It is, how is your boss interpreting that.”

“I would miss work for appointments or if I had a procedure I would have to be on bed rest and I was not telling my work what I was doing. That was sort of stressful because you do not want them to know, to have unexplained absences is kind of tricky because I have always been really good about my attendance and my reliability. We tried to avoid miscarrying by being on bed rest, it was a long time maybe a month. That was hard because I felt that now everybody was going to know what I have been doing and then it was weird because I came back to work and everybody thought I had thrown out my back. They had a completely wrong idea of what it was. Anyway, there was stress involved about missing work.”

“I was in a major project at work for two years and at the time we were about ready to deploy, we had to go overseas and that was difficult because I could not tell my work too much. I did not want to tell them, I am a private person and this is very private matter so I talked to my boss about it. I gave her a heads up we are doing this. She had gone through the same thing, so I felt I could talk to her about it, but, had she not gone through it, it would have been much more difficult. With that and then the IVFs here, we missed work for that and I would have to be at home to take care of her.”

“I missed a lot of work. I had to get creative and I am really not. I have a very difficult time being less than 100% truthful. It is very difficult for me. I had to either make sure I was just not telling them where I was going or I have to be out. I never once called in sick, I have never done

that my whole life and I did not do it during treatment either. I would say, “I just have a doctor’s appointment.” I do not know how I did it, somehow I made it. I am not going to tell them because they are not going to get it. I am not going to waste my energy telling them how sad I am and have them go “Oh you will be fine.” Because that is more hurtful than not telling them anything.”

Flexible & Accommodating

“The last job they were really wonderful, it was a small firm and they generally knew what we were doing and they were very accommodating. I had several surgeries and sometimes I would say, “I might have to be out for five days in a week and a half from now. I cannot tell you which five days, but I will let you know as soon as I know.” And they were very accommodating and that was good.”

“One of the trips to Colorado, thank God I had been with that company for a very long time, they let me work part of the time because back then I was just doing follicle checks every three days but I was in another state. So they let me do little work. One of my employers was pretty good. Although it is still stressful. You know you are doing IVF but you need to be in wherever Phoenix on a sales trip. So It was hard.”

“I have not had an issue with that. The group that I work with is totally flexible, they were just “Go for it!” but I work a lot so I am done with the typical work by Wednesday and I can afford not to go to work for four hours on a Thursday for doctor’s appointment.”

“I was fortunate. I took some PTO for the surgeries. My job is really flexible, I commute to Houston, I have an office here and I work from home too. I can do whatever I want. They do not really know what is going on. I did not tell them, I might say I am going to the doctor, but they are really not aware if I am gone for an hour.”

“I was really lucky. I told my job I was doing IVF for the first time and I told them either I want one month off or I am quitting. They did not want me to quit, so they gave me a month off. My boss actually had done IVF himself and it was successful for him. Also, my infertility clinic was five minutes’ walk from my office. So I just walked and did my IUIs. I did not have to make up excuses or miss half a day like a lot of women do during all the procedures.”

“My employers have been really understanding about all this. I have had two different employers. The first one did not know about it. I set my own schedule and they did not even ask. My current employer has actually been through IVF herself so she is really understanding.”

“I have a new employer and they are really great about it. I have talked to them and my boss has two little children and so he knows what we are going through all that”

“I missed a lot of work, but I never got reprimanded. I do not think my advisor knew because as a PhD student I am very flexible. I never had a problem with people wondering where I was or having to take time off of work. I know a lot of people with the nine-to-five jobs would have a difficult time with these treatments. My concentration was bad; I was not focused on my work. So it kind of caused me to miss work that I should be doing.”

“I missed a lot of work because of the transfers, the surgery, things just going haywire, and having to leave early. I was pretty straight up with my boss I talked to him and he was very understanding. So it suck that I had to miss so much work, but it did not suck that I missed a meeting because my boss was like “do not worry about it. Do what you need to do.” So I did have that support which was really nice.”

“I am blessed I worked for myself, so it was not an issue. I did miss work but there were no consequences for it.”

“Just a couple of days with surgery. I took the next day actually because I was still in pain, but work was fine. That is the good thing about my work because we are social workers we take care of each other. So work has been great.”

“I felt bad about missing so much work, but I was lucky that my supervisor was pretty nice and that he did not ask a lot of questions. He is kind of funny, a little old fashioned. If I just tell him I am sick I am going to need to be out, he does not ask in case it is woman troubles of some sort. That is good. Sounds perfect, do not ask. You do not want to know all this and I do not want to tell you. Missing work was frustrating at first but got used to it and my boss di not really comment on it, so it did not cause stress at work.”

Knowledge/Information

Knowledge/Information describes how one gets information and from what sources information is acquired during the Fertility Treatment Experience. The sub-affinity titles or various components as indicated by the participants and their interview responses are listed in the following order.

- ◆ From Medical Staff
- ◆ From the Web
- ◆ From Family & Friends
- ◆ From Support Groups
- ◆ From Books
- ◆ Asking Questions
- ◆ Understanding Information

From Medical Staff

I saw this person for ten years and that was always a very hurried experience

“Well, this is where I was really disappointed with my primary care physician who knew that I was trying. I feel that the only thing she ever asked about family building is “are you trying to get pregnant? Yes or No.” and even the question about irregular periods did not take form. That is not even connected to how that might affect whether you can get pregnant or not. I did not even have a sense of yes they are irregular, so I did not have a sense that that could be an indication that I had polyps. I saw this person for like ten years and that was always a very hurried experience. I remember when I was trying to get pregnant and I would I asked if she had any recommendations for obstetricians. She said “oh we will cross that bridge when we come to it.” not anything like “let’s chat about this or how is it going” Then after it had been six months of us not conceiving, she gave me the referral to see the reproductive endocrinologist.”

I do not think they did a very good job of relaying information to us. They expect us to know

“I think the information that was given was very sterile. It turned out to be not very applicable in a lot cases. Very general. They would give these statistics and you do not really fully understand what the statistics mean other than sixty-forty and it is hard to relate that to your own experience whether that is a good statistic or whether it is a bad statistic. Luckily, my partner got all the information that she needed on her own through the computer, through discussions, or her own understanding of the process. So there was some information available, but I do not think they did a very good job of relaying that information to us and making that information fully understandable how that information relate to my particular experience.”

“I feel they only give me a little snip bit of it, obviously they do not have an hour to talk to me. Like when he says I have low ovarian reserves, I am supposed to know that. I have never done this before. So I have to go home and get on the internet and research that and then I get all depressed because I am like, “OK, I am old and I am not going to have any eggs left.” They expect me to know what these terms are and what everything is and I have no clue what they are talking about.”

“This is so every day for them. Like if they ask you a question about what you do for living, you will throw out terminologies and you sometimes forget that the layperson does not know what those words mean or know the background behind anything. That is the same thing for the medical staff. So I do not blame them completely, but I think they forget that this is our first time hearing these words and this is our first time trying to wrap our head around what this means. They forget that because they are in it every day and they are saying it all the time, and they have gone to school for it. It just becomes old to them and for everyone else this is a whole new world and on top of that you are hormonal and stressed out and anxious and scared. So I think they could do a better job of dummifying down the information and giving you a lot more and waiting for questions as opposed to not giving you much. They are always there for questions but you do not even know what questions to ask.”

“They would answer specific questions but they did not go out of their way to say what it means or give you any real idea if should we even bother trying? Should we just keep trying like crazy and hope to get lucky? They really did not want to venture an opinion because I guess they did not want to be wrong.”

“The medical staff really did not provide much information. It was more on my own especially for the Ob-gyn doctor until I got to the fertility specialist, which was a little better, much more informative. We did a three-hour seminar that anybody who is interested in understanding the process and the procedure can attend without being bumped by the practice. I say bumped because some patients do not want to go there and do that unless they understand the procedure or the process itself. So they offer once a month seminars and the doctors would go and speak. That was great. I think that was actually why we decided to go to that practice. There were maybe forty or fifty people or other couples. It was very relaxed, very comforting to know that others are going through the same process while we were learning the same thing.”

Overall I got Good info

“Overall I got very good information more from the fertility doctor than from my primary OB. The really good doctor would deliver information really well. He would sit down with you, in his office lots of times, he would explain things in a very clear way. It does not mean I committed it all to memory because a lot of it is overwhelming but at that time, when he is explaining it and we are going through the steps and making decisions, his information was good, he was good about relaying the information and trying to make sure you understood it. I feel overall they have been pretty helpful and positive in their information to me and my husband. I would say especially the fertility doctor did a really good job of giving us all the latest information. They would always weigh all the options out and [be] informative.”

“I did not get much at all in the IUI and I would not until the IVF, until they actually thrown out these labs and so to speak I started to get really interested. When I started really drilling down and interfacing with both the Internet and people particularly I thought it was quite positive, it

kind of answered appropriately every question I had, so I thought the knowledge that they imparted was true and correct.”

“My doctor stays ahead of the technology, he is always researching and he is part of a lot of different boards that deal with infertility around the nation. So, he knows what is going on, what is the best technique, and he is good at informing you. I have all these pictures what he has drawn. Like this is your uterus and this here is what is going to happen and this is what we are going to do. When he just draws it up for you and even if you never knew anything about this, you walked out there feeling you know a lot. So he is really good.”

They do not tell you the whole story

“I do not think they are helpful. It is discouraging as to how you get that information. It should not be so hard for people to get. The thing is that half the time you do not know what to ask. The doctors’ offices are great in giving you pamphlets, and there is jargon and that is great knowledge, but a lot of times you do not know how to educate yourself, how to proceed. It would be nice if they were the ones taking on the role of education. It is like a student walking into a classroom. I am here to learn and I will ask good questions if you have good conversation with me, but I am not going to know everything that is going on right off hand. Then when you go in the eighth, tenth time, you ask, “what about this?” They say “Oh, we have got great information for you.” And you wonder, “Why did not we do this back there?” and that is where the discouraging part is. Every time I go in, it is like anything else we can look at? Is there anything else we are missing? Is there any other test that my husband and I can do to get us more information? “We recommend that you do this one test.” Then seriously why did we not do that in the beginning? We spent five hundred dollars apart for two IUIs and then you tell me about it?”

“I feel they are not very forthcoming with information, they know it but they are just not sharing it. It is really frustrating and sometimes it is that I have to ask the questions, “What will the next step be?” “We will talk when we get there.” “Well I am going to need to plan ahead. I need to

know what is around the corner. You cannot just say next month we will do IVF and then expect me to have that. What is the cost, what is the procedure?" and I said, "We do not have the money. I am not taking a loan with no guarantee. You do not know what is wrong?" There is no guarantee that it will work, so that is why we quit. I am a social worker, we talk about our feelings and emotions and that is really huge. That is the biggest piece that was missing from the doctor, "How are you doing with this?" Instead of just this robot, "Keep doing this, this and this." Like, "Let us stop for a second and how are you dealing with this? How are you coping with this? Are you taking care of yourself? Are the two of you doing ok?" There is none. There is no human connection there. Maybe that is amplified because I am a social worker, that is what I do. There is no regard to the mental health component of it."

"Not overly informative, he does not volunteer a lot of information. He gives information as you go, but he is sort of vague, he is just very like surface. If you want any kind of detail you have to ask for it. Maybe that is his style, I like him, I think he is a great doctor, but I would like more information instead of having to ask. Their paper work is good. The brochures are good. They have this whole IVF overview thing that is good. They have a cost thing that is good even though it is not fully accurate. Overall pretty good, but there have been a handful situations with the nurses that I have had to prompt them to tell me information. Sometimes I feel they could ask more questions or they could be more informative to get more information out of me or I could get more information out of them, because I do not know what I am doing. I feel I am very ignorant going into the process. They send you to a class that is in IVF not so specific. The course was really good, but it is also very confusing."

"I think they do a good job of limiting your information. I think they could do much better. With the fertility clinic, they had a one hour or two hour seminar that they walk you through the information, discuss different things and then we discussed with the doctor as far as what could happen at some of the appointments leading up to it. So, I feel that at the fertility clinic if we wanted that person be available to speak with they would be available. But how much information we get? Oh yes, it is limited. I feel for the medical staff it is a job. They are there every day. They are seeing who knows how many patients every day. They start every patient at

step one, and then they take every patient to step two, and so on and so forth; when not every patient is the same. They should not start every patient in that regard. I think they could do a much better job of divulging the information beforehand.”

“My fertility doctor was good at explaining things. My only complaint would be they tell you one step and not the one after it, unless you really pressured them to tell more. “Let us just worry about this one thing and will get to the rest later.” And you feel lost because you want to know everything. They do not tell you the whole story, they only tell you what is next. I do not think they fully explained the process to me enough to be able to figure out how to do things and when I could start. I feel they were holding back information.”

“I felt I came to my appointments always armed with information. Should we try this, should we do that. I have read about this. I have heard about that. Sometimes I felt I was the one pushing things. My doctor loved it because she and I could actually have an intelligent conversation back and forth. I think she felt challenged by my questions. So that was good.”

“My reproductive endocrinologist was pretty good about relaying information. I would get a little frustrated sometimes with the nurses. It was really nice when I had the private meeting with the nurse for the support group and I could ask her many questions. Definitely there were always more things that I wanted to know, so I went to other sources.”

“It was never given enough information because I am one of those people that the more I know the better I feel and I never knew enough. Maybe because they could not give me any guarantees. At first the information they gave us was his number, his statistics. Yeah, and that was not enough and of course you have to wait until you go in and talk to them. In that time I am using the internet and looking things up and that is crazy because I am looking up random at numbers on the internet, you find all kinds of crazy answers and then even when we went in I thought like, “Ok, they give the number and say it will not happen unless you do IVF and that was it” which for me was not enough because I want to know percentage chance and how likely it is that this will happen naturally and how likely this is that it will happen with IUI. That information was never available.”

“I got the overall picture but then they would focus more detailed on each step. Of course any questions I had they answered right away but they would take me to a process and say, “The big picture is this, but we are going to take each ordeal at the time and try not to worry about what is next.” That kind of thing.”

“They were pretty good at explaining our options just like they are biased for you know, “Do things this way. I feel we were really misled and taken advantage of and my view was that they were just cranking us through for money. Not really interested in helping us or seeing what the issue was or anything.”

From the Web

Most information I get from the web is from people like me

“I sort the web a lot, went to the “trying to conceive or taking charge of your fertility” forum. Like in the early days when I had questions about charting, I got some really quick and thorough responses from people. So I really appreciated that. I have read about multiple people caring their harshness and how to do it. I feel like I have learned more from that.”

“Well since I am filtering it, I feel pretty good about it, but I also take it with grain of salt. Most information I get is from people like me who are navigating and trying to figure out what to do. I do not tend to read a lot from websites, I trust more the casual conversation I have with someone who has the same condition that I have and who has had experience with whatever it is that we are talking about rather than a website that is trying to teach you something.”

“I did a lot of that. I know it is not the most reliable information, but I was in it. I am in this national infertility support group and they have an online support where people can write and ask questions. I would read people’s questions and learn a lot. Sometimes information is right, but you have to try not to run with it if you do not have it confirmed by the doctor. I did not probably read as much as some other people because I tend to be skeptical and so I am not sure to believe everything I read. Anyway, it is good having that available, but you are not sure if it is reliable. When I was going through the miscarriage we were trying to do it naturally. We knew the baby had passed away, we were trying to see if I would pass it naturally and I was really nervous about that. So, I was trying to find other women’s experiences on the web about miscarriage. It was not that easy, I was looking and looking for stories to see if anybody had this happened and to find people experiences who had DNCs, people who did it with a medication, and how bad was it. It is helpful that it exists but you have to be careful.”

“That is something we all do, search and try to figure out, self-diagnose, learn. I think overall it was pretty good to comfortably on my time find out information and learn a little bit.”

The web never lies

“There is a lot of information on the web. It is trusting the information on the web. If you are going by whether it is reliable or not it kind of depends on your sources. Anybody can put up a website. I sought it from Mayo and reputable websites, but that is information they share at the physician’s practice. My wife would from time to time go to the web; I just told myself if it is not on WebMD or if it is not on Mayo I am not going to look at it just because there is so much stuff out there like not drinking seven cups of coffee every day really solve your fertility problems, and someone would have believe it”

“The web never lies. The web is not good and bad things can scare the bee gees out of yourself. I could get out there and write all the crazy crap.”

“There is lots of information, the only question is how much of it is accurate versus not accurate and that is hard to know. I do not think we found any real information on the web that was ultimately inaccurate. Very accessible, very easy to find. Maybe it is overload and a little not understanding whether it is accurate or not. You do have to weigh the source of the information but a lot of web MD is not going to have the specific in-depth information, how did you feel after this, how long did it take you to recover, why did the doctor prescribe this instead of that? So I read a lot of blogs and messages, words and posts from specific people. I fund stuff on resolve, but it is not as much or as in-depth as I would like it to be. It gets in-depth in the blogs but you do not know if it is reliable. It is kind of a combination of the two.”

“The web is good for quick answer, but there are a lot of idiots on the web. I would read the message boards when I was looking for something specific and you get a lot of information some good some bad. I never took it too seriously, but it gives you a good idea when you have questions to see what other people are talking about. I joined a resolved web group and you

could set up the email features so that they would email me every day, but it was too much for me. I had to turn it off, I do not need to read all of this every day and half of the things they were saying were not relevant. So I did not spend too much time on the web. I just went to the web when I wanted information, but I did not spend a lot of time.”

“That is a mixed bag for me because on one hand you can get a lot of information but you can also get a lot of confusing information. Every cycle is completely unique, one person might list their experience like: I did this, this, and this and it worked. Another person would reply: I did this, this, and this, and it did not work, or our numbers were this and this and I had a healthy baby boy, and my numbers were even higher than that and I did not complete the pregnancy. So from the web I have a majority wins mentality, but I spend hours and hours on the web, I think all of us who have gone through this process do. It is hard to think or concentrate on anything and it is ok, google: “What does a implantation look like?” You know for everything it is like that. So, I love having access to information so readily, I do not necessarily trust it.”

“Mix bag. It is hard to know what is reliable, what the sources are. If you are looking at any of the threads that are on chat rooms, [it is] either people that have gone years and maybe have a success or maybe not, which is really disheartening, or people that are nineteen and they are like, “What do I do? I just got pregnant.” It is kind of a mix bag. I was more of the kind of a bias reader. I am not going to submit stuff and participate. I just wanted to see what other people have gone through. Or you are googling some things or IUI stuff just to figure out, ‘Is this normal, is it not’ It is hard because anybody can put anything online. So I do not know what the reliability is. I do not feel there is a ton of information about infertility itself. It is more about the IUI or IVF and not the infertility piece itself and those links tend to be the more are you getting a massage, you go to acupuncture, you eat some herbs. So, I feel that was not totally helpful.”

Doctor Google did not do well for me

“All I did was read it and get stressed out. I diagnosed myself and I was never going to have a baby according to the web. Yes. Doctor Google did not do well for me. I tried to stay off but I did not. I could not. I cannot now.”

“It is not specific to you. It is just the whole world out there and it makes you paranoid; makes you doubt yourself. Makes you try crazy things, My husband was trying espresso before we were set to try. It was crazy. It is nice to look stuff up but at the same time...”

“The web has so much information, and so many different stories about so many people. I probably drove myself crazy and probably did not help my emotional state by searching on the web. I see that now but I would search the web for hope.”

I did not use it too much. I just did not trust it

“I tried to stay away from it because I feel like what do you trust? There is so much out there even within endometriosis, starts stage one to stage four. Even within stage four it depends on where it was. I just did not trust it. I did not want too much information. If I had a question, I trust my doctor and my nurses that I would go to them. I did not use it too much.”

“I am the queen of Google, especially since having a baby I am up all night researching everything. But to be honest I did not do a whole lot in this treatment and I find that odd looking back on it. I do not know if I did not want to know because I did not want to go to that point. I did not even know that Clomid was a pill when he prescribed it, I thought it was an injection, so I had no clue.”

“I did not really look to the web too much for information,”

“That was a mixed experience simply because there is so much information out there and because of that you cannot filter it and so you read anecdotes, people stories, everybody has a story and you have millions of stories out there. In truth I was only peripherally involved with web searches, as I would be listening to my wife, we would be discussing in bed; she was driving Google and I was in the passenger seat, I do not believe half of what I read in books and a quarter of what I read on the Internet.”

I used the web for specific information to educate myself further

“I was able to look at sites I knew they were reputable. If I had more questions I would go to the web to educate myself further. I did a little bit of looking on the web especially when her HCG levels were not coming up the way they were supposed to. I had trouble understanding that and I did some looking on the web to try and understand what that meant.”

“Google and just searching different websites and forums has been informative. I like to go in knowing all of my options. My husband is kind of the opposite. If I can take a world of choices narrow it down to two or three, and get his input on that he is good. But if I give him a world of choices, he gets overwhelmed and shuts down. I love having it available.”

You get into rabbit holes

“You can surf the web almost too much if that makes sense, and get overloaded with it. I did a lot of searching. There is stuff you have to filter out and find what really applies to you. I thought it was helpful. I think the web is actually pretty good because you can find anything, but then you get these rabbit holes and, I am sure you have been on fertility blogs and all that stuff, those things are crazy. Unfortunately I spent a lot of time researching things on the web because there is not that much information out there; but the information there was blogs and it was a frustrating experience.”

From Family & Friends

The dumb dumb things they say

“It was non-existent. My mother for far longer than is appropriate just kept saying the same old fashioned thing “put your legs up after” and after years I told her, “enough with that.” Friends were saying things like, “Oh you are worrying more than you need to,” like I was causing it. I had one relative who end up having difficulty having her first child tried to give me some advice, but the way she did it, I did not appreciate her comments. She said, “You just have to go right to IVF. Do not even bother with acupuncture or any other stuff.” I would tell her I was working on mine, I was going to a counselor, and she would say, “Oh you are wasting your time.” She could have been a good resource, but she was not.”

“People say things because they feel they have to say something. It is not intentional but the dumb dumb things they say, “You should give up” and the really dumb one is “You should relax.” Yes, it does not help. The only thing I wanted to hear was, “I am sorry. I love you.” That is it. You cannot say anything, nothing else. Nothing is going to make me feel better.”

“Just in terms of being relevant and helpful, not that they are negative but the information I get did not make a lot of sense. It is the usual, “If you guys would just relax.” Oh, honey if you do not have tubes we can be relaxed as we want to be and we can go round here like jackrabbits, but it is not going to happen. So you just relax, you know, that is a good advice thank you.”

“Well, my husband listens to the podcast and tries to give me little knowledge tips. I want to be like “Why do not you do it?” So that makes me I frustrated.”

“This one time my husband’s grandmother, who is very sweet and she is really not very old at all, she is a very young grandmother, mid-seventies; very young. She called to see how I was doing, which was so sweet, I talked to her and she said, “Oh cousin L had endometriosis and she

had three kids and it is not a big deal.” It was not worth my energy to go into why my endometriosis might be different than hers. It is stuff like that, that they kind of dismissed a little bit and to us this was a massive diagnosis and really rocked our world and I felt they were dismissing it. My husband’s parents were in town this past week and something came up about how much we spent in infertility and her jaw hit the floor. And it was like, “where were you? what did you think we were doing these last five years?” They just did not realize the severity of it. So any advice that they would give and the knowledge it just seemed they did not have it all. Mom would check the internet a lot and say, “I hear milk is not good to drink.” And then you felt judged you had a glass of milk or she could find this off the websites that would say, you know “Wearing pink was bad.” It was absurd but she is just trying to help. Everyone was in it for a good reason but it was not good.”

“We did not talk about it with people. To the ones we talked about it, they are always trying to help and they suggest to try this, or what about this, or I read an article about this. So they are not really helpful.” People saying, “As soon as you stop trying you will get pregnant.” Really? Really? I feel more comfortable with family telling me stuff like that so I can say, “I have been trying.”

“Oh, yeah. Relatives are plenty and everybody wants to abide, but it is a showering of love more than anything else, so it is a positive experience whether it is good or bad information or right or wrong.”

“[It] was really difficult for me because I go to these support group meetings and everybody would say how supportive their friends were, how supportive their family was and I was thinking, I do not get any of that. It was awful. My mom, my family, and my sister knew and my mom was always telling me what I should be doing or what I should not be doing and I was like “You have no idea what I should or should not be doing. So just shut your mouth. It is so not your place.”

We did not talk about it

“I do not even want to talk to them. Because everybody has got that story about one friend who got pregnant against all odds and I am tired hearing it.”

“We did not talk about it a whole lot with families and friends and so I do not think I got any information at all from family and friends. We did not talk to many of our friends while going through this, just because we are twenty-five and most of them are still single so they did not really have much application to what we were going through. Our parents would go to the internet and tell us what they learned to drink those seven cups of coffee and never eat sugar - which is hard because then they would come visit and buy ice cream. My wife’s mom did not have much information about infertility, my parents are friends with a couple who did IVF, so they were trying to tell us what to do. Three years later they were finally aware that what they did was totally different from what my parents were telling us to do.”

“I do not talk to my family about it because my mom cannot keep her mouth shut, the whole family would know. She knows very little. She knows we had a miscarriage and she knows we are seeing doctors. Very rarely now she will say, “Are you still seeing the doctor?” and I just say yes or no. I am not going to give her more than that. My mother-in-law keeps asking when we are having kids, which is really annoying. Finally I said to my husband, “You have to tell her. You just have to tell her, I know she means well, I know she wants grand kids and she has no idea, but it is driving me crazy.” Until we told her and she cried and she felt really bad and then a couple of months went by and it stated right back up. Obviously if I could fix it then you would have a kid by now, but I cannot. All the time it is, “When I am I going to have a grand kid?” “I do not know.” “I need some grand kid.” “I get it.” “What is wrong?” “I do not know.” I do not want to necessarily talk to her about all of it, she had four boys easily, so she has no idea what infertility is. She is old school, you know, go be with your husband and make a baby. I have one friend that went through some infertility stuff and she has not talked about it much. I tried to pry and she is very little forthcoming. I would talk about it, but all my other friends did not experience anything. So, I do not talk to my friends about it either. It is a very isolating

experience. I do not particularly mind to talk about it, like it does not bother me. I am not embarrassed or ashamed, I think other people are and they change the subject. So it is very isolating. You know soon as we got the miscarriage, my boss was pregnant. Then somebody else at work was pregnant with her third child, and everybody on Facebook, of course you are more sensitive. I counted one time I had like twenty nine friends that were pregnant. My younger brother has had two and he is eight years younger. So it is like, "You are not supposed to have them before me because I am older." One of my best friends when she called to tell me she was pregnant, it was a little bit early, but I said, "Oh my God, me too." We are going to be due the same time and our birthdays are close together. It was really neat and then we had a miscarriage and she did not. So it is hard to be around friends and see that little girl, and I love her she is my pseudo niece. So, that part has been you know very isolating."

"It is just boring to them. With my mom it is great and she really tries to understand. But I feel for some it is not important, and I feel guilty for saying that because they reach out and ask, "When is your next appointment?" so they are interested. It is just that I feel that not everybody understands and that is not their fault."

"We kept our families and friends in the dark for a while. I did not want opinions nor negativity, I had a group of friends who were great but as far as family there are so many details involved in infertility and our parents are older, I did not want to sit down and have to answer to all their questions."

"We have not told anybody we are doing this because it adds stress to have people calling and asking questions and I do not enjoy talking about it no stop. So, my close friends, my parents, and my sister I will be open and honest with them later, but I have not talked about that to them. This time no one knows. I have a cousin who knows, but she went through it. She can relate and she understands the terminology."

"I feel I am the only person going through this in my family and I do not know anybody else personally who is going through PCOS. So I have not really gotten that much information from

family and friends. People always say, “why do not you just adopt because people always get pregnant when you adopt.” I have started answering I do not think adoption is an appropriate fertility plan. That is not what the purpose of adoption is. They did not get it at all. They just totally did not understand. Everyone has no problem getting pregnant in my family; I had one friend who understood but then she got pregnant so...”

We shared only with people who went through IVF

“We did not tell my family other than my sister nor our friends. We finally told a friend couple who did IVF. They were really nice and gave us good advice and they said just go for it.”

“I had some friends who went through IVF before I did and they helped. She kind of told me her experience. So it sort of gave me something to go by. Because we have had friends go through it we were able to talk to them. The experience is great but as far as getting useful information from them, I do not know how helpful it was, but it was still a positive experience.”

“I have one friend who went through all this before me or simultaneous with me and she will read everything. Now, she comes across as an expert and I am not sure she is right about everything, but it was helpful to have a friend who was going through it that I could ask questions and she had given me an answer and I could try to find out if it was the right answer. In terms of family, my husband’s family I do not think really knew much about anything at all, I am still not sure what they understand about it. With, my parents, it was minimal the information from them. Then you had friends who knew you were trying to get pregnant and they chime in with something like “Oh, you know, I read that soy is bad for your hormones or getting pregnant, you should not use it.” They give you this advice, but I did not really pay attention to it.”

“We got a couple from some of her friends she met through this infertility. At the time they were people in the infertility group and she would find out they are from here and they would have meet ups at places and she got to be good friends with them.”

“Yes, there was a co-worker that I knew she had been going through infertility struggles too, so she was able to give me some help.”

“We did not talk with our family and friends very much about it, but I talked with a friend I work who cannot have another daughter. Doctors were able to say that she no longer had enough eggs and I guess that is a different deal and also have been told it is unexplained; [for us] they have explained it. So, I am still crossing my fingers that someday something will work out.”

“[Yes, with] these friends I have, five really close women, I am probably going to call them support group because if you just said general friends and family, you are picking up people who did not experience infertility themselves. They just do not understand it or get it. Like my mom, it is very difficult to explain her. I did not tell her about IVF till the third one. And she thinks, “Oh it is definitely going to work.” They do not understand the percentages and all that.”

“I have so many people in my life that have created families alternatively. They were all like, “I am so sorry that you are part of this tiny, shitty club, but here are all the “things I did that worked and did not work for me.” They have been a real resource and have been very understanding.”

From Support Groups

It was more than just supportive environment

“None of us were experts, but at least we were talking as someone who had been through. I joined something that was already out there. The one I went to has been around for fifteen years and it was a really really good group of girls. That is how I got so much of my information because they all had been through so much and hearing about other people’s stories made me aware of everything going on.”

“I was getting towards the end of my emotional rope, I was leaning on my husband a lot. Everyday coming home crying, falling apart and not knowing what to do. I have no friends left. I was just living this isolated life and I heard of resolve from my web searching. I really wanted to go to a meeting, but something happened and I was not able to make the first meeting. I was so heartbroken because I was like, “How I am I going to go a month before I go to another meeting?” My husband did not want me to go because he did not want me to share anything with anybody. It turned out that the first meeting I got to go to was actually the couples meeting. He came with me, and he is like, “Let’s not say anything. I just want to take it all in and see what these people are about, see if they are trustworthy.” When we left there he said, “Ok, you can go to the meetings and you can share everything.” I started going regularly and I made amazing friends. It was a place where I could, all the ugliness and all the hatred, I could share all that and not be judged for not being a good Christian. I could just tell them what I was feeling and I could seek advice on different treatment options or cheaper medication. You know, the medical staff failed to tell me that this needed to be refrigerated, I left it on the counter for two hours. What do I do? And they are like “Ok, under two hours if your house temperature is set at this, you are fine. But over two hours, if your house is set at this then you are fine.” They were just a huge resource. I do not think I would have made it without them. I really do not. I think I would have gone bonkers. I think I would have literary gone bonkers. That helped me, he did not go to any of the meetings, but it helped me to not feel so alone.”

“I was not in one until I came here after my surgery and I joined this resolve infertility group. I was very nervous about going, but it was awesome. It was more than just supportive environment, people told you what to expect from a patient’s point of view as opposed to a doctor’s point of view. People had already had the test that I was about to go in for or had already experienced the treatment I was going in for and they were able to give you the girlfriend advice as opposed to just professionals. They told the truth. They said when it sucked or what was not that bad, do not be scared of this, or worried about this. They also totally understood as opposed to family and friends. My husband was awesome, but no one else understands, even your best girlfriend tries to understand but if she is not going through it, and eventually once they have all had kids, they are afraid to ask you about it, they do not want to bring stuff up. So it was great. I suggest it to anyone who is open to it.”

“That was really helpful. I went to some meetings, that was a good way to get information. But my doctor says one thing and my support group says a different thing. I have to analyze that and everybody’s experience is different. There is a lot of people that did not like my doctor, but I have a great experience with her. I did learn a lot from these support groups, I learned generic information like not everyone goes to this fertility clinic some people use other clinics.”

“I go on resolves websites and to their support meetings when I can. They are in the city and I am in a small town. We do not have any in my town. It is a fairly big town and I do not know why there is nothing there. I have been talking to the women who are going through it about their particular experiences plus the stuff on the website. Last time I was at the meeting probably six months ago, they encouraged me to go to the reproductive endocrinologist, even though I am twenty-eight and a lot of people, my family, say “Oh you are twenty eight. You are so young. It is ok. You are fine.” But when you talk to people who are going through it they say, “I wish I had started going at twenty-eight because maybe I would be closer to it now.”

“I find the support group really helpful and sometimes the information is really good but then sometimes people say things that are hard to believe. Overall the information is very good. At

one point there was a woman, who was running the support group, who was very knowledgeable and I was convinced that she should quit whatever job she had and become a fertility specialist because she really had learned so much, real academic sense of it. She had studied a lot on her own.”

“I finally found out about Resolve. Getting to that point was a little frustrating, because I kept asking the fertility doctors if there were places where they have other patients that are likely to speak with me about having a natural child and going through the donor process, in fact was very difficult for me to wrap my head around. It took forever but finally I had a doctor who referred me to Resolve. It is great to be around likeminded individuals and hear about other people struggles make you feel not so alone in the process. They were able also to hook me up or connect me with other women who had natural children and then donor. They were great sources on eliminating any concerns I have that this is my child I am carrying, and that they do not have feelings differently towards the children.”

“I am involved with two support groups. One is local where we meet face to face, really *really* good. I just got involved with them. I went to my first meeting last year at the end of the year and they are really really good. I just think it gets people a form to talk with other people who have gone through it, because you really do not get it. I have three sisters and they all have a bunch of kids and my mom had five kids and so we have these conversations, “Uh ok. I love you all to death and you are fantastic, but no you do not get it.” Another one I found is online. It is called Neighborhood Fertility. It is an online form and normally I do not like the online thing. I do not like chat rooms and that sort of deal, but there was one called Twenty-Twelve Cycle Buddies. It is one group of ladies that we all hooked up mentally and so we all stay connected even throughout this process as people have had children and some of us have not. I just received an email today asking “What is going on? We have not heard from you, what is going on?” and so we report back our betas, and our frustrations, and our triumphs and the whole thing. It is incredible. What is interesting is that some of us have forged friendship out of there. Most of them are from the northeast and it is really cool because they talk about how their insurance is covering this and that. But it is the same struggle, same journey for all of us and so we really

formed this amazing friendship. Nobody else joins it now because it still says twenty-twelve cycle buddies, so really it is just us. It has been really really neat, and we had quite a few babies born, so it has been fun.”

A man's point of view

“I only went once to the support group my wife goes to. They had one occasion where the partners came and that was a positive experience. I also had a positive experience with my wife going to those groups even without me. I thought that was good for her even though I know it is very painful for her to talk about. Myself I am not sure I would want to go to one. I am not happy about this process and it is hurtful for me, but I feel I was not as in need of support as my wife was. That was the support that I could not give her. She needed the support of people who were going or who had experienced the same thing she is experiencing and she would not want to talk to people who had no idea what she was experiencing. I feel a little bit in that category too, I was one of those people who did not quite know what she was going through. From my perspective opening up to my wife and talking to her was enough for me. We are both feeling the grief, but she is feeling an additional quantity that I think is something women feel above and beyond men. I am feeling it. Do not get me wrong. I am pretty upset about how the things have worked out. I had friends I was able to talk to more readily than my wife, the one who found out they could not have a second child and some other friends that even if they were not going through what I was going through, I had a relationship where I could talk to them about it. So it was helpful to me to talk with my people not strangers.”

“I did not complain about it, but it does not seem like there are infertility support groups for men. If there was one, something along the line as what women have, granted it will be different, but they talk about things. As the husband you are like, “My wife is going through all of this, what can I do? Or you know sometimes I feel completely helpless because she is having to do this stuff, what can I do? What are the things you would have done when you all get stressed out? What do you all do?” You know just talk about things. You may not get anything solved, but it is

like there is someone else going through what you are going through. See actually, if you can take one, you are going to take many things from your research, that will be one thing.”

“Me, again I am just perfectly involved with my sweetie. I think the information that she was gathering helped her.”

A different point of view

“I did not know that there were support groups. I even remember searching and somehow I never found a support group. I went through this on my own. I found resolve after the second IVF, and I wanted to meet people who were like me, who went through this terrible ordeal and try to make the best of their lives. Get through the hard, get through this and then move on, and what the support group felt like was that this group of women, everybody, is pushing each other not to give up. It felt sort of unhealthy. I do not know how to explain it. I liked that they are there for each other and if you are going through treatment I think it is good, it is great. But, maybe there is almost too much focus on the end goal being a baby. I saw women in there who for years have been trying the best that science can offer. Now they are trying surrogates. Now they are trying adoptions. I felt sad that this industry is telling us we should not stop, we should not stop until we have a baby. I am also worried for society as whole. I feel that not accepting infertility as a potential outcome is damaging to our society in several ways, making women and couples feel they must have a child and that they can with new technology. I just feel it is creating a lot of unhappy people and a lot of false expectations. Then when they do have the child, they are at risk of realizing that this was not going to make their lives the best life in the world. I know that a little bit too because I have stepdaughters and I know that raising children is actually very difficult on couples. It is actually very stressful and disappointing and heartbreaking and there are just a lot of things that raising kids involves that is very negative. I have that perspective, but I wish that society had a little bit clear image of that instead of just pushing to have a baby. It feels that the support group was keeping up that image. It was not actually supporting people to try to be healthy and move on and do what they needed to do to have a healthy life. It was supporting them to keep trying, keep trying, keep trying. That was really sad. I felt sad because I

thought it means that this is going to perpetuate. I also felt sad because nobody else out there is like me. How can I find people like me who want to try to move on with their lives, live with their hurt, but then move on? I could not find that. If there were support groups focusing on coping on this type of decision to stop treatment and just accept the situation and just move on and live childfree I would join in a heartbeat. I would be an active member. I would be a leader. I feel we do not only owe it to ourselves but society is pushing this image. Hollywood is pushing this image. It is just exhausting. These treatment centers are pushing this because that is how they are making money. In the past when science and technology could not allow many of these procedures, people got on with their lives, and I think people could have happy lives. Everybody understood that a certain percentage of couples did not have children for some reason and that was ok. But now, it is just not ok. I was very disappointed that the support groups did not accept healthy minds over having a baby.”

“I only went to one resolve meeting and I was not impressed. That was nothing against the resolve people. I felt comfortable and all, but I think we could have all walked away with more from the support group, but again I have never ran a support group. I wish to do that one day. I felt that the person who was leading the support group was very strong and opinionated and I noticed how she would be like “No, you need to do dadadada.” I just felt it is a support group, so how about a little bit of structure where we do provide that support as opposed to the person bringing everybody together and constantly talking about her thing. I am not saying it needs to be very structured like, “Hey, you have ten minutes, tell us how you are feeling today.” Not like that at all. Create a community where everybody gets on that same page and then shares experiences that help nourish the future for these people. When one person is dominating, I feel you are inhibiting the growth. Yes, you have been through a lot, we have all been through a lot, but if your role is to be the monitor for the support group, you cannot dominate. I think it is great that these women dedicate time to do it, do not get me wrong, I think it is awesome and I think it serves a great purpose for certain people but for my personality, I did not feel it. I felt more of a support group when I went to the yoga group because we were relaxed, we were learning, but we were also giving back our stories. So, that felt more like support. Those classes felt more like support groups because it might just connect with the way I am.”

“I went to one support group and it was a very positive experience. It was part of what helped me realize that there is really no answer and that there is nothing I was missing, because there were ten other women who had been out there for much longer than me and gotten nowhere, and relationships had gone bad. I realized the cost of this emotionally and relationship wise and to hear them saying that their relationships had suffered while mine was really suffering. You know that, but to have people tell you that – one woman had gone through two marriages.”

“I definitely feel the minority in that group because I am not doing IVF. It is not female factor for me as far as we know. So some of the women are like, “You can just get sperm somewhere and be fine. So it is not as bad as...” But a lot of the emotional components of it are the same regardless of what we are doing or how we are going through it and what caused our infertilities. So on that, there is a lot of united front and being able to talk to somebody about that. A support group that was more similar to my situation, I would really like to experience that. Yes, that would be useful. There are unique things that I feel would not be as well received by a group that is predominantly female factor infertility. Like that nagging feeling of, “If I had picked somebody else, I would not be having this problem.” That is a horrible thought, and I judge myself a lot for that feeling because I picked the perfect guy to have kids with. I am getting everything lined up and figuring all these things out and so it then hits me all of a sudden, it is not fair. It is not fair. I worry that I have so little time left and the only reason that this is not easy is because I picked the broken guy. It is horrible; I hate that feeling. In those moments, it is just like shouting, screaming, punch the walls you know, not that I do all these things, but inside. I feel like disclosing that with women where they are the infertile one in the couple, they would feel like, “Well, maybe my husband feels that way about me because I am the “broken one.”

From Books

They never really helped me in any way

“I read a few but I do not feel like they really helped. I got books every now and then, and then I have done a few pages it never really helped me in any way. I just felt like I needed to get it. For the DES exposure, I would read some things. Every now and then I could pop, I would end up on a page that would be too technical and I would read over, skim it a little and not really understand it and move on.”

“There is a lot of conflicting information. I looked at academic journals to see what the instance of this was and took a lot of my own research. I had a fertility book that I consulted at times, but I found that it was not really helpful either.”

“There is still not a lot of books out there that deal with infertility not in a real way. When I first realized that I was not going to be able to have children in '94, I was in my 20' and I was looking for information, I could not find anything. I only found one book and I kept it. It is called “Childless is not less” it was horrible, I do not agree with anything she says. Basically what she said is just give up or adopt. Basically it was the premise of the book. I realized that there was not a lot of options at that time but even the psychology behind it and all, “Maybe God just made you to be like this so that you can be the mother of many many children” and I say “Or maybe not. Maybe he made you differently than that.” It was terrible. Even now when I google for books, just trying to find, there is just not a lot. There are so many resources a lot more now, but there is not a lot of resources that really get into the heart of the matter like how this diagnosis, one diagnosis, changes everything. It changes the way you look at the world, it changes your relationships, it changes even how you feel about yourself. I love that you guys had questions there about sex because I remember when I was at that point and I was thinking, well if sex is supposed to be for procreation we are only going to do it when I want to and I am happy. But if it is recreational, we are going to make truly recreational. I mean it just changes every single thing

and it is not something we talk about a lot either. In my groups, we talk and we talk, but then we go home or we go into the world and it is just silent. It is silence. Even in the doctor's office, it was the funniest thing, it is just silence. I mean we are all sitting there and we know we are there for the same reason because there is no other reason to come here. We do not talk about it. In my church groups, we do not talk about it. Now having gone through, I start thinking back on my neighborhood and people who I knew. This is probably a pretty birth control, they did not have any children, [so] fertility issues because you cannot be married that long and not have children in a day of no birth control. Anyway, it is so hard when you look for resources and things like books and journals. "how to conceive" had a journal at one time, I do not know whether they still print the magazine or not. But it is so lacking and it is really kind of underground almost."

"I got a few books on PCOS. Again I do not know that was really my diagnosis. I did not really use them much at all."

"I did not use it a whole lot, I had one book on taking charge of your fertility at the beginning and that was helpful in explaining how everything worked and it went into the other options a little bit."

"Not too much there because I guess we got so much information from the web and from the other stuff."

"We bought some books and they were helpful but my mind thinks more scientifically, so a lot of what they told in the books we were not going through the process. It is good to read the suggestions and see what their thoughts were on eating and things like that. It is good that they are out there and I would say it was positive in the fact that we could access books."

More self-help than knowledge

"I had a lot of self-help. I picked up every "infertility for dummies." A whole stack of books and just trying to research, try to learn and do things on my own. I try to figure things out, books,

journals all that kind of stuff. I learned a lot through that process. Yes, I have had positive experiences with books and journals. I have definitely bought a lot of books; There is a really great comic or a graphic novel I should say. A couple who went through infertility did it, it is called “Good eggs” and it is awesome. I bought one fertility book and that was more self-help than knowledge. I remember reading “The empty picture frame” and that was good. I share that book with all my family members. I sent them each a copy and said please read this book.”

It has hard to find books that are up to date

“It has hard to find books that are up to date. I have found some but mostly what they say is “these are some fertility problems that can happen, if you are going through any of them talk to your doctor.” But they do not tell you like anything other than that. I have not been able to find information; I would expect to find more”

“I did not rely on that that much. I would occasionally run across a journal article, but I would say I did not do very much of that. I feel that most of the books are not up to date. If I get a book I usually get it from a library but I would not feel most were up-to-date.”

“There are a couple of really good books out there that have really solid information, but you never know how old is the data or how complete it is, what are they not saying. It is not like you can ask questions to a book. Some of these books have been around for, you know this is their sixth edition, they have been around for ten years. They are solid, but anyway.”

Asking Questions

It is hard to get the doctor to sit down and go through it

“Well I think it is hard for me to ask the questions. I do not know if it is just that stigma involved. Like who I am I asking and figuring it out. Who to talk to? I do not really have a lot of people to ask, so I mostly just look for them on my own.”

“Honestly, I asked the Internet most of my questions because it is hard to get the doctor to sit down and go through it all with you. I got pretty fair answers.”

“Not really, because sometimes I do not know what I do not know. So I do not know what to ask. I google it on the web or if I have a doctor’s appointment. And you get a rushed answer from the doctor.”

Asking questions is the only way you can get the knowledge and information

“We asked a lot of questions to the doctors. The information that we got back was not very helpful. I relate some back to the diagnosis process where the doctor did not seem to understand what was wrong and in terms of giving you an accurate forecast of your statistical ability to conceive or not conceive.”

“If you do not ask you are not going to learn anything. I was asking everyone everything I could all the time and it really helped. I asked lots of questions to the doctors, the nurses, to the lab techs, to surgeons to everybody. They are the ones doing it, so asking them what should we be doing between the IUIs procedures and three four days afterwards, what is best for my wife, what do we need to do. Same thing with IVF what should we be doing to get ready for it. What we need to do based on her endometriosis and how do we make sure that it is fast enough and

things like that. I think asking questions is the only way you can get the knowledge and the information. If you are afraid to ask the questions you will never know.”

“I ask a lot of questions, when you ask questions you get the information. My husband and I are very inquisitive, we asked a lot of questions; we put the doctor on the spot a lot and he handled them very well. I asked professionals. We did not have any peers, any folks in our situation, you had to wear the trousers to even really understand and so no one other than asking questions to doctors.”

“If I found things online that I was not sure of, I could go back to my medical staff and ask some questions, they were always able to handle them. I would ask things about the alternative medicine. There were some doctors here that did not encourage it, but I was fortunate with my last doctor, he had no problem with it. They were very informative about it and if they did not know the answer they would find it for me.”

Not knowing what questions to ask

“Well, that is the only way I got any information at all, but sometimes you do not know what to ask. I do not think you can juggle all of this and manage your treatment over the course of years without being very intelligent, very dedicated, very determined. It is a full time job and it is not easy to understand or synthesize the information and see what that means to you or heard of it before. I am glad that I was in charge of what I was experiencing.”

“When I am in the office I am just absorbing everything they say and I do not think of the questions until I leave. I would just go home and look it up. It is easier for me to process the information when I can go look for it myself. It is hard for me to ask a question and then be able to process and comprehend the answer when I am sitting with the person. I write down my questions for my doctor and I ask him but then I forget to write anything down and I get home and I will be like looking at my list of questions.”

“I think it goes back to if you know the right questions to ask. The information was great, but if you do not know the questions to ask. The best analogy that I can give now that I am currently pregnant is we just went to a childbirth education class, and it is like I kept thinking they need one of these for IVF. You go to the class but it is really not just child birth education, they are bringing up all these things, they are telling you things to expect with your new born, and I do not know much about new born, like some weird thing that the new born might have on its face. I would not have known to ask that question until it is happening to you. So they are preparing you and then you know the questions to ask.”

“Once we realized that we were not going to get all the information, asking questions gives us that information. In that regard, I wish we could be more prepared with our questions to ask.”

I just trusted the process; trusted the doctor's professional opinion

“For asking questions I do not know if I really solicited a lot of that. I just trusted the process; trusted the doctor’s professional opinion about what I need to be doing, going through. Ever since I realized that there is reproductive specialists, there is endocrinologists, there is people who can actually treat and diagnose you well in advance prior to taking three or four years of my time through the initial process. That is probably something I wish I would have known then.”

“I ask a lot of questions and I seek out information, but I think I did less of it through this process that I do in some other aspects and I think because there was a certain part where it was too much, it is overwhelming. I do not want to stay faith exactly, but just kind of assume that the medical profession you are clinging your trust to sort through all of this for you and give you that information. I do not want to say I would not ever read anything because I would. I definitely know people who went out of their way to get more information than I did. Some of it is that I felt the whole process was time consuming and that I was going to have to trust somebody else and go with their recommendations. I do not want to say I did not ask questions, when I asked questions especially to the doctor it was positive.”

Understanding Information

A need for programs or classes with basic and quick info

“I understand very little and that may be more because of being a male. I understood very little about the process, so the information that I got needed to be toned down to a level that I could understand. I probably needed more basic information and I do not know if it is the doctors’ job necessarily to give me that. Going into it I did not have a very good knowledge in understanding of the whole process even of the reproductive process. So I could have used more basic information so that I could be able to process some of the higher-level information that have been given to me. Before you even start the whole process, you have to have a full understanding of the reproductive process. You do not know you are going to need that until you are into the situation. So unless you on your own happen to get a lot of background knowledge you do not know you will need it. So it would be very good for the doctors’ offices to have some programs or some ability to give that information at quick level when you need it. Because again you do not necessarily know that you are going to need it until it is too late.”

“They will give me something that I can read that was helpful and not difficult to understand. It was not too medical, but it was always on one topic, limited focus but easy to understand. I wish in the beginning they gave you a booklet that explains everything, all procedures, so that in the very beginning you have everything that you could take home and address it, that would be nice.”

Specifics may be incomprehensible

“Until the immune stuff came along it was pretty understandable. But the immune stuff is numbers and letters and totally incomprehensible. So that is why I had to hire an expert. I do not think it is easy to understand. I cannot even explain it very well even after all these years of doing what we did. Like somebody would say, what is your AMH level? And I could not tell you

that. That was tough. I cannot explain it very well. I do not feel like I even understand now. I still probably cannot explain the ins and outs, but overall I could.”

Find the right resource

“Once you find the right resource, I think I was able to figure out and understand it and if I did not, then I could find a resource, my therapist or go to support group or doctor.”

“The best thing that I did from the very beginning was to bring a notebook to the doctor. I recorded everything; well my husband did. I would listen and he would record everything the doctor said; every lab result, every word, anything. We still have that notebook, and it still comes with us to the doctor every single time. It is the one I went back to look at, when we got diagnosed. It helped understanding it. If I did not understand something I could flip back and be like what exactly did he say? What were the words he used at least as close to what we wrote down. And if I did not understand then I could ask those questions.”

“There was a considerable amount of the female physiology that I had not realized even existed. I am not even going to go on how that works, so yeah that was very enlightening, definitely it was a very positive experience understanding the process. I would ask questions [and] if I did not understand it, I would make sure to ask questions that I would fully understand.”

Very confusing: You almost need a medical degree

“Understanding what is going on in my body, what the issue is. That is just not the answer. It is not the piece of information itself, it is why. It is the why that I do not understand.”

“We are very lucky that we understood it as they explained IVF and the diagnoses, and what is happening inside of her. I wanted to be a doctor, I studied to be a doctor, so I understand biology and I know how it works. They explain things very differently to people that understand it than to people who do not. I understand when they talk about what is happening inside of you in

medical jargon, I do not have to ask questions to understand phrases and terms. But once they describe the process, I do not know someone that does not have that education how they would understand it. Asking the right questions and paying attention, I think that understanding and asking are related.”

“I have a medical background too, so we were able to converse on that and I understand the physiology. I think it is helpful that I have a little bit of a medical background coming into this. So I understood a lot more that. I feel I understand. Like I have worked in the ER for a long time, so I feel like I have some medical knowledge. That part has not been a problem for me.”

“I was a biology major. One of my jobs, I am in currently right now at work a quality assurance tester. So all times I basically have to analyze information. It can get overwhelming with the amount of information out there, but as far as reading the information or understanding what the doctor is saying, I found that [ok]”

“I still felt confused with some of that and I felt like I understood a lot. I felt I had got a good understanding of IVF from the orientation that the fertility center did going in. If you were interested in IVF they had a night they do a power point presentation and have the doctors up there and the embryologist answering questions. I thought that was really helpful. So I feel overall I had a good understanding, but from a lot of the sources still very confusing.”

“I still do not understand how they used that sonogram to measure the size of the eggs and the uterine lining. But overall we have a pretty good understanding of what our bodies do and what the lining needs to be, the eggs need to; that sort of thing.”

“Understanding it when it is thrown at you there is just so much and so many different answers and conflicting things. It took a while to get it all. It is a lot of new terms and ideas, but looking back at it now I feel like I have a pretty positive understanding of what was going on at the time and where things are.”

Treatment Outcomes

Treatment Outcomes describes the various outcomes of the Fertility Treatment Experience. The sub-affinity titles or various components as indicated by the participants and their interview responses are listed in the following order.

- ◆ Medical Conditions Treated
- ◆ A Baby
- ◆ Miscarriage / Loss
- ◆ Continuing Fertility Treatments
- ◆ Donors
- ◆ Surrogacy
- ◆ Adoption
- ◆ Living Childfree

Medical Conditions Treated

I become advocates of myself

“I am being treated for subclinical hyperthyroidism. Once I started compiling my own chart of my thyroid results through the years, I was seeing a pattern that was slowly rising. The normal range for people is up to 4.5 or 5, but that is too high for trying to conceive, the range for women who are trying to conceive should be up to 2.5. In the early days my thyroid was not particularly high, but it kept creeping and then the only way to know that was because I started going to the clinics more and having it drawn more. Usually it is drawn once a year, during the physical. It is a snapshot in time, so from one time to the next it could change very often but because I had all this data from my fertility experience, I had more regular snapshots of it. I was able to bring that and I ended up deciding before doing IVF I wanted my thyroid to be low. It is not something that the doctor said, it is something that I learned on my own. So as soon as I got on medication I had my first conception and had a miscarriage. After that, my thyroid was high again and so they increased the dose and I got pregnant again and miscarried. So after four years I can see the link, but once again I pretty much figured out this link. Trying to figure out what is happening is a mystery because they say “The blood tests are not very conclusive and even if you know what it is, it does not really matter because the treatment is the same.” Well, it does matter because you

want to know, but they do not really investigate further. I am on medicine and actually I am nine weeks pregnant now. This is after a year I have been on many levels of medicine. Next week I have to go in and get the medicine checked again, levels checked, and whether I am on the right dose. I need to be on the right dose and the doctor is like “Oh you can come in six months” but so I said “I am coming in at five or six weeks.” And that is the other thing, try to have me come in not as regularly as I want to. Well, I have had to be such an advocate and really get myself in there.”

Not any real change

“The things I can relate to is my own personal experience of low sperm count, doctors treating me and not getting a positive outcome, then not making me understand why there is no a positive outcome and not knowing where to go from there. As well my partner going through the process, she was treated for several conditions: fibroids and endometriosis and it seems like after all those processes, all those surgeries and treatments were done there were still many question marks about whether the issue had been fixed or not, what impact it may or may not still having on the fertility experience. They have only given me progesterone and it does not do anything. We have tried some different medications and different dosages and things like that, but they have not given any real change.”

“My main medical condition is PCOS and it has kind of hard to treat. I am on Metformin. I feel it has not been resolved yet. I do not really feel I have been treated for PCOS. I am going through fertility, but that is negative because they have not really treated me.”

“It was frustrating because it was unexplained. They kept trying a lot of things. The laparoscopy removed the endometriosis, so technically they treated it, but it did not seem to help. Then over to the hysteroscopy, they scraped the fluffy stuff, which is some sort of polyp, but that did not particularly help either.”

“The polyps to the extent that they could be, they would be taken care of but would be for a brief moment and time. With the uterine lining problem, I do not feel there was anything that got done. Anything that I did fixed it really other than maybe time and diet, maybe the acupuncture.”

“Nothing that they can really do for the premenopausal and the endometriosis. The outcomes were great, but the actual treatments themselves was negative; nobody likes to go through that many surgeries.”

“He had low testosterone and it is not solved but he is on medication for it still.”

“There is still lots of questions. We do not really have any idea why I got pregnant this time.”

“No, I have not been diagnosed. The first labs showed good numbers, so there is no reason why it would not be explainable for me to be able to get pregnant.”

“They said it was [treated], but there was never any. From the hysteroscopy for example, they said, “Surgery went fine. We got everything; we got all those scar tissues. You are fine.” And there was never any further mention or look at it or let us make sure that a year later no scar tissues has regrown. I think it went well, but I do not know. My husband asks frequently, “do you think that there is a problem from that, that they are missing and they did not look at?” I think, “Well no, they would say something.” But are they looking? Not really.”

“It was not really treated, we circumvented it. The uterus is what it is.”

“We have unexplained infertility. Now we are pregnant through a surrogate so we stopped treatment with me. Right now I am on birth control because I am doing induced lactation and that is part of the protocol. Once all is over done with, I am going to stay off birth control possibilities always exist. I know it is going to be hard because when you are pregnant there is no guaranty there that it is safe, but you just cannot give up.”

“I guess my endometriosis is under control, But to keep it under control was not easy. It is been very expensive; a shot after every three months, and the side effects are not fun. They are treated but it is not fun being treated for it. It is not. I see it as an ongoing. I do not know what you need to do to get rid of endometriosis, I would assume you will have to take a full hystorectomy, but it was treated down to a point where we could do IVF.”

“When I was taking the different pills that I took, my counts went up marginally. For my wife, they never treated the PCOS, which is weird because their treatment idea is just to do IUI or do IVF, not to fix PCOS.”

“We did not identify any conditions. What we did was we tried. For the IUI we noticed that ovulation might not be happening every month, so we treated that with Clomid. For the IVF, we do not know why it did not work.”

A Baby

Feeling of elation if you finally achieve something

“Well, I do not know how to explain that. When a baby came, well part of it is let me decide for a little bit between a baby and a fertilized embryo. Obviously it is one and the same to me and to some people, but it does feel a little bit different when there is a fertilized embryo in a freezer versus in a womb. So obviously when there is a baby it is elation you have been working so hard. So when there is a baby particularly when that there is a positive pregnancy, that is a feeling of elation and you have finally achieved something. But if that is followed by a loss then it is an incredible low and just the absolute opposite of elation.”

We are just precautions, hopeful that I will get a baby out of it

“We are hopeful but we are not at that place most people are. But that is what we want and I think we are just precautions. We are not all the way there.”

“We are still hoping that is going to happen. I am fourteen weeks. So my chance of miscarriage has dropped way down. I am very hopeful that I will get a baby out of it.”

“We are not yet, have the frozen embryos. We have frozen embryos, so pretty positive so far. I think it is just getting to a second spot. It is like we have not crossed the goal line.”

I am pregnant now but it sure did take a long time most of our treatment was using my own eggs and we did not get pregnant. It was only when we switched to donor egg that we had the success. But I did have a lot of treatments with my own eggs

I never got pregnant through any medical intervention. I am pregnant now. I am eighteen weeks and five days. I got to see my baby today. It has taken a long time to get here. I just got pregnant on our own. So we were shocked.”

Miscarriage / Loss

Emotional and relationship losses

“No miscarriages, but the loss of my relationship. Emotionally it set me back and I am trying to get everything back, but it is very hard to cope with for sure.”

“It was such a shock that I got pregnant. I mean because I had not had a conception in four years and I was doing the medicine to prepare for IVF, I was already thinking that it was not going to happen without intervention, assisted reproductive intervention. [the miscarriage] was negative because it was a loss, but at the same time I was overjoyed that my body was able to conceive. Also, [there was] I guess loss of positivity or growth and wellbeing with my husband. It did shift and stirred things up I think in a good way. Then having to exploit the questions of if it does not happen how am I going to be satisfied and fulfilled in other ways? I had to go through the loss of something that I really want and it is not coming easy. And so I did go to a therapist to try to get to the bottom of me.”

“No miscarriages, but emotional and relationship losses. Yeah, between my husband and I it was difficult. Sex just became scheduled and he would joke about that, but I think definitely there is a loss of spontaneity of things. Even having the baby has been definitely a struggle in the relationship, just feel like we have lost each other. By default just because there are so many needs and I keep telling my husband “We will get better. We will make priorities and we will take time for each other – but definitely loss.”

“There is failed loss and it is a real loss you just have to experience it! I will just exemplify for you as a layout. My wife feels, because there is a latency to her period, she feels pregnant than when the period comes that can be considered as a loss. Emotionally talking I think it was a moment of great gravitas – a moment that went on for years, and we certainly were not altogether focused on constructing our relationship during that period, so there is a loss there.

There is also a loss just because the two conflicting things: if you are unable to conceive a baby, there is a biological regret that worked there, a function hopefully that can be well-managed but if I cannot put the sperm in the proper receptacle, then I am at fault in the same sense if she gets good sperm through whatever process and is not able to conceive then she can be considered the guilty party and that bears into a relationship.”

“Yes. We were really excited and so it was really hard for us. Two years and nothing since then; not a positive pregnancy test for two years and so that was really hard. I told one friend at work and my mom knew because we had just told her that we were pregnant. But it was very isolating because we had not told a lot of people. Of course my mom kept asking, “how are you doing? Are you guys going to try?” I do not want to talk about it, I know that she means well, but she will talk to family in kind of her own kind of processing talks about things and I do not want my business to the rest of the family. It is hard because I want to be excited for other friends who are having babies. I just covered for someone to be on maternity leave and somebody else is on vacation and she came back pregnant. So the sense of loss is compounded each time someone else becomes pregnant because it reminds you, it is a fresh reminder of what you do not have. And because we feel so isolated in that, I think the loss is also compounded because you are not processing it. He will say, “Well stop looking at Facebook.” Well, I am not from here, all my friends are away, so if I do not have Facebook, I do not see what they are doing. Some of that is just being nosy, but also that is sense of connection to our friends and their kids. It is not that I do not want to see their kids grow up, I do, but it does hurt. It is this catch 22, “Just stop looking.” “I cannot because I want to have that connection with my friends.” I think we deal with things differently. He is more of a processor kind of verbally and I am a little more introverted and not talk as much. I think sometimes he will think that I am OK with things, but just because I am not talking about it, then he will bring something up and I snap at him. So that has affected our relationship a little bit too. We are still fine, but has impacted us in terms of our ability to communicate about it. He will say, “Well, we cannot afford IVF” and I will say “Fine, we will never have a kid.” And so, it has just been very frustrating. His daughter of course has no idea. She is sixteen and a half and so she will say, “Dad, when are you guys going to have kids?” he is like, “Well, we are working on it.”

“Of course miscarriage is also loss period, feelings or emotions. Even the women in my group, I am in this group now of women who have graduated from the infertility group because they ended up getting pregnant, a lot of them have similar experiences and we all have kind of like a gun shyness. I think people who have not gone through infertility do not get, you are nervous to tell people that you are pregnant., especially to tell them early. You are worried all the time you are going to get bad news that something’s going to be wrong. You are just real un-at-ease and it is hard to enjoy our pregnancy maybe the way some other people do and are more care free kind of way, which is nice that we are all in that same boat.”

I happened to lose some friends over this experience. I had a friend that I supported, that supported me but then going through this process made me realize that they actually did not love me as much as I loved them. That caused hard feelings and then they did the same procedure and it worked for them. So it caused a lot of pain. They never tried to reach out and repair the friendship, they are moving on with their exciting new life. So it created a loss of friendships that happened more than once. And yes that is the big thing that I lost. Of course there is the loss of dreams of the future.”

There are losses in all areas of your life; when you struggle with fertility it affects everything

“We had two [babies] and we lost one. I carried them. We went to Czech Republic. I had two boys and one of them was still born. Pretty awful. Pretty awful stuff. That does not go away ever. You go through birthdays or whatever and it is always like “Oh, I wonder how it would look like?” It is hard. We have his name up in his brother room and we had him cremated and he is in an urn. Other types of losses, oh yes. Lost friendships, lost hope, lost connection with people I love. I lost faith in people, lost money, lost time, lost all the joy I should have been having, lost my trust in people being there to support me. It goes back to that sacrifice thing. Our pregnancy was really awful; really really difficult and really scary. Just such a traumatic experience all the way round; pregnancy, the delivery, the baby’s death, our child was in the NICU for a while. Everything about it was just horrible, horrible. So all of that counts to me as loss. I wondered, I

used to go to the resolve meetings and I thought, I specifically asked people, “So, right now you see a child and you get angry, hateful. You hate the people, you hate the baby. How do you get to a point where once you find success, I do not want to be the person out there pushing a stroller while there are infertile people walking around looking at me, I do not want to be that cause of pain to other people, How do you deal with that?” Everybody I think forgets how hard it is and they are like “Whop, I got mine” and they just do not care about other people. I still struggle with that every day, if I go somewhere with our kid. That is hard for me. The point was I did not get to enjoy, I was afraid that I was not going to enjoy having a child because I would feel bad for all the people who are seeing him and not being able to have their own child. It also took away the excitement and the joy of pregnancy. Nobody threw me a baby shower. I did not get any of that stuff. It was just a traumatic thing. I was on bed rest. I was in the hospital. Then, not to keep harping on this loss but then, for eight months we had extreme feeding issues because our baby was premature and so we were dealing with feeding issues around the clock and getting about three hours of sleep every twenty-four hours and not consecutive three hours, just little pieces. For that first eight months, it was just horrible. We had lost our other son, we are struggling with our current son. There was no joy. There was not rest. It just was pure hell for two years straight. All the five years of infertility led up to these couple of years of hell. All of that to me is loss and it does not mean I am not immensely thankful. I could not be more thankful than I am. One thing I try to convey is, people would say things to me as I was struggling, “You got to be thankful for what you have.” And I would say, “What? I just told you I am sad about something, that has nothing to do with the fact that I am very thankful. Why would you assume I am not thankful because I am sad about something? They are not related. They are two different things.” Being happy that one child survived and being sad that one child died is the ultimate you can be happy and sad at the same time about two different things.”

“I have had two [miscarriages]. I had one before I even realized that I had any issues. I was about four months pregnant, I was also in a different city at the time, and the medical staff was not good, I was in the ER for eight or nine hours and it was a very negative experience. I also lost one early on, when I found out that I was infertile, it was a disappointment. Physically was definitely not as bad as the one before, but you get so hopeful after finding out you are infertile

and to have that loss it is just a very negative experience, there is no other way to explain it. I ended up having to get on anti-anxiety medication. I think some of that might have been my body out of whack from the prolonged exposure to Gonal-F. It took me about a year and a half to get myself back both mentally and physically so there was a loss there and the strain on my relationship with my husband and I had a daughter still to take care of during the time. I think the whole family lost a little bit during that time, but we pulled through it together but there are losses in all areas of your life; when you struggle with fertility it affects everything.”

“It becomes a drag on your entire life and everything you do is impacted by it. Then there are these additional surgeries that may or may not be required as part of miscarriage or loss. And you went through this feeling of elation because you got a baby, now by losing it the exact opposite, a severe and extremely acute depression.”

“Yes, the ectopic was the only real pregnancy that I had before this one. So implantation failure was really my main problem. Just repeated implantation failure was like the main big hurdle. That is really what we are focusing on getting over, that is a life suffering loss.”

“I guess all the loss in general would be where a lot of this growth comes from, but It is still a hard thing.”

“No, miscarriages, I definitely fear loss of time. I have lost time for sure. It has been very stressful, but I have not experienced loss yet. I definitely fear getting pregnant and losing it. If this transfer does not work it is like just lost opportunity.”

“That has been the main, probably the constant feeling over this whole period, that feeling of loss and of emptiness. Seeing all my friends and family raise their families and you are not able to share that connection. Not being able to share with my girlfriend what it is like to have a child and talk about our kids. I just had a birthday party for one of my friend that I have known all my life, she has three children and her youngest just turned one. They had a little birthday party for him. It was only me, her, and two of her girlfriends. All of them have kids, and that is what

people talked about. They talked about their kids. So it leaves me quiet. I imagine what it would be to have that experience. So it has been difficult.”

“By my fourth or fifth one I guess I was just numb and that helped because I did not get my hopes up but still, going through it no matter how strong you are it is bad. I felt I lost myself. I think my biggest thing was just, being a woman and I cannot produce a child, being labeled as old, when I really tried to be healthy, like a failure I guess.”

Loss of the ability to become a biological parent

“No miscarriages, but I felt like suddenly something was wrong with me. Why is not this working? That something was missing from me that I could not get pregnant. Ok, we waited a while, we were being responsible and then we decide to try and nothing happened. So that was sort of a loss. I have not seen any positive pregnancy test until December. For all the trying there was never a positive. I did not know if I ever could get pregnant. So in the sense there was like a loss of feeling of something about myself.”

“Well, I have lots of those. Six. Yup, it has never been easy. Also, we ended up using donor egg and donor sperm. So we both went through a loss of genetics and we lost the ability to carry the pregnancy. So it was a lot of emotional and a lot a lot of process.”

“It is very painful outcome. We went through a lot of it. I mean just privately as a couple, emotionally as we bury it is hard to think about.”

“Not miscarriages, but definite other loss, My whole life I always knew I was going to be a mom. I was going to be a good mom, and not having that seems like an insult injury. I am the only one of my grandparents’ grandchildren who does not have a child, and they all have tons of children. I feel I am fertile. I feel I am super fertile. Genetically I am super fertile. This is not supposed to be happening to me.”

“I never got pregnant, but I feel there was a major loss that I could not carry my son. So lost being pregnant and I cannot have another one, so the loss of not giving him a sibling still makes me sad. Yes, a tons of loss. But of course I am so grateful. If I could carry I would probably try and talk to my therapist about maybe doing donor. But since I cannot I do not want to put that much to have someone else’s child”

“That was devastating. I know one for sure. I do not know, sometimes it is kind of hard because they called it a chemical pregnancy. I will call definitely one true one when we were pregnant for eight to ten weeks and then lost that and the other couple of times we did not get pregnant. Yes, that overall experience was just devastating on so many levels and especially for her, for all the stuff that she is having to go through physically with all the shots and the pain. That was tough.”

“That has not been an outcome yet. The first time I got pregnant I was eighteen and I had HG (Hyperemesis gravidarum) and you I puked twenty four hours a day. I also had a threatening allergic reaction towards one of the anti-nausea medication that they put me on and I had a false negative pregnancy blood test in the hospital at eight weeks, which is not supposed to happen. That is how jacked up my body chemistry was from being so sick and they put me on more medications. I finally stopped vomiting and I realized that I missed my period and this ultrasound said I was twelve weeks and four days. They said, “Well, since you had no prenatal care and your body chemistry was all screwed up and the second round of medications that we gave you to stop puking is known to cause birth defects both physical and developmental, we really encourage you to not continue this.” At eighteen I was ok. I can deal with that, but a lot of that has come up on this journey. Feeling like even though, knowing everything I know now, I would have made the same choice. A part of that is like, “What if that was my chance that I threw away?” kind of feeling. Then, later I thought that I did, but that was not from treatment, I thought that I had a couple of early miscarriages. It was all psychosomatic. I wanted a baby so bad I fooled a pregnancy test into turning positive. I went through the grieving and all of that before we found out there was no way that was possible. [In terms of other losses] Loss of hope that I ever would have had my husband’s children. He would have made really pretty babies, really

pretty babies; so yes, loss of that; huge very negative. Just like, “Hey, there is no hope. None at all. None. This is never going to happen.” That sucks.”

Every failed outcome is a loss

“Even though I never had a miscarriage, every month, every time you get a negative, especially if you have done a treatment, is a loss.”

“Every miscarriage was different for us. You could argue that we put two embryos into my wife and only got one baby. Is that a loss? I kind of think so, but if you do not lose things you do not gain them, that is also something that I kind of learned from this. You are going to have to be ready for that failure to happen before the success. I would also say that every time that IUI does not work it is a loss, that it is negative certainly not nearly as awful as losing a baby.”

“We have been through one cycle. lost that. This is my second one. We made it through the whole cycle and the positive is that we had a positive pregnancy. So that is a good thing.”

Acceptance

“We had a natural miscarriage prior to it after doing the IUI. It was actually when we started. So that was one. I think through the process, it was difficult. But, we understand that God has a plan. We have a solid relationship and we got through quick enough to recover and feel ok with the process or why it happened. So the same thing with the tubal, what could you do? It is sad that it happened, but it happened.”

“I did get pregnant once on my own and I miscarried very early. Then I got pregnant with Clomid and I miscarried very early. So that makes me not blame Clomid as much as I might otherwise. I know miscarriage is just a thing that happens. Actually the miscarriages have been a lot easier on me than I thought they were going to be. I have been able to move on past them and they were so incredibly early that I did not even know about one. I just had a weirdly period and then when I had the other one I thought back to that and I suspected that was early miscarriage. I appreciated the chance to be pregnant even just for a few days. I thought that I was able to sort of be a mother in those few days. So I am really grateful that I was pregnant.”

Continuing Fertility Treatments

Very frustrating, you need to put a limit

“I was getting very frustrated and I started to think I needed to talk to a psychologist. I was considering calling something available through work because I was getting very depressed and frustrated with it not working and we had spent so much money and time. If in December would not work we were also considering just not continuing with the treatments. And maybe I would try the acupuncture again. I just did not know where I was going to go. I was very frustrated at that point with continuing with the treatments. That was a negative experience having to go on and on and keep trying new things.”

“At this time I do not want to anymore, and it is nice to know I never have to think about birth control ever again, but do I want to keep doing this thing? No, it was not fun, not pleasant and not good outcomes.”

“After a while it gets, I guess, frustrating is the only word to describe it. Obviously there is always that feeling of potentially succeeding but the more often you fail or you have miscarriages or just does not work, the more it continues on and on, the more frustrating the process becomes of continuing the treatments. At some point there is a breaking point of this is too frustrating to continue. Again, we talked about sacrifice earlier, you are sacrificing, really your entire life is put on hold while you concentrate on this process. So, continuing those treatments while the result and consequence could be a baby, which is the ultimate experience, more often than not it turns out to be a very negative and depressing process. So continuing fertility treatments I say is very frustrating.”

“We decided about eight months ago we were not going to. We are ok without kids and we have talked about it and come to peace terms with it. It is OK and we can always adopt later. The donor egg option is our situation, so that is something that we know. That is part of my infertility

issue as well, we were going to do the donor egg and then we were not, but we do know that it is still an option for us. So, we know we still have options but as of now we are not pursuing anything.”

“I am almost at the point where I just do not even want to do it just because it is so stressful. But then I feel that maybe I am only supposed to have one kid then I do not want to force it. So part of me is like maybe I should not do it, then there is a part that is like well, we have modern medicine and that is what it is there for “To help you.” So we are going to try. I only would want to do it for maybe two months and that is it because I hate needles. So if nothing happens in two months then I am just going to be done because it is too stressful.”

“So my husband and I decided to put a limit and we looked at it as gambling. To some extent it is because there is so much unknown, when you have two gametes coming together it is just a chance. The fact that the embryologist picks this one sperm and puts it into this one egg; everything is just by chance. We said, “This whole thing is just going to be by chance. All of the information is saying this or that, we cannot trust it anyway, so let us just do it and we will do it these many times and this much money and if it does not work, we are moving on.” I accepted that decision. I personally probably would have wanted to try more, but I felt I needed to compromise because my husband never wanted children to begin with. He accidentally got pregnant when he was dating his first wife. His marriage was terrible. The wife actually told him that since they were probably going to get divorced, she wanted their daughter to have a sibling. And that is how their second daughter got born. So it is very strange. My husband never intended to have children, so he got a vasectomy. Then he met me and he did all this for me. So I wanted to compromise and agree and say I will not make us poor. I will not make this into a great hardship on us. I need to compromise. He was doing his compromising by going through surgery and being willing to take on another child in his life with me even though he knows how hard that is and it was a terrible experience for him. He was willing to do that. So I am willing to stop at two times. So anyway, that being said it was very painful.”

“We would have to save money again and tried again. We told ourselves no more than three times. Yeah that was the most terrifying part! I hated the treatment and the medications, but it was the not knowing; the chance that we were going through not having our own kids. We had three eggs and they put three eggs in me and, even if they told us the quality was not that good, two took. How shocked we were when we knew we were having twins. It is hard to explain to people what it feels to have twins after the fertility because we were, “Ok it works once we would have one kid and then we will go through all this again because we do not want that child to grow up by itself” and we do not know if it would work again. When we found out that we were having twins it was a miracle, what one more could you possibly want. That was the hardest part talking about what would happen next if it did not work.”

We have to if we want a baby, but...

“I think we will because we have embryos, but I just wish it was over.”

“Because of my dangerous pregnancy, I have a bunch of health issues now. I am under treatment and hopefully within six or seven months I will be medically clear to proceed with one more round of IVF. We are going back to Czech Republic. We have two frozen embryos. They froze them together, so I do not have an option but to transfer both of them otherwise I would transfer one at a time. We are going to go one more try and whatever happens, happens, and then we are done. I do not know what is going to happen with that, it is just very uncertain at this point. Part of me is really excited and “oh this last one is a fluke and everything is going to go great next time.” The other part of me is terrified. What if you have twins again and I am afraid they are going to die.”

“We definitely think of it because we have two frozen embryos on ice and we even talk about how soon you put those eggs in if it does not work. I think we are very blessed that it worked this time. But if it does not work, you want to know right away because you still want to be young enough if you decide to go through egg retrieval again so that you are getting good eggs. If you had looked back five years ago, how do you want to space your kids, we would have spaced

them much further apart but now it is a race against time. So we still talk about it even though we are in this position. You never stop thinking about it. Once the baby comes, what medication do I need to go back onto for the endometriosis? You are still planning. Or even if we did not want kids, I mean if we were totally done through do I get a hysterectomy so then I do not have to deal with it? Or do you keep taking these shots? I am sick of thinking about it, even when you are on a break it never leaves your mind. You are constantly thinking of the next step and sometimes that is the only thing that keeps you going when you are in these dark places. What is the next option? You get to a point that you are just fatigued. Your brain is tired. You want to talk about something else. You want to think about something else going to bed at night.”

“My husband and I talk about it all the time as it is something you have to as the last conversation that I had with my doctor was do not waste your money because it is not something that you are going to do when you already know what it is when I am going through early pre-menopause. There is nothing I can do about how bad the eggs are, or if there is any left. You cannot fix that. That just is what it is.”

“Yes we would continue but it [is] negative because of all the things that go with it, the cost and the unknown, whether it is going to work or what the long term outcome on her health is going to be from taking all these medications because it is completely unknown. That still weighs on me sometimes “How is this affecting her?”

“In the future if we want another baby we have to go through surrogacy again. We had the first surrogacy and it is a very difficult thing to do. It is not easy navigating that relationship with your surrogate and she just had the miscarriage and going through all that subsequent testing. So it is not an easy thing for sure.”

“It is hard to say. When I started fertility treatment I said I would never do IVF. I always said if IUI does not work we are not going to do it. It is too expensive and then our parents offered to help us pay for it. So here I am doing IVF. We have not thought or talked in length about what we would do if these four embryos do not work. So never say never because I am doing

something I said I will never do. If these four do not work then I do not know that I said I can do it again or I would want to do it again. I am fearful of that.”

“I hear the women in the fertility group say, “I never thought I would do IVF” and here they are in round three. That escalation of interventions is something that terrifies me and people are so quick to jump to it. I am not receptive to that yet.”

“We do not know what the future will hold, but if everything goes ok with this we might try again because we have a couple of embryos frozen overseas. So we might try for a sibling. But we try not to get our hopes up because we could have the lining problem again or whatever. After every failure you have to decide to forgo or try again. I think for me as long as I had money in the bank and as long as I had some medical professional in front of me telling me that they do not think I should give up, I was going to want to continue trying. That may not be the best of strategy because you could say they are in it for the money too, but as long as I have a doctor in front of me telling me that there was hope that it might work, I was not going to give up unless we just were destitute.”

“That has been hard because I wanted to continue while my husband does not. I guess in terms of our marriage it is been difficult, but we are continuing, and I am glad, I am so glad that we are going to do an IVF because we have never done it.”

“Yes, we will keep going until we are done. I will do another IVF cycle, we will use the other nine frozen embryos.”

“You could spend the money every month then they will continue to take your money and not tell you what is going on. We stopped to take a break with some of the alternative stuff, I need to stop stressing so much. It is true, without the two week appointments and increments it is easier to forget about it a little bit and so we were saying, “Let us just take a break and then reassess in a couple of months where we are at.” Then we reassess the first three years and say, “What are we going to do? Are we going to continue to do nothing? Are we going to go back and look at options? Are we going to take out a loan?” I cannot continue with nothing, not plan or anything.

I need some idea of where I am headed, and he just gets really stressed about the financial piece. He works a couple of jobs and I work an additional job and so we are trying to save money, but he does not want to spend it all on IVF. His big thing is that there is no guarantee for it and so you are putting all of your eggs in one basket. There is no guarantee especially because it is unexplained. He had a friend at work that somehow end up on this topic. The friend went to this men's clinic in town and found out his testosterone was really low. He gets weekly testosterone shots paired with HCG, because testosterone itself can lower your sperm count so they give HCG in addition as supplement. Then his friend was saying, "My wife is late on her period and I think she might be pregnant. It has been a couple of months." My husband got very excited and said, "I know that is the problem. It has to be it." So he went last week and all are low as well. He got a second shot today. So we are, "That is a cheaper option. Let us try that a few times." His doctor was like, "You can, but it lowers your sperm count." He was frustrated and I said, "You are getting the HCG to supplement it. Let us give that a few months, try that and if we still have nothing then we will reassess," then we are going to plan and we will probably be good to go back to IVF."

It is not an option, because the cost and the unknowns

"It is not an option. Yes, if the cost was not an issue, I would think about it. I am so incredibly lucky that I had someone even help us to have one because, I mean IVF is so much and to use a surrogate, way way too much."

"When we were going through it, there was definitely going to be a stopping point, we may have done a couple of IUIs, but I do not think we ever would have done an IVF because of the cost it would have incurred upon us. I think we would have gone the adoption rout, before we did IVF just because it is almost more of a sure thing. You are probably spending as much money but you get a baby or a child. At this point we are sort of on defense on whether we even want another baby and I think that even if we decided we were ok with that, I think we would just leave it open and say "If it happens, it happens" and we are not going do other infertility treatments."

“My doctor only recommends two or three cycles of the injectables with Letrozole before we move onto IVF. My husband and I have decided that for ethical and financial reasons we are not interested in IVF because it feels it is too hard, it is too expensive, there are too many questions about what you do with the embryos you create. How much is it really worth? How much should a baby cost to bring into the world when you can have a child who needs a home? So we know that we are not going any further than these two or three cycles of Letrozole and that has actually been comforting because I woke up knowing that we did everything we could up to that point. Then we will be free to pursue adoption with no regrets.”

Donors

I was not ready to give up yet and you have to come to terms with it

“I looked at donors when I was getting to a point where I thought my eggs may not work and it was a very very negative experience. All I did was cry and I was pretty sure I could not do it. I wanted it to be me and I could not wrap my head around it. Every different thing you do, every treatment, say surrogate or donor, whatever, until you are ready, you cannot really see it as something you could do and I just was not there. So I was looking but my head was not in it and I could not do it. I was not ready to give up yet. So looking just made me feel devastated because I was not ready and you have to really come to terms with that. You have to go through the mourning and all that. And I had not gotten there yet.”

“I did not. That was the biggest joke that my husband did and this is also before he had done the testing on his sperm and his joke would be “We are just going to do donors then” and it made me mad. I would say “There are so many steps we could do before we get a donor!”

“We talked about it. I expressed to my husband that that is something we should consider, but that is not something he wants to do at this time.”

It is like going shopping

“It was overwhelming especially at first. The egg process and the sperm process are completely different. The sperm process is all commercialized you can get sperm from anywhere, you have all these choices and it feels like you are going shopping, very strange, like you are going to Amazon, shopping. For the egg donors we looked here but we decided to go to Atlanta cause we did not like the profiles here. Every clinic has their own pool and with a lot of them you can search online to limited extent and once you sign up with the clinic they will give you more access. You get pictures and you get personality profiles. You get some childhood pictures, but

not adult pictures. They usually give you at least one picture maybe two, and we picked the donor that we really liked. Her baby picture looked just like me. They have frozen eggs, that is the reason I went there. They gave us six eggs. Unfortunately that cycle did not work, we did not have more eggs for that girl, so we needed to go to our second choice, which is fine but you always want your first choice. That is disappointing, but now we have some embryos in storage. So hopefully and luckily we will not ever need to do that again. It is a very strange process and you make a lot of compromises along the way. You think you know what you want and when you start looking you are like “Wow, I cannot accept this or I cannot accept that.” It is very expensive and part of why we went to Atlanta is the cost, not using alive donors is cheaper. The tradeoff is you only get 6 eggs, you do not get how many she produced, but there are immediately available and it costs less than doing the traditional cycle and they guarantee you two embryos. They give you eggs till you get two embryos. It was kind of a commercialized thing and we did not like that part. They never established relationship with us, the doctor was some guy that did not get to know us and we only got one embryo out of the first cycle with our first donor choice, we got one embryo and we implanted that one. So they said that since we did not get two embryos we would get three cycles. That helps with the cost, we are getting a free cycle and since we are paying sixteen thousand dollars it is hard to say no to that. So even though I did not like the clinic and I did not like the doctor we did two cycles with them and got the third one too. Ultimately we got all of our embryos. So they get credit for that.”

“I think because we used donor banks, both for the sperm and for the eggs, it was able to cut out a lot of the time... we were daunted by the idea of hiring an egg donor or selecting an of egg donor, then someone would basically be undergoing a round of shots and everything. In Georgia, the frozen egg clinic, they were able to offer a rapid access to existing eggs. They had a pretty good database of donors, a lot of information and some pictures you could look at. It was cheaper and they also offered a guarantee of two embryos. You were guaranteed at least two embryos or viable pregnancy, and since the first go round did not produce, the second one was free. Obviously we rather would have gone with the first one. I feel positively about the donors; very positively. I wish I could give back. From the way that we have received, I wish I could give back.”

You totally floored when they tell you how much it is going to cost

“We are not going that direction, mainly because of cost, there is no moral problem for us with donors or surrogacy. It has just it has starting to get really complicated.”

“Well you totally floored when they tell you how much it is going to cost. Even when they tell you thirty or forty thousand dollars, if you knew that was going to work you would say, “Where do I sign?” But when it is thirty or forty thousand dollar gamble and your biology is letting you down so much, you are like “oh my God. What are we getting ourselves into? What if it does not work?” That is part of the reason overseas was appealing to us because it is so much less. It was less than a regular IVF to do a donor cycle overseas. We had to sacrifice some things, if you do a donor cycle here you know a lot about the donor, while the one we went was very minimal amount of information. While here some give such detailed personal information on the donors I think it becomes overwhelming. Looking at profiles of these young girls you are just trying to find yourself in somebody and you cannot really do it and that is where it starts getting frustrating. I am an educated person but I really do not know what transfers biologically, genetically. You see someone who does not look anything like me or my family, but you like this person. Then you see somebody who may physically look more like you, but they wear something you do not like or they did not finish school. You just do not know and it was hard to figure out what we really need, what we require. With the overseas clinic we gave some physical things and we know her age, her height, her weight, that she was in school which was important to me even if I do not know for sure how much of that passes. In some ways that was nice, after you look profiles [here] and it becomes overwhelming, you decide to put it in somebody else’s hands and just get this minimum info and go with it. That was liberating. Some people asked me, “What do you really know about this person?” I do not know very much and it is tricky too because you worry about the medical history, but at the same time I think what did I know about my family’s medical history at twenty three years old? my mother did not have breast cancer at that point. When you are younger and your parents are younger, a lot of the stuff has not shown. So you do not really know what you are getting. I was worried about the mental health but there

was no way to gauge that. Now if I had gone through the donor here, my doctor had said he would be meeting them himself. The donors' experience in the states was really hard because looking at profiles gets overwhelming. Overseas it was much easier. Here also the expense is so outrageous because you are paying your doctor, you are paying for the donor's meds, which were very expensive, but then the donor gets the big chunk of money, then the donor agency gets the big chunk of money. In that process you feel everyone is profiting off of you and it just seems ugly. Overseas the clinic I went had their own donors, so you do not have to pay an agency fee. My donor overseas got paid and I hope it was not an insulting amount of money, but it is definitely not the amount that American donors get. It is mostly done with the intention to help and the money they get it is very minimal. That is how they justified it over there. There is a lot of good people out there. I think at that age if I had known more about people who are suffering in our situation, you might have been able to convince me to do it, but over here you feel everything is about money."

"I was really blown away from the selectivity of the people. I mean it is just the same 43 guys and they all live in the same town in Pennsylvania, it is weird. I thought there would be hundreds of thousands, but no so I was just stunned at the limited availability of sperm. When I was twenty if somebody just asked me I would be like, "Ok, I have some already!" So, why is that? I have to analyze the market. Well the market supplies is driven of supply-demand and there is a market for sperm but it is a limited market, so they do not release large quantities of analyzed and treated sperm because in doing it they would lower the cost. Market forces at work. God bless America."

"We actually did double donor, we had an anonymous egg donor and an anonymous sperm donor. Everything with our experience with the Czech republic clinic has been off the charts positive. They are so thorough and so responsive. They pick your donors for you and it is anonymous. You request things that you want, they cannot tell you if they gave you everything you wanted, but they can tell you certain things. The cost for a double donor, a round of IVF, was right around fifty-six hundred dollars, which here was thirty-six thousand. Thirty-six thousand compared with five thousand is a pretty huge difference, and the level of treatment we

got over there was just incredible. They are a destination clinic so, they are used to people travelling. They hold your hands through everything. Every step of the way is easy. It just was really well organized thought out and they are so respectful. It is such a different feeling working with them. They are just so compassionate and respectful. Donor over there is very common. I do not know if it is less common here but I think there is probably a stigma here and there is the legal constraints.”

“So we had an egg donor as part of the process. This is overseas, so there was a little bit of not knowing and that is by design. They do not want you to know who the donor is. So it is a little bit of, I do not know if frustration is the right word, but wish you could know who the donor was and maybe if not meet them in person and at least know a lot more about their history and background and genetics and all the things that might impact the baby. I think it is fantastic that they have the ability to go through a donor and the donor is available and willing. I would say donor process is very positive. The down side is it is a sort of additional reminder of the problems that exist and the inability of yourself to become pregnant, of that thought that it is kind of a recognition that you may not be able to do it as husband and wife. But it is a good thing that they are there and available.”

Hard on the relationship

“No, this was not a good experience Well it was not about the website or the agency. It was just between us. Put a strain on our relationship definitely.”

“In the back of my mind for years I thought that if we used donor sperms it would be so much cheaper than doing all these other things and ideally was the only thing that was going to work, but I was scared to approach the subject. I tried to think of ways to soften the blow. I was going to need the doctor’s help because I was so scared to tell him myself. Then, when my friend used a donor egg and got pregnant, I thought, “if ever I am going to approach the donor topic this is the time, while it has been a success for someone else.” So I asked him. At first he said no, but later he said, “You know that may not be a bad idea. What would it be like?” I suggested to do a

swirl with some of his and some of the donor's because we had already started fostering and it was very apparent to both of us that we did not need our own biological child. The donor ended up being more expensive I thought it was going to be. It was all on the internet and crazy expensive. The more popular the more expensive. There were some guys who could be as low as \$400, and then there were a bunch of guys who were in the five sixty, five eighty range, that is just their fee then you have to pay for the shipment. For IVF it could be as low as \$300 but not for IUI, it is a volume issue. We did another IUI with the swirl, but was unsuccessful.”

“It was negative for my partner because it was really hard for him to deal with me going and picking someone else to have a baby with; but for me I enjoyed it. It is fun to think about. You have to get online, and there are a number of different organizations and it turns out they are pretty much all based out in the Virginias. So, you have to have it shipped to you, it is a huge container, and it is a bit expensive. They just ship it to your doctor's office and you do the IUI with that sperm. The cost was very expensive but it hoped us to rule out - at least in my mind, whether it is a sperm problem or an egg problem.”

Not an easy process - you want to find someone that looks like you

“It is difficult for two people to decide on one individual. My husband and I struggled quite a bit. From a female perspective I started to feel a bit resentful, “This is my body! I am putting it inside me and I should be able to make the decision.” Then to make matters worse for the donor we had selected the doctor had given us a price quote, we had set that money aside and we were ready to go, and then the doctor completely changed strategies. This girl, for whom we were having to pay several thousand dollars extra because she is a proven donor, was living in another city and was going to travel multiple times for this. All of a sudden she was not able to do that because she had just graduated from college and had gotten her first big grown-up job, so she did not have the availability to take off. We were even willing to supplement her lost income, which it was going to be thousands of dollars more for travel expenses. All of the six months that took us to find our donor fell apart. That was heart wrenching, that was the only time I had an emotional breakdown I even cried while I was on the phone with the office staff. This is not an easy process

and they would not work with us. Finally she referred us to an egg bank, so we went that route. At first that was a little bit difficult because I wanted to find somebody that looked a little bit like me, you want to have some physical traits that might represent you and you might see yourself in your child, and there were any. All of a sudden, a woman here who had similar physical characteristics had just donated a month before and just got on the site. Once we selected her it was a very easy and positive process. We were excited because it was going to be half the cost and because it was so close, it was great for me to just be able to drive there in the morning, get it done, drive back home and rest at home in my bed, which probably would helped my situation because it was less stressful. They sent me pictures of her, but I did not keep them. I have her information, her family traits, but I did not keep any pictures and when I called to get them, since I am no longer trying to get pregnant I cannot get access to the donor site. I wish during the process they would have told me. They cannot give me pictures now, because they do not want people to find them since that is an anonymous process and with the facial recognition on Facebook now. At the time I did not even think about saving the pictures because one of the reasons why it took us so long to pick out a donor was my husband did not want tell our child and I did not agree with that. What if you get a divorce and you were angry at me, and you decided to tell our sixteen years old child she is not your real mother? I had a friend who found out she was adopted and it changed her whole life when she was that age, and I have other friends who adopted and from the beginning it was never a question, so that was the way I wanted it. So, he came back agreeing that honesty is the best policy.”

“This is our first time. It took about a month to pick her because my husband has blonde hair and blue eyes too, so it is hard here where everybody has dark hair and dark eyes, because you want to find someone that looks like you genetically. So, it took a little longer than we thought. Also, we wanted to go through the doctor’s office because if we went through an outside agency my insurance would not cover it. We did have to pay for the donor out of pocket. My insurance did not cover the donor’s fee, but since it was through the doctor’s office it was minimal, compared to going to an outsider. The doctor’s office has young girls and college students. Normally they are looking for money. If you had to pay out of pocket for a normal IVF plus the donor fee it is from twenty to thirty thousand dollars, but for us it was only four thousand dollars and that goes

to the donor whether it works or not. We have seen her picture and her background. She is new, she has never done it before. She is about ten years younger than me. We started the process in December. This is our second round, the first time she was not taking the right dose of medicine, she is having the shots but not cranking it the right way and she was only getting not even half of the medicine. She had the follicles, but they were not growing as wanted and the nurse found that she was doing the shots incorrectly. We stopped and started over.”

“Our first choice is going with a known donor for a lot of reasons. Right now that is the best option for us, but that pool is rapidly shrinking. We found a sperm donor, we did a couple of rounds and then that situation imploded. I have a theory of why the gingers are dying out. There are only four red headed donors in the national sperm donor registries, that sperm can be anywhere from a month to ten years old. I have a red recessive. I dreamt of having a little herd of ginger babies. Now I would be happy with one and I do not really have a preference for hair color any more. But it kind of seemed I should be that forward, it is supposed to die out in the next several generations, like let us keep this going. Our first donor choice ended up he was low testosterone as well but his treatment worked and the doctor signed off on him being a donor. We went a couple of rounds and there were some interpersonal things that happened so x to that situation. My husband, I picked the perfect guy. I picked the absolute perfect guy that I wanted to have kids with and everybody else is not as good and now it is just figuring out like what I am going to sacrifice from here. What I am I willing to sacrifice from that package.”

The organization was really thorough

“We used donor sperms, and what was good about that was that the organization was really thorough. I had complete medical history on him and his family back as far as grandfather and grandmother. In addition to that, they gave us his personality profile, so you got to catch an insight of that, and an hour interview with him so you got to hear his voice and what his motivation was. It was funny, I did not say this to my ex at that time, but I probably knew more about my donor than I did him moving in. I had a really special situation because I am CMB negative and the majority of people are CMB positive and so I had to find a donor who is CMB

negative as well. That knocked it down to three or four people. After I had time to go through and see who they were, what they did and education attained, I mean got to see a whole lot. It was really positive and it was not like just“ ah that one has green eyes, I want that one.” There was a lot more to it.”

“That is an option. It was shocking when they told us about my infertility, the only option they gave us is donor egg because my eggs are not going to work and of course, I never heard of it. At my doctor’s office they have a donor program. At first I was, “No, absolutely not” but then over the year I was open to it and I was onboard. We picked donors and we had number one, number two and number three and we got really involved in it. They made it very easy.”

Surrogacy

That is not an option

“We looked at it and considered it, did not do it, extremely expensive but great that they are there. But it was limited information. It is expensive. I would have loved to do surrogacy but financially it is not for us. We just briefly talked about it and I did a little research.”

“If I cannot have my own babies, if I cannot birth my own babies then we are going to adopt. That is not an option.”

“We did not have any issues with me, so we had not thought about it. We did consider it moving forward because things were so dangerous this last time, but I had a great OB/GYN team here and a great perinatologist and I have talked with them at length about it. They say that is there is absolutely no reason that I cannot have a successful pregnancy again.”

“We briefly talked about it, but we want to try IVF [first].”

Establishing a relationship

“I found a clinic in Colorado. They had someone who had already been screened and checked out there with an agency out of California. So I went with them and she did not work out. She was really unstable. They were going to move, so I had no idea where she was going to live for the pregnancy. She had no family or friends around. I could not just accept her because she did not have a support network. The second one, the doctor rejected her because her medical records, she had signs of preeclampsia with one of her pregnancies. Then I picked my girl. She had normal pregnancies with her two daughters. But at twenty-seven weeks her cervix started opening. She went on bed rest and then she delivered. So it was pretty stressful. We went to probably half the appointments and if not we would be on our I-phones with face time so that I

could see the ultrasound and talk to the doctor. We got bad results when we did the first blood test, so we had to do amnio, that was really scary and stressful and she did not want to do it; that was terrible. But we loved each other. We texted many times a day. I am fifteen years older than her but we were like best friends. She is super funny and our personalities are very similar. It was a good experience and I love her to death. She did everything right and you know, we made the decisions together. It was not always easy but...”

“I learned a lot through the support group. The lady who runs it is a positive example for me and it helps knowing she has been through it. When my doctor first mentioned surrogacy my first thought was no way, never, but you get desperate and you give up a lot. My doctor recommend agencies, they do not run a program themselves. It is somehow similar with donors, you get profiles. She is two hours away and unlike our donors we call her on the phone. We interviewed her and we decided to use her, she went through medical testing, we did council sessions together. Then set some ground rules and run up a contract. We were there when they did the transfer. I have been to appointments. Her friends want to throw a baby shower for me. She has really been great. I think it is great that we have this option, cause it is our only option, well there is adoption. Surrogacy is expensive. So you pay the agency fee, the agency was sixteen grand, then the surrogate fee is about twenty grand. And then you pay all the medicine. So when I estimated, it is between fifty and hundred thousand dollar but it just depends on you, what you are paying for.”

“The support group that my wife is a part one of the women there had gone through the process. They were able to recommend an agency and the woman who runs the agency is very friendly and personable and did a very good job. This is very scary process to go through. You sign up with the agency and you think “ok now we have to pick this woman based on things she answered on a piece of paper” It turned out to only three choices. There was not a huge universe of choices and meeting the surrogate and her husband was kind of awkward but she is proved to be the right choice.”

“Originally my husband’s sister volunteered to be a surrogate for us but then we did not think we needed one. My surrogacy experience is a little bit different. I have never been told that I needed to get a surrogate. Most of the time women are told because something is wrong with the uterus. For me, and this it may sound weird, I was just done cycling. I did not want to do it anymore. We still had six embryos and financially we were able to hire a surrogate, so we went that road. First we ruled out family members. We actually talked to the psychologist at the infertility clinic about it. The more I thought about it I was just not comfortable with a family member doing that for us. A little bit too close maybe. I really like his sister, but just all that is involved. So we contacted three surrogacy agencies and found one we liked. Then we met the surrogate, make sure we are a good match. I flew back for transfer and two of the ultrasounds, so not very personal but yes. His sisters lives out there, so it was nice to stay with them and be able to borrow their car and go to the appointments. So it is good. But overall I still say it is a negative experience because it is just hard; just a really difficult thing to do.”

“I thought about it just because my sister and I just the other day we were joking around. See, my mom, had fertility issue and so does my sister. My sister has two children, my mom had three. They had different issues than I did. My sister is not getting pregnant but she is very good at being pregnant, and so she is made several comments and my husband and I have made comments about if my uterus will not carry maybe my sister would carry my baby for me. So it is something that we have thrown around but I would think that would only happen if say we might seriously consider asking her if we had only one embryo left. I think she would say yes. But that is the only surrogate that I would consider. I would not pay anybody or something like that.”

“We did talk about that. I do not think we ever got to that point, but we did talk about it. I remember because we were saying, “Who could we... who would do it? Do we get somebody unknown?” She said, “We will talk about our younger cousins doing it.” I do not know, we did not look so much into that.”

Adoption

Adoption is complicated and very expensive

“We thought about it and I even got some information, but I did a master’s thesis that involved adoption and birth mothers and I was very pessimistic about the chances that we would end up with an infant. People think there are, but there are not that many infants out there that people are willing to give up for adoption, especially domestically. And internationally it is very tricky and hard, and places we could get infants years ago like China has dried up. Sometimes family, my mother one time, and people a couple of times, would say something that offends you like “Why do not you just adopt?” Oh, that phrase. It is a ton of money, you could still end up empty handed, and it is a lot of waiting. At least with this procedure I felt I was doing something, but here you are just waiting. I was on this email group, and I had read about people who had terrible things fall through or they had to drive all the way home from far cities empty handed because at the last second the birth mother takes the baby back. Also the birth mothers, because of the move towards open adoption, which I think is a good thing, have a lot of say over who is going to get their baby. So the idea that we were going to put on a song and a dance and shine it like summer and sell ourselves to these teenagers. To somebody who is seventeen years old, we are ancient, it would be like giving a baby to your grandparents. So I feel they may not go for us. They want somebody younger. Although that was an avenue that I would like to do and I still talk to my husband about how I would like to try to go through the foster care system, at the same time I know that is also froth with a lot of emotional turmoil. If I could get pregnant then I could control all the prenatal where with adoption you really cannot control at all. I mean if it was more of a sure thing, I would have been willing to do it, but I really did not feel it was and I do resent a lot of my feelings. Like the doctor who told me you should just adopt or even people who are well intentioned who say, “Have you thought about adopting?” they do not know how hard it is. They think it is an easy thing to do. Another thing that was unappealing to me and it is not because I have secrets, I feel it is very offensive and invasive of how much they want to go through your life and your history. It is a very invasive process in a way that birth parents do not

have to go through to be parents. You are very scrutinized versus anybody else who is not and you are the person who wants this baby. I have people in my house coming over and checking me, checking my husband, checking the rooms, checking the cleanliness of my house. I just felt I should not have to do that. I even think it is offensive how the foster parents do not have any rights and are treated so badly by the system and the kids are treated badly by the system too with their return to terrible parents and there is always this preference for their family and the family might be a terrible choice for them. Anyway so that road was really a turn off even though sometimes I think maybe we could try it, especially if we are going to have one baby.”

“I looked into adoption and I found it to be a little bit complicated. I looked online and did not find easy to find places here or I thought it seemed they were faith based. I was looking for an infant. We did look a little bit into fostering. Very expensive. I felt it was comparable to IVF or more; more so perhaps because when I started looking into IVF I made the decision to go to it because I thought maybe this is the intervention that my body needs to make it happen and I would regret not trying it. But at the same time, I knew that if we had done IVF and it did not work, that might wipe out all the money. Then adoption might lend me an option. But we were going to go IVF.”

“That is maybe something that we would consider even having being able to conceive a child, I think that adoption is a wonderful thing. We got basic information, but I do not think it is readily available. I found some good websites about adopting newborns, but to find that and the cost, which is astronomical, and to know all your different options, or even a foreign adoption, I think it is a really rough road, I think it is hard to find them. We are not quite there yet. If we do not get pregnant within the next couple of months then we probably will pursue adoption. I think adoption is obviously a very beautiful thing. I think there can be more complications than a lot of people believe. My family just says “oh it is so wonderful you get to give a child a home that does not have one.” I do not really know if that is the reality of things. It gets complicated.”

“We have looked into it and it is a little scary because you put a lot of your time and money into it and you are not guaranteed anything. But we are open.”

“We attended twelve weeks adoption seminars and we learned about foster adoption, domestic adoption, and international adoption. I would have thought we would have leaned towards international adoption because I am mixed-race, but we liked open adoption. The birth mom selects you basically. You choose degrees of openness. You can just have their names all the way to maybe do pictures now and then or phone calls or maybe you do in person meetings. So we decided we really want an open relationship with meetings and contacts, kind of best interest for the child. But we had a scam in September where we contacted her for a couple of weeks, pictures, sent all these kind of stuff. She said she would pick us. We thought we would end up with twins in November, but it ended up being a fake pregnancy. That was really hard and then just this week, Monday, we had another scam. That only lasted for the weekend so we were not really emotionally investing like we were before. Last night we got an email that seemed like a real one and our coordinator checked out her background.”

“Before we even tried to have our own child, we thought we would adopt. We wanted to adopt through the state, but because my husband’s ex-wife has for years been trying to make his life miserable, several times, she has tried to call CPS to make false allegations and we end up having to go to court and go to therapy and nothing has ever come out of it. And we cannot fight back because the laws are put in place to protect people who make allegations. What it did was it made it so that CPS said, “Of course you can take our training classes and we will be happy to represent you as adoptive parents, but when children come up to be adopted and they see your folder, they are going to see these reports and these allegations and it just looks bad.” I was really upset that they could not figure out a way; this woman, is diagnosed with bipolar disorder. She has committed herself to mental hospitals two or three times in the last few years. She has cheated on her husband. Once she alleged that I kidnapped the kids and took them to Mexico. I get papers to appear in court. I mean she is crazy. And they cannot take that into account. It was very frustrating. She has made him take a psychiatric exam, which is really infuriating when somebody makes you take that kind of thing, and he was fine. We cannot do the same to her. It just feels really unfair. Here is a couple totally willing to adopt. We wanted to do this about five years ago, so the child would be closer in age to my stepdaughters. And yet for nothing I did,

none of this was my fault, this was all this woman's vitriol as well as my husband's decision to have sex with her. All this was not my fault, and yet I was not allowed to adopt. It was very upsetting."

"Well, the adoption thing – and I will be quite candid since there is just you, me, and that recording device. My ex-wife plays significantly into the adoption scenario because she is just a scandalous woman, and has debased me on many occasions, like legally tried to railroad me filing kidnapping charges; it is just never well. All things end, all things pass. Right? But it went on for long time and I just spend another few thousand in a another rewrite of the divorce decree, so the point is that because of the legal difficulties there is perception that I am of a lesser quality in terms of a potential parent and so, that influences the adoption process considerably. My wife was stultified by that; it really drove us out of the whole process."

"I am in the social work field and I deal with foster children. So we thought, since we have always wanted to adopt, we just wanted to wait until we had biological children before we started the process, maybe we should go ahead and start that process. At the time we decided it was very difficult with a lot of crying, it was a very dark time. I argued with him for a while because I was not ready but eventually I was ok. And maybe we will get pregnant naturally. We have not been told that there is any reason we should not. And so, we started focusing on foster care."

"We have a license to foster now. That is just another weird thing. Our agency, is on a placement hold because they are in trouble with the state. One of their families, a couple lost custody of their child to CPS because they were using meth and it was a baby that ended being killed by the woman's ex-husband, he was not even supposed to be at home. This has affected all placements. [They] have to do all kinds of new training and do all these things in order for them to be able to start placing children again. The death was so horrible. It happened in November and we got licensed in November. It was definitely another loss. We finally decided we were going to walk through this adoption door and focus on becoming parents in another way and then that door closes."

“I am actually looking into foster adoption. I am looking into CPS foster care and CPS adoption. I would like it to happen tomorrow, which is not possible, there is a lot of hoops you have to jump through and you have to prove that you are not going to kill the children – but that makes sense. So for me, it is kind of taking some pressure off because I can still have kids. They are not my kids but that does not matter to me.”

“We went through adoption for a few years with three failed adoptions, actually two failed adoptions with three kids. My brother has a daughter. I raised the child for the first two and a half years So we have her, but we are legal guardians, we are not her adoptive parents. We are working on that. Then in addition to her we put in for children between the ages of new born and four years old. We were with this seemingly great adoption agency and it took about a year to get approved. Then we got matched with a young couple that had a daughter and they were pregnant with a little boy and they wanted to place him for adoption, they wanted to maintain an open relationship. We spent several months building a relationship with them, loving them, talking about how their son who we would adopt would know his sister and we would get together four times a year, really make sure they had that connection and it was just going to be a beautiful thing. Then the day of the placement ceremony the birth father said he was going to raise the child, the birth mother did not want the child but the birth father did. We pray and hope that they are doing well and if he wanted to keep that child and raise that child then I am happy for him. It was a huge loss for us. Then we waited for another placement and things got really weird with our agency. We were asking them some questions about how many birth mothers they were working with and how many couples they had waiting, what the time frame might look like because we were thinking of moving and building a bigger house. They got mad and said it is not your job to ask questions and if you have a problem, then your problem is with God. So things with them just went downhill. They started offering us placements that were an additional \$20,000 dollars for each one because they were bringing them from another state or all these weird things. We finally said, “Just give us the child that we already paid for so that we do not have to shout out any more tens of thousands of dollars and we will be good.” Once they realized that they were not going to get more money out of us, they offered us a placement of two siblings. We were very excited and we met the siblings. There was a three month old girl and an

almost three year old boy. The boy would not speak and he would not connect with you. We were willing to adopt children with special needs. We did not have a problem with that. What we were worried about was dissociative, because we had our older daughter and we did not want to put her at risk and we would have the three month old and we did not have a child that would be dangerous or possibility kill or injure another child. We prayed about it and talked to a bunch of specialists and they all said, "Have him go through some testing to see if is he just struggling with communication or is he dangerous or what is going on." They said "No. we are not testing him," and "by the way, for asking, you guys are out. We are firing you and we are keeping your money." So that is how that ended. They are supposed to be a Christian agency and I think everything they did was backwards. They cancelled us and said, "We have another couple that is interested." We said, "OK, but please have him tested. They do not know what they are getting into. They do not know if their insurance is going to pay for stuff like this. He has needs. Serious needs." So that was really really difficult for us. And they fired us right after that."

"Adoption is expensive, not as expensive as surrogacy. The thing for me was that it is like a two-year wait. I do not want to do that. And it felt like going backwards. We already have these embryos. When we were deciding surrogacy or adoption we went to Dallas to see a doctor to questioning the diagnosis of my ability to carry. He was a little more definitive than the doctor here have been and so it was comforting to have someone who is a little bit more upfront about that, say "you should do surrogacy, you have these embryos, use them." I have never been opposed to adoption, I think it is a noble thing. I do feel selfish for doing all of this when I could have just adopt. It is my own personal guilt. I think adoption is scary because even if you go all through all that you still do not know if you are going to get your baby in the end. So we felt surrogacy is a safer choice for us."

"We thought about it and it seemed it was going to be even scarier that we would be subject to changes of heart on someone else's part and there would be very little to do about that. Could have really long lasting uncertainty attached to it. I know that probably the majority of adoptions happen without any kind of reversal or bad process but you do see on TV and you read in the news about people who change their mind and ultimately someone has got a paramount claim to

the child and I did not want that. I know one person who has done foreign adoption. They spent four or five weeks in the Ukraine. I do not understand how anyone can do that, how anyone can afford that. I know that my wife feels guilt that we want a surrogacy instead of adoption just from the standpoint that in adoption at least you are helping someone else. In terms of money, we both felt that it was going to be a long and equally expensive process.”

“We are fostering right now to adopt, but we are on our third child. Since day one we really thought that we were going to get to adopt our first one and then family showed up out of the woods. We could do straight adoption but straight adoption is more expensive than IVF. So we are trying to do it this way. We definitely will be adopting a child at some point.”

“There are so many children without homes for us to have to jump through all these hoops.”

“We did look into the process and found out everything you have to go through, all the huddles you have to jump to get a child, the waitlist, and the cost involved. We were looking for a baby, a child as young as possible so that we could rear him as our own. We had discussed after our children are a little bit older fostering to some capability and we had wanted to adopt at some point in time anyway, but it is a bit intrusive to have to go through it all and the cost! I could do another IVF for less than I could adopt. I would think it would be a little bit easier.”

A recognition that you are not having your own biological children

“I think if we could have our own we would not have to adopt.”

“Adoption is kind of a recognition that you may not be successful in having your own children and you are looking for an additional outlet and additional possibility and almost giving up on the process of you having your own baby. Lots of question marks about adoption in terms of which baby you are going to get, what condition the baby is going to be when you get him, who the mother is, where the family is, what their background is and circumstances surrounding the

pregnancy. Not knowing all of that before you go, before you end up with a product and the baby is the product, I think it is very difficult.”

“We have not taken that extra step. I think it is part of just the fact that I assume that we take a lot of time to get there. I do not even have a clue about the adoption process. Once we get on the same page, because of course we always want our own biological and that makes me think if is that selfish. That is what I struggle with a lot. So that is pretty common. I am sure you hear that a lot because it seems like that we would want have our own biological children. We are not ready to make that extra step to invite another because we want to be parents but on our own terms. That is the thing.”

“We had discussed it but had not gotten really far with that. I was considering it. My husband was not really open to it. So we did not actually try or apply.”

“I have been pretty strong about not adopting, I have always been strong and saying I just want to raise my kids. I told my wife about a month ago, that if we were only able to have one child through this IVF cycle, I would be more considerate; I would consider doing adoption for the second child. I think if we do not have any children of our own, I would say we are not going to adopt, but if I we have one child through the IVF, I would consider adopting.”

“We were going to try one or two times with the overseas IVF, and if it did not work that was the route we were going to go. When I told her, I was like, “If that is the route we were going to go let us do it” but by proxy knowing friends our age or older, this is tough because they want younger parents all the times. We actually have a couple of friends who are going through that right now. They have had three or four different kids through fostering and they have been dead set on a couple of them and it is amazing that these kids will automatically go back to a relative. It is not a much better situation what they were away from, and I think that rips their heart out at times. So part of me is glad we did not have to go that route.”

“I have never been against adoption even when I was single because I love kids. I can embrace any child as my own. I got no problems with that. When all this started, I was still very open to it, but my husband was like if it is not going to happen for us, until that day I do not want to think about adoption. So I did not seek further information. I did look at a few websites before I got pregnant. I just typed in adoptions processes just to see. I mentioned it to him several times throughout the past five-six years, “If we want to adopt, we should really just start soon because it takes time.” He was always like “no, we got time.” He did not want to go down that road. So I did not gain much adoption knowledge.”

“Yes and no in the sense that if this still did not work yes, we would have adopted; that would have been our next step. We have looked a little bit into it – not the process, just researched and looked into other countries.”

“I have had friends who adopted. Just so much bureaucratic BS, cost, and prejudice. It is a very noble thing to do and if you have got the stomach for it, please by all means do. I worked as childbirth doula. I have been a volunteered doula for about ten years. Working with women giving birth to healthy babies, you build up a lot of ideas of when is my turn, and I am not willing to give that up yet.”

“He really wants his own, our own biological children. I would need to at least try an IVF cycle, at least once, before we automatically bypass that.”

“That was kind of always what we thought will be our next step because we never imagined we would consider surrogacy and we have kind of, we have never gone to the step of going to an orientation. We just looked into that a few times. It is very conflictive.”

“We had thought about it, neither one of us really wants to adopt but we both said that if we have had a relative who needed... so, my husband’s niece is twelve say something happened and she had a child and she just was not ready and able to take care of it we would consider that kind of scenario, but that is about it.”

Living Childfree

Not to that point yet

“I did not want to really go that road and because there were avenues we had not tried like the IVF. I thought it could work. But it did not seem like something I wanted to do.”

“The positive benefits of being able to set your own schedule, you have more money and you are more free and none of that gets to set in until you have actually made the decision to no longer seek out or no longer seek to have a child. I do not know whether I have gotten to that point yet.”

“Yes, we tried embracing that, but it never sits well. It seemed good at first and then it was horrible. I am still struggling with that.”

“During the treatments experience, we did not talk about that, we were singularly focused on having a child. When my wife and I first stepped in the relationship, we just put a mark on the calendar and we said, “Here is where we stop, until then I will love you fiercely.” That is the same thing that happened, except instead of a date we had a number of reiterations.”

“This past winter was particularly hard in the aftermath of losing our first choice donor and having the other people in our pool drop out for one reason or another. Seeing that pool get smaller and smaller and getting frustrated with the whole situation, thinking we could just opt out and not deal with any of this and travel a lot and volunteer more. I was married once before, we were young and stupid and right out of high school with the guy that I got pregnant with, and my mom has been divorced five times, so I always swore if I do this again I want to be really sure. So in a lot of ways I feel my husband and I got married to have a family. We both wanted a family. We wanted it on the same time schedule. We had similar ideas about raising kids. He had great genes and I feel I found the person to share my life with, to build this family with. There are a lot more reasons for marrying somebody. I love him, but that overwhelming romantic, “We

are so much in love” I do not know if we lost it or if it was artificially inflated by the thought that we were going to have a family. Since that possibility has diminished we do not know if we have enough in common if we do not have kids to stick together, which is an awful feeling because he did not do anything wrong. The thing that each of us would need in our life to feel satisfied and whole without kids, it is starting to look more and more different. Plan A is crashed and burned. That life plan is not going to happen. I was so stuck in that hole of my dream did not come true, it is never going to come true. I could not figure out a different dream. So the possibility of not having kids or living childfree and enjoying that life, I had to embrace that possibility to be able to see more options. I am still not sure if it is the right choice for us, but it is something that I can see myself doing and being happy. I do not know whether he would join me.”

“It has been nice in our late twenties and early thirties. We have been able to do a lot of traveling but for the long term, that was something that was going to be negative for us.”

“We considered that. At first, before we started trying, before my biological clock started bothering me, I thought maybe I will be fine without kids and my husband could go either way. Then I felt like I am going to be missing something. I could see the positives in that, but I still was not willing to let go of the other.”

Not an option for us

“I felt like it was not an option for us. I know our marriage is strong and we would be fine, but I think we would feel incomplete as a family without some child however that child came into our lives. So I think we were fine if we exhausted our options through fertility treatments that we would have moved obviously to adoption. It is not that it completed our marriage, I think our marriage was really strong. But when I think about us thirty forty years down the road, I picture our family around the dining table and it does not matter how it is made up. It is a family you know.”

“It is just not an option. I just cannot imagine it because we have been so miserable. We just cannot give up. It is not an option, well not for me. That is not an option for us. That will never be an option for me.”

“I would say now that we have started fostering it is not going to be an option for us. It is crazy when we do not have kids, we do not know what to do with ourselves so we are sitting around depressed.”

“We have enjoyed ourselves in the sense that we got married late, we did a lot and we used to go see great places and do things. There were times when I thought if we are not going to have kids we can do these other things. But it did not seem an option for me. It is not what I wanted to do.”

“It is not an option. We will adopt or have one of our own. I have no desire to live childfree. There is absolutely no interest. It is not something either of us would be very happy with. We will think about it, we have talked about it; it is very overwhelming.” “Not an option for us, that never been anything that my husband or I wanted to do.”

“We talked about it but that was not an option for us. I remember when I was in college or even in high-school I used to say, “I am never going to get married but I want have kids and I am going to do it on my own if I have to.” I always wanted a kid and he always wanted a kid.”

If this does not work what is there to look forward to?

“Yeah that is kind of what I am reasoning myself with and there is actually a lot of positive about that. We have talked about living in other countries, travelling, a lot of fun stuff. In fact that is what made the whole process so hard too, because we could easily see our lives together without children, we have such a great relationship and really enjoyed each other and there were definitely doubts about doing this, because we could really see ourselves living childfree.”

“Yes, we have talked about that a lot. I try to think if this does not work what is there to look forward to? So you try to think, we can go on a lot of vacations and we can spend money on things other than children, we are going to Europe for two weeks. I guess we are trying to have that as a positive experience. If it is not meant to be, it is not meant to be. We can be happy and have lots of nieces and nephews and we have this crazy cat. We got a dog. So we try and make that a positive thing. If it does not work out then we can make our lives happy.”

“Sometimes I think living with no kids would be amazing and I told my wife if these four embryos do not work, we are going to quit our jobs and spend 90% of our savings and go on some crazy year or two around the world trip. Then I think I would have greater days when you get together with families. That is emotional. I definitely want kids, but we can still be great aunts and uncles. Actually it is funny when we first started out we said we are only going to do IUI and if we cannot get pregnant with IUI then we will not have kids. Then that did not work, so now we are doing IVF. I think there is this measure of if we do not have children we will be ok, which for me is a little less negative overall or I guess less emotional. I certainly want children. I want a family, but because we have talked about it, we will be ok if we do not. It makes you think different about it.”

“It could be a positive experience. If you are going to have a child, you are going to sacrifice some of your own personal freedom, your own personal happiness, but at the same time you are going to have this child. So there are a lot of rewards with that, but I feel that we could have a very happy life together without children. I feel we would still be just as happy if we did not have children or I do not feel it is a validation of my life. I do not feel it is critical to our marriage or my success in life. But at the same time we do both really wanted to have a baby. So it was just like a reward.”

“I think in the perfect world we are willing to accept it. I do not know what it would have been because we were on the edge of going back into infertility treatments. When I was really sick, we never thought that I would get better and we thought, “Oh, this may be it.” Yes, so we did talk

about it I guess, but it was not a bad experience nor a positive experience. It was more of a “we thought about it. It could be an opportunity for us”

“I am going to say this is not applicable today. But the truth of the matter is that I realize that may be an outcome for me and I may have to get to a point where I am going to live childfree. I am ok with that too. Not that is a preference at all. I have a plethora of amazing nieces and nephews who call me mama and they are just as cute and adorable as can be and we are really close in our family. I know if that day comes where I have to make that choice, we made out through all nine and none of them took then we may be living childfree. It may be adoption too”

“It is something we have not thought of. Either we go forward with looking at alternatives or we stay where we are. We kind of live in the moment.”

Time

Time describes the urgency various aspects of time during the Fertility Treatment Experience. The sub-affinities comprising time are presented in following order.

- ◆ Years Trying
- ◆ Schedules / Cycles
- ◆ Waiting
- ◆ Biological Clock

Years Trying

A long time

“Four years. I think the time is the biggest thing for me. How long this took is the most frustrating part of it.”

“Seemed long. In April it will be five; so four years, just under five years. That is a long time.”

“Five years.” “Going on five.” “Five years.” “Five. Very difficult.” “I would say about five years. It was hard. It was hard and hurtful.”

“Took us fifty six cycles before we got a positive. Several years.”

“We have been trying since over ten years maybe longer than that, fifteen years maybe. Maybe not that long, but many years trying. Never succeeding, just continuous frustrations throughout the process. Hope is still on the horizon but the longer you go the more frustrating it is. There is nothing good about trying it for years and years.”

“It feels really long. We have been married almost eight years, and been together for ten. When I think we have been together for ten years and five of them have been taken up by this thing, that seems just absurd. That is half of our relationship. But then you see people who have been trying for much much longer and I feel very blessed when I know people have been trying for ten years.”

“All you have is your time. Time is the most valuable thing that you have, how do you spend it, what you do. You only have so many numbers of years to conceive easily. We are lucky we started when we did, I cannot imagine have we not met until now and then taking the years that it took to figure it out and trying to go through. My heart goes out to those people. Would not have been great to have it the first time with the first IUI? but it did not. I had aunts and they tried four years without doing any fertility treatments until they had their first kids so it is not always as quick as anybody would like it to be though.”

“We have been trying for about two years; a little bit more than two years, which is very short compared to a lot of people in infertility world. It has felt like forever and it is way longer than I wanted to.”

“We started trying at thirty-two. I am thirty-nine now. We did three IVFs, My first IVF was when I was thirty-four, the last one when I was thirty-seven. Out of my five friends, we are in different phases, they all have their babies whether from fertility treatment, adoption or surrogacy, I am kind of the last one.”

“So tried for three and a half years. It was very frustrating as time went by.”

“We have been medically trying and undergoing treatment for over two years. We started the fertility process maybe three years ago. I hate the waiting. I wish it would just happen for us. I hate getting delayed. You want to be pregnant you want to be pregnant now. You do not want it to be three years later.”

“Every time I added another year, that was pretty painful because we tried for five years. Even before we started with fertility doctors, we were trying on our own and then there was that one year that we were in this hole because of the uterine lining.”

“We started trying as soon as we got married in 2004. It took us four years to get pregnant with my daughter, so we have spent our entire marriage either trying to get pregnant, being pregnant, trying to get pregnant again and meanwhile recovering from my surgery. That is why we finally reached the point where we said, “Ok, we are doing donor, it took us a while to get here and if this does not work we are done.” Now we have one egg in the bank and if this try did not take we would try again. I said that at first, but after going through the whole process with the injections I do not know if I could do it again. We are still holding onto the egg but we are interested in donating and help people out who cannot afford it because it is ridiculous to think that is going to waste. So, the years trying is a negative experience. It takes up a lot of time.”

“We have been now truthfully up being two years trying if you want to, well that is not true. I guess I have been ten years trying if you include all those appointments that I made that we never we able to completely realize.”

“That is a long time. We tried probably three and a half years. We tried from the moment we got pregnant on our own to us deciding, “We are ok not having kids”.”

“Forever. I feel like it has been of a long time. Well, two years since the miscarriage. We got married, I stopped birth control. I was thinking it would take a while. I asked a nurse practitioner friend, she said, “Oh, probably a couple of months.” It turns out it was not a couple of months. Every month we get more and more frustrated, more and more depressed and irritable about it and less interested in sex itself, “It is not going to work anyway, what is the point?” It is an appointment, it is not? I am tired. I do not want to, but we have to. It is this battle of who is going to initiate what and you are like, “What has my life become?” It should be fun and it is not. That was also part of the break; it was trying to not have appointment sex, not scheduled to make it more fun.”

“It is about four or five years, and it has been a lot. Five IVFs, seven IUIs, eight donors, so all the treatments, medications and whatnot. It is a lot of juggle and keep up with and try to make it work especially if you both work.”

“We tried for a few years, that is a lot of time and energies poured in, very outcome derived.”

“I have not been trying as long as other people that I encountered. I had only been trying for a year and a half. For me that was still pretty negative, just because I felt like it would happen instantly and I knew people that tried their first time and got pregnant, so I was, “What is wrong with me? I am twenty eight, that should be pretty easy”, so on every cycle I was feeling like a failure and wondering what I did wrong or if I ate something I should not have, or if I was stressing out too much. and then even when you decide to just calm down and relax there is not absolute way of doing that.”

“Two [years]. There was a lot of hope but also a lot of stress and frustration. Nobody likes waking up first thing in the morning and jamming a thermometer somewhere.”

“Exhausting, very negative”

“We have tried three years. It was positive the first year trying before we started testing. Now trying is just disappointing”

“Trying to plan everything right was frustrating. At first when I started to try I would come off the pill and I was charting. I was not ovulating as regularly or as often and so that was very frustrating. When you are doing Clomid you had to have the timed intercourse and that was frustrating.”

“Well, it is been six or seven years. I wish I would have known what I knew when I tried. We got married when I was thirty three and I wish I would have known stuff then that I know now.”

Schedules / Cycles

It's living from month to month

“It is just very stressful to live from month to month and to try, especially when my months were not working. It was not month-to-month, it was kind of here is the time. You were at fifty days between. For a couple of years that was like twice a year and usually it coincide with visiting my family and so I was like “Oh my God. I am visiting them I am not ovulating.” This is the stress, that is so much.”

“Body does it only once a month, I cannot even imagine trying to make it twice a month.”

“There has been a lot of scheduling. There has been a lot of planning around two week increments. It has been pretty frustrating; it goes back to living my life in two weeks increments and waiting. I feel like sitting around and waiting for one particular day every two weeks”

You can lose the opportunity

“That is a pain in the butt. Because it always comes in the end when you just do not want to have sex, you say: “Really? I have just finished to work out.” When you have lots of troubles and you have to get it just right and then you are not really in the mood right then but you have to. You can lose the opportunity.”

“My husband has been out of town occasionally and it has just thrown a wrench into everything. He does not go out of town often but when he does he goes out on the boat in the Gulf of Mexico. He is unable to come back and I cannot even drive to the town where he is working for the night. He is unavailable to me. And I have been really frustrated about that.”

It's time consuming

“Time consuming, just you are always focused on the time, I had a period tracked up. You look at every day, analyze and make sure you have got enough ovulation kits and it does affect you.”

“That was really stressful trying to negotiate the time, it always takes longer than what I am willing to wait.”

“Because of my cycle I always get delayed because I always need more drugs.”

It consumes everything

“Yes, your entire life revolves around schedules and the IVF process including the cycles and setting very specific dates and so it considerably encompasses your life, your lifestyle and your entire scheduling process.”

“You cannot ever stop thinking about it even when you are not doing it. It consumes everything. It is hard thinking how you cannot go for a vacation or when is this going to happen and all that.”

“Coordinating everything was bad. It just takes such a toll on you. You already got a full time job, you are already trying to survive. How are you going to survive with this other job? It is a full time job and that is what people do not seem to get. Even the women going through it do not seem to give themselves credit. You are going through a second full time job because you are trying to watch yourself, your eggs, your everything, maintain your schedule, but also have that schedule course onto your work schedule and your regular life style. Hopefully you could still make it out for margarita once in a blue moon and blow out some steam. Just hang out with your friends. How do you do that without feeling you are not sacrificing your fertility rules?”

“Your whole life ends up changing to accommodate when you are trying to get pregnant. You are scheduling to either have sex when you are trying that naturally, or the doctors’

appointments, and when my husband can take off work, and if you have a daughter who is going to watch the baby while I am going to the acupuncturist or to the doctors' appointments."

"I use a fertility friend website to track my cycles, and I keep seeing that number grow of how many cycles I have done. It is over sixty and it is very frustrating. In some ways I feel that I am wasting so much time and efforts on becoming a parent, but I do not know how else to be. It is my drive, an instinct that kicks in. Then I think, "Gosh. Am I going to look back at these years and feel regretful because I was not living in the moment or is this robbing me?" In some ways it is, but I am being hopeful. I feel this is some kind of desert time for me, and I know that it will not last forever. It is what it is. I am just going to keep trying."

"It took a long time to realize that I ovulate later and the first four or five cycles I screwed it up because I thought I had ovulated and I started taking hormones and that probably prevented me from ovulating. So it was confusing and it is hard to figure out. I ended up doing the basic body temperature just to even figure out when I was ovulating and it was confusing."

"Everything became so technical, stressful and impersonal. That was the worst."

There is no such thing as perfect time

"There is no such thing as perfect time, and to some degree I wanted time to be perfect. When my ex and I first got together, he was like "Let us wait a little bit to get to know each other better," and so we did. Then, "oh let us get some degrees," and so we got some degrees. "Oh let us build a house." We built a house, and then alas let us get a divorce. Even with this cycle here, the same day I went in for my hysteroscopy, my father went for surgery too. I went through my process, he went through his. They found out he has cancer and it is terminal. Even at this time I am just thinking, this is not a good time, this is not a good time. There is never going to be a good time. At my age I do not have the opportunity to wait. I do not have the time to say, "Ok let's get a couple of more years." That is not going to happen. So for me it the component of time, the time is really difficult."

It keeps hope up

“Every time we get into one we are going to try and we are going to be hopefully successful. Even though we have not yet, every time we get to one, I feel pretty positive because it is kind of starting the game over a bit.”

“It increased awareness of my body and gave me some feelings of control. Feeling like I do not know how much time I have left and the grand scheme of things, kind of sucks. There is that feeling that every month that goes by and we are not at least trying is wasted.”

Waiting

A bit of a roller coaster

“So the two biggest memories about waiting are: when you are waiting to see how many embryos you got out of the process, that is always an exciting time while you are waiting, and when they come back with positive results, that is exciting. So waiting in that scenario is very exciting. Then when you take your pregnancy tests, there is again a bit of excitement because a lot of times going into it you have a feeling there is a good or bad chance. So usually the waiting process, it is a bit of a roller coaster, and sometimes it is probably more positive than negative.”

“The waiting to find out if you are pregnant and then the waiting to see if it is going to take. My miscarriages were anywhere from five weeks to eighteen weeks, so I would have to be six months pregnant for me to be comfortable with it.”

Two-week increments wait

“The two-week wait, horrible. My mom always says “just put it out of your mind” it is really hard when that person just had a baby or little six months old baby lives next door. The babies are surrounding me literally. The wait is hard because I find myself checking my chart all the time, it just takes over my brain. I do not like that and missing out on life. It is the worst”

“Waiting was the worst. I think about the two-week wait and finding out if you are pregnant, that is painful, you know I would rather be doing something than the waiting. For us waiting financially to have the money to be able to do it, are we ever going to have the money? How long is going to take us? How old are we going to be by the time we get to this point?”

“Oh God! That is the worst! Two weeks of every single month is waiting, it is not drinking, trying to optimize your rest, and you diet. I did unofficially more rest and good diet choices. It is

so horrible because it feels like half of the time and then when I would get my period I would be really disappointed. My first reaction would be “Ok, at least I can have a drink tonight! At least I do not have to worry about this for two more weeks.” That is really hard.”

“You never like to wait. It is just the aches and the anxiety, just wanting to know. Once you had that procedure done, waiting those two weeks to find out if you are pregnant, those two weeks are hell. Keeping your mind off of it is impossible when you have been trying for so long, it is impossible not to think about it every spare second.”

“Wait to find out if you are pregnant, two weeks to find out if there is a heartbeat, another two weeks to find out if there is no heartbeat. And so you have spent six weeks of essentially not knowing whether it has worked or not.”

“There is a lot of waiting every month. The two-week wait was always very hard. Then when you found it did not work you are going to have to try another month and again wait. That was very frustrating.”

Time between or after procedures

“Waiting really hits on everything we have been through. Waiting that first year, bang gone, I am a year older. Waiting every month to see if your period starts. Devastation hits, “Oh my gosh. It did not work, we have to wait another month to find out again.” Waiting through all the diagnostics; waiting for a chance to have the green light. Waiting through holidays for Peter Patter little feet. It is waiting every minute of every day, even when you are sleeping. Every minute while you are sleeping, your mind is thinking when is this going to end. At some point I was thinking, “I do not even care how it ends, it just has to end because I cannot sustain it any longer. It is just eating me up.” Everything we did was waiting. Everything we did for five years. You put your life on hold.”

“Every time I would do something, I would need a few months to recover and a lot of women will just go back to back, back to back. I could not do that. I had to emotionally recover correctly to do something, but then I was losing time. When you are ready, then you have to wait. Then you have the two-week wait. It is horrible.”

“I it is so stressful to sit there and think until this works. Between IUIs and find out if it worked or it did not work with the pregnancy tests, those days feel like a very long time and then obviously there was a huge gap between IUIs and IVFs. That was difficult.”

“Well for me years trying and waiting equal the same thing. Some people might have only tried one year or they got pregnant the first IVF, right? So yes.”

“Every time you have a procedure you are waiting. An IVF you are waiting for the outcome and that is so stressful. Then I had a hysteroscopy but I had to wait till I was able to try something else. I mean, there is just so much waiting involved. The clock was crazy because you cannot relax during the waiting.”

“The times you had a fail or when we got pregnant and we had a miscarriage and you had to wait three or four months. I forgot about this one part, a lot of times her lining was thin. They would be doing measurements and they would say, “Oh, it is eight. That is good.” and then all of a sudden it would drop to six for no reason or they are thinking maybe it is a reaction to all these estrogen treatments. I mean it is hard to tell. So there was the unknown thing there.”

“I hated that. I remember when I hit the two weeks wait or waiting for results or waiting for appointments. Oh, waiting is always hard. Expecting results and not just the color of the stick of course but there is so much expectation along the way, we engaged a lot and anticipation.”

“Everywhere you go you wait. Waiting for lab results, you are waiting for doctors, you are waiting for it to be popped, you are waiting for everything. There is so much waiting, you get the IUIs done and then you wait. Every time it is just waiting and waiting and then you are two days

late, the Femara drug makes your period late, you are really excited but you are just late and that is all, so it absolutely destroyed me every month.”

“It was that waiting period when you are going through the medications, then you have to wait until you find out if it worked or it did not work. Even before we were waiting, we were saving our money to have enough to start. It felt like you are always waiting; you are waiting to find out that something good is going to happen.”

“Waiting and waiting. Waiting to ovulate, waiting for ovarian, waiting to ovulate, waiting for ovarian.”

I feel I am wasting my potential waiting

“I cannot handle it. I feel I am getting older and I guess this is in biological clock too. I have never really been that interested in my career. I like teaching but it is just a way of for me to pass the time. I really want to be a parent and I have always wanted to be a parent. I was home schooled. She was a professional mom and a teacher. She was busy all the time because she had all of us all the time twenty-four hours a day. I have always wanted that kind of life because my mom did it really well and she gave us a great childhood. And I feel like I could do a good job too. I just enjoy children. That is what I have always always always always wanted to do. So this just feels like so much wasted time. I feel I am wasting my potential and I do not like working for money. The waiting is not going well with me.”

“How many days I have to wait before I can take a test? How many days we have to wait before we can try our next procedure? How many days I have to wait for my husband to get over his surgery? How many days I have to wait before I can have enough money to do it again? You feel you have been going through this for a long time, you are not getting any younger.”

“You are in limbo, you cannot do anything. I like to be able to do something and waiting is the ultimate not doing anything. So it is very hard. Waiting at the doctor’s office for hours until I get to go see him. But here we are seven years later. So yes, I would say probably not good.”

Biological Clock

Not as big of an issue

“Because I did start when I was thirty-three, and I have a friend who had her first baby at thirty-nine, I was ok. Other people in the support groups were similar; similar age. And I never had really bought into this biological clock.”

“For me it was not as big of an issue. I feel very blessed that we met very young; that we found out when we were really young and we could have even if we got married young like waited a really long time until we wanted to try. Thank God we decided to try early on.”

“I was not concerned about that. I am thirty and I still have a couple of years to decide, I do not have to decide right now. If in five years I decide that I just have to have a kid it is not too late we can move right then and we can do it, so I feel like I have a little bit of time to figure it out.”

“I do not feel like the clock ticks because we have these four frozen embryos. We are definitely on a schedule and do not want to be these aged parents. But also, we have four, so let us say it works this round and we have a kid a year from now, then we will wait another year and a half or so and then try again. So we are definitely on a schedule, but I do not feel any biological clock pressure. I want to do all four, but two at a time. I am perfectly fine with doing two sets of two. My wife wanted to do just one each time, but because of all the struggles that she is going through personally as part of this, she is considering putting in two the first time. She only wants to have two children, but I think because we have four embryos that we should do all four. So, I do not know. We will see.”

“It was not that big of a play. I will tell you what, because I understand why doctors and society and statistics categorize and label, it is structured. Makes sense. A lot of people fall into that. They do and that is why they do it. A lot of people do not, and just because I am thirty-seven and my biological clock is ticking and my eggs are getting older, I do not think it is always fair to

throw people into a category if you do not know their entire makeup. I am thirty-seven years old, but my internal health is going to be very different from a woman who is thirty-seven years old on crack. If both of us cannot get pregnant because we have been labeled with PCOS, I am in the same category with this same woman, but I could be at my optimal health. So the biological clock, yes it is labeled, clock is ticking and you got to keep moving, but I am in a different place. We may have similarities but I am still in a different place. I think it is all apparent too sometimes.”

The light at the end of the tunnel is the train coming and coming actually from the other direction

“It is a very negative process and that is because at later stages in your life that becomes, you know the train, the light at the end of the tunnel is the train coming and coming actually from the other direction. So a biological clock is an obvious negative implication that something is not going to happen and the closer you get to that, the end of that biological clock, it becomes negative.”

“I was almost twenty nine when we got married, and we did not want to have kids right away because we wanted to enjoy each other and focus on our relationship, and I think that was wise. So we started trying when I was thirty-two and I never thought it would have been as much of a struggle as it was. So definitely that was a big thing because I knew the older I got, the lower the chances were and higher the chances the complications in pregnancy and that was a tough part of it and even thinking, “What if we want two? We are going basically back-to-back because I do not want to be forty when I have a baby.”

“I know we are young and that there are people who have kids in their forties. My mom had me when she was forty, and that was a time when moms were not forty. So I had this personal experience of not wanting to be that old when I have a child. So, we start it when I was twenty-eight and I wanted to have a baby when I was thirty and the longer it took the more frustrating it

got me. So yeah, it was not like biological clock in terms of my body but it was more I need to be young enough.”

“I feel I am getting older. I feel time is getting away from me and I can never get it back and it has never going to be ok. Things would be ok. Well one day I will have a crib in my house, and that will be ok. But this time, I can never get back my twenty seventh year when I was a parent because I am not.”

“I will be forty this year. So it is kind of getting to the point where it is time. You know what I mean. It is time already. Why do we have to have a biological clock?”

“I will be thirty-three next month and I know that is not terribly old but I definitely feel we are up against to a little bit of time clock. I do not feel I am super old, but I am not getting any younger by any means. But it is not my main stress, I am not always stressed about how old I am.”

“That was getting worse and worse. I got pregnant at forty-four and that is my age now. I was starting to think this is becoming impossible. Especially if the doctors tell you once you get to be above thirty-seven, your chances are just diminishing greatly with every year. I was really feeling this race against the clock and not only that, but also bitterness towards the first two doctors, I felt I wasted precious time.”

“That really messed with me because I am so young but I heard it ticking when I was a kid. I really wanted to have a baby when I was really young, and so the idea that I have a reduced number of eggs and I have less time to screw around, it was negative too.”

“Tick-Tock. I feel like mine is stuck on overdrive.”

It is already over

“It ticked and I feel like it is already over. It is the reason. It is done. My clock is done.”

“Especially when you find out you are premenopausal you feel that time is ticking even more. When you find out you have one good egg, there is not any good eggs left, you realize that your biological clock is done. So you have to open up your mind to different aspects.”

“When you want to do something you want to do it now. You make a decision to do something and then when it comes the time to do that you cannot!”

“When I was told at thirty-seven that I cannot have kids, I knew that thirty-five is when fertility starts to decrease but you hear people getting pregnant all the time, thirty-seven, and forty-two, I just could not believe that my biological clock was done. That is basically what it was.”

The magic number

“I just keep getting close to thirty-five and that is that magic number that everyone, the doctors, talk about. That is where all the research points to. That is the number that may mean start trying earlier and for my husband was a while to get onboard and see that. For the longest time he has always said, “ No. You will get pregnant. We will be pregnant.” Only within the last year he is finally coming around and see that maybe there is a problem.”

“Yeah, in the sense that we knew that if it did not work this time we only had so much time before it got harder and harder. Luckily we started when we were younger, but if it did not work this time then you have to save money again and then once you are thirty-five they say it gets so much harder and it just added to the pressure.”

“I know you turn thirty five and things change but I was half marathon runner, I am a vegetarian. I never thought my age should have been that big of a factor. I always felt I am pretty young and

healthy, but when they said “You are too old” it was like “oh shit.” You just ran out of time. The year we spent in the nearby city caused us our potential biological children. Thankfully, I have never been too hung up on genetics. For me genetics is not one of those things that is really important and I know for a lot of people it really is, I have all different things that we really want, and I really respect that about people. That would be a serious loss, a devastating grieving loss to have to say goodbye to your genetics. The two reasons that I am OK with it because I always figured out I would adopt at some point, from the time I was a little kid. I always thought I would be pregnant and have a biological child but I also thought I would adopt and I had my niece since she was a baby. I adored her and loved her and could not possibly imagine loving her any more. So it is not that big of a deal to me.”

“It is ticking. I will be thirty five this summer. It feels old. I do not feel that old, but it makes me feel old because now you are high risk pregnancy. Plenty of people have healthy pregnancies after thirty five, but it is still like, “Dear God. I am high risk pregnant,” I have a little bit of urgency and he is older. He is forty five and he is like, “I do not want to be an old dad I will be fifty when my kid...” There is some urgency. My mom was twenty when she had me and so she is only fifty four right now. You know she is very young and, you know I was not ready to have a kid at twenty, but I think, “Gosh, when my kids are my age if I had a kid right now, I would be like seventy.” That adds a little bit more stress and urgency to it”

Empowerment / Choices

Empowerment / Choices describes the degree of control or power over the situation one might have over the Fertility Treatment Experience. The components of Empowerment/Choices are described by the participants in the following order.

- ◆ Seeking Information
- ◆ Choosing Doctors
- ◆ Choosing Treatments
- ◆ Controlling Cost
- ◆ Controlling Diet
- ◆ Control Over Body
- ◆ Support / Sharing
- ◆ Choosing How Far to Go

Seeking Information

Support groups are good sources of information

“I was able to seek and find. I feel I found some good ones with those forums and finding that acupuncturist right away was really great.”

“Down here there was this support group, up in Minneapolis I do not know if we just never looked and I think that is something that probably could have helped us because as a patient you have a duty to yourself to seek what you need.”

I left that up to my wife

“The information is there, it is trying to decipher what is real and what is not, what is important and what is not, what is applicable to you and what is not. My personal experience is very limited because I did not and I do not understand the process and so I left that up to my wife.”

“I attested that was left pretty much in my wife’s hands to drive. I could have been there more, I could have served better”

Web gave me mixed answers and the doctors gave me quick information

“I feel I can get information on the internet easily, but I do not know how accurate it is and then the doctors just gave me a quick answer”

“There is not very many places to go to seek that information. There is the web that I feel is kind of mixed. It is mixed bad like you do not know what you are going to get and what you can trust. There are some books out there, but again whether you trust, you have to read the book to be able to know. So really you are down to doctors, and it is really how good is your doctor.”

“I feel I had lots of power especially with the close relationships I have with doctors on a daily basis. Yes I feel like there were a lot of different sources I could have gone to.”

“That [information] is from the doctor’s piecemealing to us.”

I do not always know what I am looking for or what to ask

“When I knew what I wanted to ask I usually was able to find the answer. I feel like I can ask, but I do not always know what I am looking for or what to ask. If I ask usually it gets answered and I would process things too. Some of it has to come from the web and then do not know what the reliability is and where those statistics come from, or if it is old information.”

Advocating for myself

“I always felt I had to be my own advocate and my own doctor. I did not necessarily like that I had to. I thought the doctor should be more willing to do that, but the reality is a reality.”

“I mean, I know that there is options or avenues that I can solicit or go. It is just a matter of trying to go source it out. I just have to take that extra step to seek it. If I really need to find information I can go and get it, it is not that hard especially with the internet. I feel I have a good amount. You can always do a google search or I can call my physician or whatever. So yes, I feel like I have power over that.”

“I do a good job of seeking information on my own, but I feel it is hard to get the information from doctors. I am getting better at advocating for myself. Recently I needed one antibiotic to take the night before a procedure and the pharmacy gave me a Z-pack of five and I had to take it back. That is hard for me to do because I tend to trust the professionals. They know what they are doing better than me. But I have had to manage my own care better and that is been hard for me. I feel I have been doing a better job.”

“You can get all the information on the website. I felt I had a lot of control because I went to a lot of support groups and I was very active in them and got a lot of information. And with my personality every time I meet someone new I am like, “oh ok PCOS, she needs to be on that. Or she had four miscarriages, oh they need to karyotype the husband’s sperm too, everyone thinks it is the woman with those repeated miscarriages but can be sperms.” So it is all those types of things. So start seeking information. I thought it is hard out there, but I did it myself.”

“I could look and find tons of information and information about doctors, like trying to decide which fertility specialist I was going to use. I have read a lot of reviews online and that sort of thing. I felt that was one of the few things you have control of. I feel like I have, I definitely seek information. I have never had any issues getting information. I have lots of power over seeking information. It is times and times of research, probably more than it was helping at that point. That is a kind of who I am, I have a psychology background and I want to know why and why and why. I can look at a lot of things.”

Really hard to find

“I have control and I could have probably sort more information. The information I look for about what was going on with my linings seemed very lacking. Also I was seeking information about miscarriages experiences. I do not want to say I am powerless, but what you are looking for is really hard to find.”

“I mean even just knowing there is a lot more out there now than has ever been, It is good but a lot of it is just medical, there is not a whole lot that speaks to the psychology of it all.”

“I cannot say I felt very in control of getting information. I wish there was more out there.”

Choosing Doctors

It is a hard process

“That was a little random. Like it is a little harder because in order to go to one doctor you had to have all your medical stuff transferred there and it is not that easy because it is expensive getting everything transferred over and following all the guidelines and stuff.”

“Very minimal. I do not think you fully understand which doctors are better than others. My wife did a bit of research so I think it is there, but I do not understand the process, I do not understand why one doctor is better than the other.”

“I felt it was kind of dark. At the fertility facility we have a choice of five. Even in Atlanta we have a choice of eight, but I do not know how I should pick one. You go online and try to read what people say, for every good experience there is a bad experience. Choosing was hard. I just need to pick one or pick who is available. Here, I did not like the one recommended to me, but once you are with the doctor it is hard to switch, breaking up with your doctor is kind of awkward. They might be totally fine with that, but you do not know. I have never switched doctor before, it feels rude. So I know it was a good thing that that doctor left.”

“I felt fortunate to be doing it in California where the doctors are well renowned, but it is still a hard thing. The only thing I wonder is that we never went to the one doctor who was with my group branch doctors who does immunology, that is probably the only question I had in my head is we never did all of that immunology. One of my friends is seeing him now and two of them went to Mexico for treatment. But if there is a line I am going to draw it there, I am not going to Mexico for treatment. That was my line. I did not know my line obviously and surrogacy ended up being ok, but Mexico treatment ended up not being ok. If that is something he would recommend, I do not know even if go to him. Sometimes in the back of my mind I wonder a lot about it, but I was not willing to do that.”

“The only thing is that, I know them all so well I could have risked hurting someone feelings by switching to another but overall I had that power.”

I had complete control to choose

“Looking back on it, I had complete control to choose the doctor. My insurance was not going to cover anything anyway. So you have the full range of doctors to choose from. Once we got pregnant and I was looking for new OB/GYN, I researched like crazy. I interviewed. I got my reproductive endocrinologist input on whom to go to, same thing as we are looking for pediatrician. I wish I had done that same thing for a reproductive endocrinologist but you are so panicky that you just kind of go to whoever is recommended. So, I did have lots of choice.”

“I can choose whomever I want. That is always something we are able to choose. Well, I did my own research on the website and then made my decisions. I do not have insurance and so I have been able to just choose whatever doctor I want to go to. I feel like I can go where I want to. I think we had total control over what doctor we wanted to go to. You can leave a doctor anytime. If we wanted to take our frozen embryos and leave we could.”

“We got some good recommendations from friends and there are rankings for doctors. The fertility doctor here had won several patients’ awards over the past three or four years so I guess patients love him. He actually has his brother specializes in male infertility and their dad is also in the business.”

“That was ultimately a mutual decision that we both embarked on and we went to interviews and talked about deeply and I am channeling a lot of these questions through the lens of my contentedness with my relationship with my wife. Do you get that? Yeah, but see that is in selfishly the way I experienced it. We went through the process of choosing doctors together and even if we made a bad choice we went through it together.”

“That was something that I had control over in the whole process. You could look up online to get recommendations or reviews and then have one-on-ones with doctors, although sometimes that was a bit misleading.”

It is a limited expensive pool

“In our area even though we are in an urban area, there is a limited number of doctors in this field. You can go out of state or out town, but that becomes really impossible. We would have to quit our jobs to do treatments out of town or out of state. The doctor that I had from a small practice I really liked his bedside manner but I was always wondering if he is the best doctor. Then the place in town that is really big that has all the doctors, was unappealing to me. I know people who had success there, but there was something about it very unappealing to me. So I feel I had a limited number of doctors to even choose from.”

“I did not feel we had a lot of choices. I felt we rolled back to the local clinic after our negative experience, and then we went to the nearby city clinic and that was so terrible. We did not know, we had already been at the local clinic and were not going back there because they saw money and time from us. I just did not know where to go or what to do.”

“Well, you get a set list from your insurance provider and then there is a world of possibilities outside of that depending on how much you want to pay. Then narrowing it down from there to what can you find out. You do not have any personal experience, you can talk to other people and see who they like, but are they in your network? It is kind of a mess and there is no easy way to do it.”

“I felt we got lucky but I did not feel we had a lot of options. I mean there are options, but when you look at the money to go anywhere outside the city is too expensive, so other than here I did not have any options.”

“I did not feel there was a lot of information about doctors at the time. As a matter of fact here, your selections were pretty limited, but hopefully that is changing too.”

“I had known my doctor, a specialist in fertility, is one of the top ones here, there is only a hand full to pick from.”

“I do. Unless insurance wears it is ugly head, but overall yes.”

“I did not have an RE recommended by my OB/GYN, I went online and did searches and compared all the RE’s that are covered by my insurance and the reviews. I picked the doctor and then we met with her and we really liked her, so I felt I made a good choice.”

“There is not a lot of people in my town”

“We did not feel like we really chose our doctors. My wife may have chosen her first doctor and then we were basically assigned a new doctor when she left. We did not do a lot of choosing. Not that we could not, but we did not.”

“You are so worried about your insurance, and there is not really any good way to research doctors. You can find resources that list doctors, but whether or not they are in your network, you cannot just take a list, you have to take a list and compare it to your insurance, cross check it and then: - Will I be **to** obligate to this hospital? - You know that kind of thing.”

Choosing Treatments

I had to negotiate

“When we first sat down and one doctor said you should just go right into IVF that seemed so daunting because of the price that comes to it. It is like going to a car dealership and the guy saying you should just buy this Cadillac versus a regular Chevy because you will want it in the long run. Yes, we want it, but we want to do the other things first.”

“I feel like I would fight with him in a way. I would try to make suggestions and he would say “Well, remember. I am the expert here.” He is the doctor, he knows stuff. Then also he was giving me this medicine and I was like why you are giving it to me? Is this the right medicine for me? Is that what is dictating this course right now?”

“He just wants to give me medicine.”

“I felt I was little pushed when I started with the OB/GYN. They did not start well. First they were just going to make sure I was ovulating and I was scared that I was going to get pushed into bigger more expensive treatments and I wanted to try the less expensive simpler ones first. They did not let me do that. For my first IUI I was just supposed to be doing another Clomid cycle. They said, “if we would tried this higher dose of Clomid with you this will potentially thin your lining. So really you have a better shot if you just do an IUI.” So, I come in for the ultrasound just to check if I was ovulating and they convinced me to do an IUI. So I felt a little pushed. On the other hand, I felt good with the second doctor. I wanted to have the chance to try the other things first and she said ok. She was not going to push me into the laparoscopy but for my psychological benefit I wanted to know if there was anything that they could fix and check first, so she was fine with doing that first and then starting with Femara and then doing some IUIs. After I got frustrated with the IUIs I meeting with her to ask about next step. And then she suggested IVF. So I felt I had control.”

“That has been difficult because of my husband. We have not been on the same page as far as what we are willing to do until just the last month. He has just now opened to IVF, but before that for years and years he was against. For him it was unethical, and of course financially too.”

You have little choice because of the limited options

“I have veto power over any treatments that are presented to me, but I do not feel I can choose any. I have to take what the doctor recommends that makes sense. They do know better than I do. So I do not want to tell them, “I want to do a six cycle of Clomid,” when they have told me that there is no reason for me to do another cycle of Clomid. I am sure they might listen to me if I said that. But I can say “No, I do not want to go that way” and they would have to respect my choice. But I do not get to choose when it does happen.”

“I think each doctor has their own protocols; there is no option. Like would you like this one? Where it works better with women over thirty five or can we just give you the basic one that is not going to work? You do not get a choice. No. I could have always said no but I was not really given choices. I have never felt like I had a choice. Definitely out of my control. It was either you do this or you are not going to have children.”

“I think finance has controlled us and you just have to be careful with it. The reason we tried the medication is that even he will not have enough to conceive, the medication might give him enough to do the cheaper course that costs five hundred dollars, the IUI. So we are trying to get the numbers up enough to do that.”

“There is limited number of treatments to try. Like whatever your situation, it was not like you would say “Ok, we can treat this with this.” It was not very many things, very many options.”

“There are only so many things you can do. You go through the IUI and if that does not work you go through IVF and if that does not work you go through egg donor, if that does not work you go through adoption.”

“Had I wanted to maybe try different protocol, I think my doctor would have listened to my reasoning. I think he would have been supportive. But then again, when I was doing the IUI I did not have full control because you need to go through certain steps first.”

“That is tricky because it is not like they said, “Do A or B today.” They put you on a timeline. We are going to stretch you here, if you do not get pregnant we are going to put you here. I asked to draw a graph. I asked for it and I said, “if this does not work, what is your next step? Then what is your next step after that? What is your recommendation after that?” the doctor sat down, took a piece of paper and drew a line and she gave it to me. She built it up for me. So I kind of had a generic knowledge of what was going to happen in a way, but I did not get to really make a lot of choices like do IUI, not the IVF.”

“You do not have so many choices, there is not just a whole lot of options. In my circumstance, I had to have a surgery once a year, it has been six surgeries since I got pregnant with my daughter, in five years. There was one year I had two surgeries. So choosing a treatment was never a positive thing for me because it would either mean a surgery or a costly procedure.”

“Well, in the end the only option we knew we had was IVF. But we had the options to do the PGD testing, we could have frozen all of them immediately and not gone forward with the transfer. Even in terms of setting up the timing for this one. Just knowing that I have some options, because up to the last day I was thinking we should not be doing this, you know your dad can be, with what was going out with your dad. My significant other says you never know how/what is going to go on. Either we move forward now or we move forward later, whatever you want to do is your choice but there is no better time than now. So we did it. Even up to that point I still had a choice and I called the doctor the day before telling him, “I do not know if I am going to make it. If we are going to do the cycle, I am thinking we need to cancel.” He is like, “I

am going to follow your lead, just called me before closing business and let me know which way you decide.” I called him back before four and told him, “OK, I will see you guys in the morning.” Just knowing that I had that choice was really helpful.”

“I feel the options being presented are not [enough]; there is a whole bunch of stuff that they are like, “Well, let us not even look at that” especially if it is not mainstream, western increasing intervention. They are not looking at nutrition as a whole picture. They are not looking at all these other factors. I feel there are choices available, but the resources for choosing things that are not mainstream are so limited.”

I had the power to make that choice

“I felt I had a lot of choices once I reminded them that I had a lot of choices. The IVFs is not all and I am glad even though they were very costly and emotionally taxing, I am glad that I tried all the things I did to figure it out”

“In Minneapolis we could choose. They asked us “What do you want to do?” we said, “ We want to try Clomid” and that did not work. “Ok Let us try IUI”. After the first time they would ask “Do you want to try it again? You have 1 to five chances” and “OK, let us give it a shot again. Then we got to a point where they were “OK you can keep doing IUI but it might be time to start thinking about IVF.” So again we had the ability to choose. In Texas, that was more “You could do IUI, but it is stupid” and once we realized the endometriosis was present, we decided to screw all the other choices and just do IVF, but again we had the power to make that choice.”

“My doctor told me that he would do whatever I wanted to do, whatever I wanted to pay for. He strongly recommended this, but he never said I am going to do that even though my chances were slim. Like for IUI he said, “You have a really small chance but if you want to do it, I will do it” and I did.”

“We tried clomid then it is, “Ok you said we try two or three months, so it has been two or three, now what?” “We can do IUI.” “Ok. Let us do that.” “We can do IVF or we can do IUI again.” “Well, let us do this.” So I feel they have given us choices.”

“Sometimes I felt like I had too much power over that, I wanted her to tell me just what to do and instead of having been given the power to decide when and what treatments I wanted to do. She basically said, “Let me know when you want to go to the next step.”

“They give you the options and it is totally your choice. We were in control. You can always choose to say no. The treatment plan I guess it is sometimes out of your control though.”

“We knew it was IUI or IVF. You know certain numbers of IUI then IVF. So we decided that.”

“I do. It was our choice to do egg donor, no one talked us into it or anything.”

Controlling Cost

You are the recipients in the market and the market sets the price

“Everything is so bloody expensive. “It will be worth it when you get your baby.” I was like, “Yes you are not guaranteeing me a baby, you are giving me a shot and I am not a good one at that. Thanks.” We have no control over that.”

“We did not have any control over that, beyond choosing the treatment, we did not have any control over cost. I suppose I had the choice to go through this treatment or not. The cost kind of gets out of hand. If you want to keep treating it, you have to go with the cost but it is out of control. It is whatever it costs, right? You can shop around for sure but you are going to pay the money in one way or another and especially in my situation where I constantly need more drugs. Right now I need more estrogen because I am having to delay my transfer. I am having to do a frozen cycle, which is fine because they said that it is more likely to get a pregnancy in the frozen cycle but you are deep into it, you are not going to quit now. So I am going to pick my progesterone and pay another \$250. Just last week I was supposed to do my transfer on Monday, but my uterus is not cooperating so we have to do another ultrasound this coming Tuesday. Everything costs money. I have to do an extra ultrasound every single time and every ultrasound that is \$200, \$200, \$200. They asked me for eight hundred more dollars for the transfer. I thought I already paid for, but if you do not do your stimulation, your retrieval and your transfer in the same month, they reallocate that money apparently to something else but they cannot tell me what they reallocated it to. So I did not pay them the other day. I said, “Well you will have to tell me where that money went. I have four embryos and that cost more money. So anyway, You have no control over the cost, it is just what it is.”

“Well, I guess we have the control of whether we are going to do such a thing, but how much is going to cost or how it will affect us, No. You definitely have control, of choosing treatments, because cost is a factor. You cannot control the fact that it cost so much.”

“I did not feel in control of that. None whatsoever. I mean you cannot control that. That is what it is going to cost and if you have to do a more expensive process you have to do a more expensive process. Very little control of some minor things like the test of your genetics and ultimately the benefits was less than the cost and so minor amount of control but almost no control of the cost.”

“I did control that and that was an area of contention between the two of us. I felt empowered during the process. I would say controlling the time is controlling the cost. There is cost in not doing it again and there cost in doing it again. Controlling the cost of a treatment? No you do not control it. You are the recipients in the market and the market sets the price, you do not have any control over it.”

“I could control it if I wanted to say no more, but short of that, the cost was what was going to be. I could not really affect it. There was no control, it gets out of your hands when you do not have insurance. You can search all day long, but you start splitting hair at some point because you want to go with the doctor that you are comfortable with.”

“There is no a lot of control there. It is just what it is. However, I saw there was a new lab procedure that they are trying right now, I want to say maybe in Columbia. I cannot remember exactly where. They say the new technique is going to bring down the cost to about \$250, but between FDA and REs and pharmacology, seem will never reach here, but it is threatening bringing down the cost considerably, and they say it is a lot more effective.”

“The doctor would be willing to do IVF if I wanted to with my own eggs and if my insurance covered it we would have done it. They would have paid for five rounds, but because my levels were low or wrong they could not do any of it but I know that if our insurance covered it we would have tried it. For us to pay twenty thousand dollars just for IVF and we have less of 1% of it taking, if it was 40% or 30% we would have done it but for less than 1% it is hard.”

Controlling Diet

I did, I controlled it

“I controlled it. I actually liked the change in my diet as part of the treatment, because you just do not put a pill in my mouth, but actually changing what you eat. I like that kind of thing. It helped a lot. Changed my diet and detoxed and I had allergies identified to make sure that was not contributing.”

“I did not have any diet issues or concerns. My acupuncturist would recommend certain food that would make you more fertile. Also finding out if it is true that if I actually changed my diet was going to do things. I gained some control by trying to empower yourself and change it up. I think that is one of the reasons why I did so much with my diet, as I felt if I was changing one little thing each month that it did not make the same as the month before and that helped me mentally because I changed something.”

“I have learned a lot about nutrition because of the eating disorder, I lived in a way where fat was the enemy. It is amazing that now I am able to eat cookies because for so long I would not. Then my husband starts to go for crossfed diet where people do Paleo, which is lots of meat. I started learning about my diet and how important fat is to our health and even for fertility. During the week, we try to eat whole foods, lots of fish and meat. I am not afraid of fat anymore. I have seen that it is a good thing. Fat is good for our hair, it is good for our skin, it is good for our ovaries. That has been a blessing because for so long I was so afraid. Now for this IVF cycle I am trying to gain weight because my BMI is 19, I have read online it is better to be around 20, 19 is on the low end of normal. It is normal, but I rather be where my best chances are. Fats also produce estrogen. If you do not have a whole lot of fat you are not going to have as much hormones.”

It is hard for me

“It is really hard to eat vegetables all the time. It has been the hardest area for me. I did try but it was negative with the caffeine and the chocolate and I felt depressed. I could not control it and it makes me feel bad. There is just not a lot of healthy non-processed food available. If you want to have any dairy it is going to be pretty hormonally charged, than a lot of soy and corn and soy especially is going to mess with your hormones; you have got BPA and everything. I feel like I do not have a lot of control over what I eat. I can try but...”

Not advised

“That did not seem like a thing. Nobody ever talked to me about a diet making it different this way. No I do not like giving things up, but if it means I am having a baby then I am ok. But, I do have control over that. That is something I have control over.”

“Of all the things that stressed me out, I did not have anything where I needed to do anything. So I would not drink coffee sometime. That was about it. Definitely my coffee and I am a wine drinker but I definitely can do that when you put your mind to it.”

“I did change a little bit. I did not think that that was going to do much, so I did not. But I feel like I could have had control over it or over changing it if I had wanted to. But I just was not going to do it. That was not a big factor.”

“I choose. I eat like crap some days. Life is short. We are going have to get things.”

Control Over Body

Out of control

“Every decision I made for two years was about trying to have a baby and still no control. I had no control over it whatsoever. It does not matter what I ate or did not eat or how I worked or anything. I did not buy a single clothing for two years that did not have belly growing because I was sure it was going to happen anytime. It influenced every single decision I made.”

“That went out the window a long time ago. That is a huge frustrating thing because you do not have any control. Of course everyone wants to have some sense of control, but it is kind of that sense of failure, “What I am I doing wrong or is it me?” My mind is working hard, but the rest of me is not.”

“I felt kind of out of control. I feel like, “Oh, I am exercising too hard? Should I not exercise during the luteal phase? Should I not exercise during menstruation? So I am only exercising for two weeks out of it, so just rigid.”

“None. I had a low sperm count and the only control I had was to listen to the doctor and to go through surgery. That did not work and so ultimately I did not know and still do not know why or how to fix it. So, out of control.”

“I just want to rip my thyroid off and smash it with a hammer. No matter what I do, I cannot control my hormones. I can control my diet, I can exercise, but I cannot fix this problem. So that is frustrating, out of control.”

“The outside definitely, but the inside not. I was not controlling what was going on inside, I could not control that my eggs were aged and I could not control that my partner’s seed would not work. So, I had control over the outside, what I ate and everything but I could not have

control of what was going on inside. You cannot make more eggs and get pregnant, you cannot. Yes you have no control over anything. I cannot control my body to produce good eggs. I have no control, it does what it wants.”

“Just cause it is biology and science, you do not really have control. Like for us when we had twenty-two eggs and eight embryos, but I am still not in control over that, for my body is going to do it on its own. I could not control how my body was reacting to all the treatments. I was doing everything they would tell me to do, but still it was not working.”

“I presented you with sperm and you did not do anything. I did it at the right time and there are still some other magical combinations of you know. It is like, “I cannot make you accept it. I would if I could.” You basically become an experiment. We do not have too much control, I guess we kind of affect it with rest and less stress and diet. Overall there is not much control.”

“I feel this is a problem that originates with me. My body was doing everything physiologically it is supposed to do. It is apparently producing the right numbers of everything. It just does not work with other people’s eggs. And so I cannot control that.”

“You are not really in control. None. Sometimes I will get short periods and that is frustrating. Gosh I feel like I have no control.”

“I just do not have any control over those antisperm-antibodies and where they came from and why that.”

“Controlling your body that is the problem, especially at the all-time low with that uterine lining there was nothing I can do about this. That was hurtful.”

A way to empower myself

“During this whole time I have been exercising a lot. That is my way to control what is happening with my body. I cannot have any kid, but I can run five miles even though I am overweight. Like get out of my way. So that is been really empowering. I do not know how my mom did this, but she gave me a really good body image. I have always loved my body. I have never had any of the self-hatred a lot of women struggle with. I have always been grateful for that. Going through this has been the one challenge to my body image because I look at my belly and I say, “You are the most useless thing ever, why cannot you do what you are supposed to do?” Other than that I feel that the rest of my body works really well.”

“You do not know how your body is going to react to the drugs, or how quickly you are going to bounce back from the surgeries, how you are going to take the next appointments. You can control by trying to empower yourself and change it up. I think that is one of the reasons why I did so much with my diet, as I felt if I was changing one little thing each month that it did not make the same as the month before and that helped me mentally because I changed something. Constantly changing strategy as simple as it may be just to feel you had some sort of control over it, to trick yourself into thinking that.”

“That has been frustrating. Because I do everything to gain control over it and it does not work properly. I keep doing things that I would think would help.”

“I was completely empowered and made the decisions about the when, the where.”

Support / Sharing

I did not share

“I did not feel too forthcoming. It seemed that in my immediate circle I was the only person who was dealing with it. And the more I shared, the more I show I am upset to my husband, he would push away. He would not want to do things that made him uncomfortable or made me uncomfortable and all that. So it was not like the most empowering time there.”

“For support and sharing I would say it was limited. Not a whole lot of support or sharing with family and friends and some of that was my fault because I did not share and so my friends and family were less able to give me the support that was needed.”

“That was a struggle for me because I do work very closely with my co-workers, and we are all friends too, and there were two of my co-workers with my same shift that were also trying to have a baby at the same time. So we did share but when they got pregnant very quickly and I did not, I did not want to share as much after all, it just became awkward so I did not control that well.”

“I did not mind it the first couple of years but now it is the last thing I want to talk about to people. I do not mind it if it is somebody who had gone through it and I do not mind If someone truly wants to know and ask questions about it, but in my personal experience I do not share that information freely. It is personal. To me it is like asking somebody how much money they have in the bank. It is very private. Then you feel you are almost judged especially when it comes to donation or surrogacy. It is still in the back of my head. I am lying in bed thinking about it at night what my best friend is going to say, she has been really supportive, but still you cannot help thinking what your friends are going to say when you are not there. What if they judge you. They all have children and they never had an issue with this. Who are you to judge when you were never in that situation? Even if!”

“It is very isolating. We shared with my parents; because we have been together for six years before we started trying and they were always, “When are you going to have kids?” When we started trying we told them and they were so excited, then nothing was happening. So, they were there the whole time; my mom got pregnant on her honeymoon and then they had kids back to back so they did not understand and so in some ways that made it harder.”

“That is our choice and we have chosen not to, but I also feel our options have been limited because we do not have a lot of friends who have experienced it”

Professional support

“I just started getting more support. I found a therapist. When I had the loss, I got a box in the hospital, inside of it was a list of resources of therapists who are dealing with loss and stuff like that. So I started seeing a therapist off that list and I think it is helping with grief.”

“I do have resources available. I have my insurance deed and it did cover some counseling so I used that and that was ok, so I had some things to do.”

“I had trouble sharing with people, but to the extent I did share, I would get support but it took me a long time to reach out. It took me a long time to see a therapist and to get the support I needed. After I have gone to see her, people tell me I looked lighter or so”

Support group

“Once I found the support group I felt I had taken control over that, it was a really positive experience for me because of getting to know all these ladies. My husband was pretty supportive, but I did not have any other support systems until I found the resolve group.”

“There was my massage therapist, she dealt with infertility herself so I told her. Definitely once I found the support group, it was wonderful. I had some support in the smaller groups beforehand, but I felt I was missing something, I needed to talk with other ladies who were going through the same thing.”

“My husband was very supportive. I wish I had found Resolve earlier. I found it pretty late in my fertility process when I was at the point to try the donor. It would have been much more beneficial to have found them earlier, but I had a great support group and sharing with my husband so I was blessed in that aspect.”

“Going to the support group has been helpful. For a while I stopped going because we were doing adoption and we had put aside the fertility treatment and I felt that it was not helpful because the people were still doing fertility treatment and so it made me feel worse as I would just want to be doing fertility treatment. I just started going back last week now that we are open to IVF for the first time.”

Partner or Friends with same issue

“We have friends that are going through it. Also some of our friends did two rounds of IVF. They have been able to give us support and say “Hey look. Even if the first transfer does not work, look what can happen.” We scheduled our transfer on a Tuesday and then her mom will be here. So if it does not work it will be certainly a negative experience, but at the least we will have some family and friends to talk to.”

“Yes, my husband and I, we talk a lot about it. There are times we are trying to solicit advice from other couples in social settings when we were at the friends’ house. Most of our immediate friends has had children, we are the only ones held up. So in that sense they all knew that we were still going to try.”

“I did not feel there was a group for me to go out. I had no problem talking with my wife about things. We have a couple of friends, we just found out they got pregnant and they were going through the same thing and we did not know they were going through all these infertility issues until they were telling us and they feel we could talk about... So that to me that was good, that felt good.”

I choose how much to share

“There were few people who knew what was going on with us. I did have some people and it was important to me to have few people. I know some people who never told anybody and I think, “oh my gosh. How did you get through that without social support?”

“I choose how much to share and how much to disclose to people and you seek their support.”

“Even today we have made some decisions about who we are going to share it, both with this process and who will know about it. I felt complete confidence in everybody that I have share it with including the medical staff knowing that it is not going to get out. With my significant other, he and I have decided to not share with the family until we know it is going to make or not. He is like, “When are you going to tell people?” “Well, when they start calling me fat.” Not the first time, but after when they starting sitting me down and having conversation, “you know, you have gained a lot of weight the last month. It is a couple of months and we are concerned about you.” Right about that time. So I have been able to share it at my own. I feel really empowered in that area.”

Nobody likes to hear about it

“People do not like to hear that it is hard to get pregnant and that even trying makes you crazy; even people that have been through I feel it is hard for them to hear it because they get it. There are very few people that I encountered, other than the ones in support groups, that have been through it and they got pregnant at the end.”

“I could not find a support group, and when I did share with my friend they turned out to be not be as good as a friend as I had thought.”

“There are resources available in my private life and in the resolve group, but still nobody really likes to hear about it or they like to slap a Band-Aid on it if you bring it up if you are not in the designated groups where we are talking about infertility. In your day-to-day life nobody wants to hear about it unless they are going through too. That is frustrating. It feels I cannot be open with everybody. My husband immediate family knows because he has a brother and wanted to make sure he is tested and his parents have been really great. But his aunts, uncles and grandparents, we are not telling them and that is one of the reasons we also wanted to find a donor who looks like my husband. I come from a mixed race family and it does not bother me, but they all look alike, if you were handing out sunscreen you need to hand it to them first. I feel if they knew, and my husband feels this way too, they would treat whatever child we had as an “other” and not like one of them. So here is this big thing about our lives, they all knew that we wanted kids and here we are almost two years later and no baby. They want to ask and it is like, “Please do not ask because I cannot give you an answer that will be any good for you.” So there is a rift there.”

Choosing How Far to Go

Compromise and negotiations

“Sometimes we would do my choice then we would do his choice. And then it is like that is not our choice. Is that our choice? So that is not a very good compromise. That is kind of how we operated.”

“Overall I feel like I was able to make the decisions. It is difficult to speak because you do this whole thing as “us” thing.”

“My husband and I did not agree, so I had to take his consideration and he has taken my consideration and we tried to find common ground. I am sure you have talked to many women and they just call the shots and my marriage is not like that. We are together and we need to talk about this together, but I would get upset and he would not just let me do it. I am emotional, he is more analytical, so he could look from outside, take the emotions out of it while I could not.”

Going as far as we need to

“I feel like I can choose to go as far as I want to go and can choose to not.

“I am very ambitious, I like to get what I want, and I put my body through that kind of hell to get it and I did get it but learning when to say when is a negative experience.”

“I did not have much control over that. I knew at the end of the day we were going to go as far as we needed to go because maybe it was more important to my wife than it was to me. It was important to me, but it was more important to her. And so I felt we were going to keep going. She did not envision having her marriage without kids.”

“That was hard. I was able to keep going until we were finally successful, but that is because my parents helped us. It is hard deciding as you go. But once I decided. When you are in it, it is really hard to decide. And you do not feel like you know how far”

Tied to cost

“It is a tough one, we knew what we wanted as the end result. So we just kept going and so you get there. But, even though you know how far you are willing to go, there is other things that keep you from that. You know finances probably being the biggest one.”

“I feel we have the power to choose but our choices are limited by finances. We can adopt five kids tomorrow, we just do not have the money to do that and so I think that limits our choices. If money were not an issue, the choices would be a lot different.”

“I felt we had a lot of control and we may not have liked the decisions we had to make. Maybe we did not have as much of control as we may have wanted to do more, but financially we would have had to make a different decision.”

“It is controlled by finances. If finances were not an option we would have done IVF ten times over.”

A gamble habit

“You know where people talk about gay and whether they still have a choice of being gay? I do not want to say it is as dramatic as that. I had a choice, but if I do not keep going, what I am I going to do? What if we have done this? what if we did not give up at this point and tried one more thing? I could always say we have to stop that is enough. But there is a part of me that feels we could not stop until we had success. Especially the further you get to it, maybe this is like a

bad gamble habit or something where we have already sunk this much into and we are going to be empty handed if we stop now.”

“I never felt in control like this was something that we wanted, this is what we had to do. We decided to have maximum three times. After going through the treatments and seeing what other women had gone through, they lost their houses, I felt I could not take that emotional toll for that many years. At some point you just have got to stop and find another way to deal with it.”

I can always say no

“I can always say no. I do not feel like I am being forced or something. I feel we have options even if they are not as available.”

“It took my husband and I about fifteen minutes in the car crying at my job to decide that we were stopping the medical merry go round and going for adoption. We just said, “We do not have to do this anymore.” Then we went through adoption. Then we found out about Czech Republic option and there was plenty of time in there for us to decide to go back and do things differently to have my husband’s varicocele repaired, to try in Czech Republic with my own eggs, to try with my husband’s sperms. We decided that genetics was of so little importance to us, that we just wanted to go as far as we could go, as extreme as we could go to make this happen as quickly and as successfully as possible. So we just thought ok, we are not going to keep trying all these different things. We are just going to fast forward, go to the ultimate. We feel what we did was the ultimate without a surrogate. If you did what we did and you add in a surrogate that would be about as ultimate as you can get and then of course now we have chosen not to use surrogate next time, next try. So I felt like we had a lot of power over that.”

“I think I had plenty of control over that, but it is overly related to the outcome. Luckily we were able to afford it so I think I had lots of control over that. I feel we had the means to do more. Some people would have to stop at IUI because of cost. Some people would stop at IVF because

of cost. As you get further in the game it gets more and more expensive or more and more timely. So I feel we had the means to maybe go further than the average person.”

“I mean we definitely have control. No one is pushing us or anything. I am glad that I made the choices I made and I am happy with what I am now with me.”

“I suppose I had the choices. It was our decision each time. I did not feel pushed into things. But then psychologically I kept hoping I would not have to go through those next steps. I felt that I had a choice to stop or not, but Psychologically I could not let myself stop.”

“We did decide, we stuck to it. It allowed us begin to heal and move on. All this was discussed and then modified along the way but it was all mutually done and really positive.”

“I feel I have the power for it, but whatever decision you make it is a hard decision. It does not feel positive entirely. I feel it has been up to us.”

Relationships

Relationships describes the various relationships that make up the Fertility Treatment Experience.

- ◆ Spouse / Partner
- ◆ Family
- ◆ Friends
- ◆ Co-workers
- ◆ Support Groups
- ◆ Medical Staff

Spouse / Partner

On the same page

“We feel the same about kids, about adoption, we feel the same way about fertility treatment but I do not feel he tells me very much about what is going on inside his head. I know it is hard for him but he does not want to talk about it. I do not think he would ever talk to anybody about it.”

“I think during that time was very good. We were onboard, we felt we wanted the same things and we were on the same page about how far we would go and why we were doing it.”

“I think during that time was very good. We were onboard, we felt we wanted the same things and we were on the same page about how far we would go and why we were doing it.”

“My understanding and my knowledge of the process was zero and luckily her understanding was much more than mine, and I was able to rely on her a lot in the process.”

“She was my other one; the only one I could really talk to about this stuff. I feel we were both going through it together and yes it is stressful at times and you get a little edgy and there are times where you basically get angry, but you are going through it with her.”

What does not kill you makes you stronger

“I think we are stronger because of what we have gone through. Forces you to communicate and learn how each other cope. I am glad that we know how each other react in really stressful situations. At the same time it tests you. You have got to have a really good relationship going into it because it is going to test everything and on top of it the woman is super hormonal. She is not thinking clearly at all and you have much stronger reactions to everything. I cannot even imagine. I am sure that is really difficult as a spouse. But he never missed a blood draw, never missed an ultrasound appointment. It felt like a mutual goal that we were working towards. I never felt he was on a different page than I was. He might have been more tentative with the finances, more like maybe we can wait. I only felt in control if we were moving forward with the treatments. I did not want to take a break. So I would say that was the only real big difference. But we both knew even though we are going about it in different ways, the end goal was still the same for us and he was massively supportive.”

“Oh my goodness! It is nuts absolutely nuts. When you are married it is like, “I am not going to leave you. We are still going to have to love each other except now she is pumped up with hormones and I am trying to deal with the obstacles and all the other stuff, but also I sit here and I think what does not kill you makes you stronger. We have gone through some crazy things that most people our age have not gone through and here we are, so I think that has made our relationship stronger. I think that has brought out a few glaring parts of my personality that I will probably have to work on until the day I die. One being I think about work constantly. I realized when my parents were in town last week that I inherited my mom’s lack of empathy, at times going very objectives about things in a situation that brought so much emotion as this, I was not going to show it to my partner and I probably was not as good at understanding her feelings. It is

hard. It was awful but it was good. I think the whole experience made us really figure out what we needed for each other.”

“I feel we are able to talk more. We shared a lot of experiences, a lot of hardship, crying a lot, like he seen me in my worse. I think we have grown stronger through it. I think going through the hard stuff is the test of your relationship, it strengthen it”

“I do not know if we are growing closer but we are definitely strengthening our bond as far as dealing with the rollercoaster that this is. I think overall our outcome will be positive as a couple even if we are not able to actually have a child. I think we will be stronger forward.”

“Going through this process was a bonding experience. I feel like it brought us closer that way. But then again, at times I felt he did not understand; he was not going through as much as I.”

“I think we have grown closer because of it but at the same time it has put a lot of stress on us. My husband has been frustrated with me because it is becoming an obsessive thing. He does not want that for me. He wants me to be happy, he wants me to enjoy life and not let this thing rob me of joy or peace. But it is such an integral part of who we are as women to want to be a mother. He knows that too. Even just being around his family, his mom is the picture of a mom, her whole life caring for her family. Her husband has always been the breadwinner and she has always stayed at home. Even being with her because she is such a “mom” even though her kids are now grown, it just makes me realize what I will be missing if I do not.”

“We are very very fortunate. We rarely went through the same feelings at the same time. We got into a really nice group where we knew how to support each other. I knew how to support him wherever he was even if it was different from where I was and he would learn the same. Once I was able to lean on the support group and not only on him, it took a little bit of the burden off him. I feel like as cliché as it is, all this has made us stronger. I feel if we survived this, we can survive anything. He has been an incredible husband. I feel very very very fortunate.”

“He was unique; very supportive during all of it. He wanted to do IVF a little bit earlier than I did. I was not 100% sure I wanted to do IVF. The only thing that was negative was early on I knew I was open to adoption while he said he would never adopt. And now seven years later a lot changes, right? Even without that it is a negative experience just because it was hard. It was really difficult. Even though our marriage is stronger it was still really the worst thing we have had to go through.”

The biggest threat to our relationship

“She is a nice spouse, but it was very hard to watch the emotional toll it took on her. She got very depressed by the whole thing. Our relationship is really strong, but I think that the biggest threat to our relationship has been this process.”

“It has been a huge strain on our marriage. I did not know that I could feel this way about him. So it has been a giant strain. I feel it is pretty localized to infertility, so when we are not dealing with infertility anymore, we will not have a problem. It is sort of when we were doing wedding planning. We were fighting and it was really difficult, but once the wedding planning was over we never fought about wedding planning anymore because it was gone. We do not fight about anything, hardly ever. I feel he does not understand what I am going through. I feel he does not want it as much as I do. He forgets about how much I am struggling unless I bring it up, I wish he would remember it more and think about it more. On the other hand, we are still married and we have never been close to getting divorced even though the thought has crossed my mind in moments of craziness. “I am just going to get divorced from you and instead I marry someone else. That does not make any sense because then you would be even further away from having a child because you have to find a new partner first.” So we have not gotten divorced and if this does not cause us to get divorced then I do not think anything would because this is ridiculously hard. It has just been awful. One really good thing is that we have a really good sex life and infertility messes up your sex life too. Some of these medications that I am on, like the birth control pills for this month to try prevent the cyst from growing, has been killing my sex drive.

So all these medications plus all the pressure for him to have sex right now, it is destroying the one good thing I have left in my life. Whatever, it is ok we still are going to have sex though.”

“My wife is a driven person and she wanted this baby, a little tunnel vision in that regard, but I support her. You want to communicate well and that involves round general set of stuff to talk about and I think that we suffered a loss there because of the focus. In terms of my relationship, and I am just narrowing the spectrum to basically, “Did my relationship get better or worse with my wife during the process?” that is a kind of a hard one. I have a real hard time putting my finger on. In the middle; maybe both better and worse would be a more appropriate response.”

“We had good communication, we were able to talk to one another. He was able to lean on me and I was able to lean on him. He was very understanding especially with the pain, with the endometriosis, and the surgeries affecting our sex life and thankfully we are able to discuss that. Sexually I am still not the same and I do not know when I will be crossing that bridge after we get this baby out. There is still more to come, but being able to have that trusting communication. I think in some ways made us stronger, at times it pulled us apart but overall it was a blessing that we were able to communicate as well as we did.”

“We had got to the point where I would get angry, I do not know why but I just would, and had to talk to him about it. I feel he forgets sometimes. Two weeks ago I was starting the Lupron and I said, “I am probably not going to be myself for the next ten days, because this is basically putting me to menopause. I am going to be irritable and cranky and I am going to be hot and sweaty at night. Do not touch me in the bed.” Finally the other day when I started my estrogen patches the next day I was starting to feel myself again, and he said, “Yeah, I could tell you were having issues last week,” and I was, “I told you!” He understands that it is the medications, but sometimes he forgets too. I do not take it personal. You are having to pump all these weird hormones into your body. He is a man, they just forget sometimes. It is not all about you.”

“I think this is probably one of the bigger areas for those of us facing fertility treatment. When I was twenty-three I got married to my first husband. We went full well expecting to have a

family. We talked about it, how many kids, what they were going to be named, first boy, first girl and had those expectations. When we reached that point where they said you are not going to have children ever, and you are young, twenties, you do not even know what to expect. That had a major impact on the deterioration of our relationship. We had other issues, but at the heart of the issue was he really wanted kids. Of course now forty plus year old me can forgive 25 year old him, but at the time, it was really hurtful for me. I wanted kids too just as badly as he did. So he filed for divorce and he left. It is really really tough, it is tough on relationships. When I met my second husband, we had conversations upfront. On third date I am like, "Hey listen, just so you know before we get all tangled up in this, I am not going to be able to have children. If that is important to you, then let us become best friends, business partners, and keep moving." At the time he is like, "well, I think we need to explore options first and see if it is a possibility and kind of move forward." What I realized later on, because we kept putting it off, building houses and all the other stuff, is that he really did not want children. It just never dawned on me that that was what he was doing. He was just putting it off. We finally had conversations after our relationship deteriorated. His issue was that, it was not that he did not want children, he just could not get in his mind spending the amount of money it costs for us to get children when you can do it for free. People do that all the time. So it was hard for him. I was really blessed about a year ago. I met the love of my life, and same thing like on day three I said, "Just so you know, this is who I am and I am moving forward, with a partner or without a partner. I am going to move forward, and if I am able to get blessed that is great. If God does bless me with children then it is what it is." He is like "Let us go get our babies." I thought he does not know what he is talking about. He has no idea. If he had any idea of what this journey looked like he would say ok I am running. So I started sending him stuff, letters between my girls and I were having about fertility showing what we are going through. She is upset, she is depressed. I said this is all the journey. This is what I will be going through. She thought she was pregnant then a week later she is not. I send him a lot of stuff and he is still hanging in here. Even up to right now, he is the most supportive person, I could not imagine this person ever existed. It has been really really good."

"Now that we gotten passed it, the issues that came up in our relationship have gone away, but when we were going through it takes such an heavy toll on your relationship and as close as we

are and as much as we had already been gone through this is really hard, because we experienced it differently. It was hard for me to accept how he dealt with it and it was hard for him to accept how I dealt with it. I felt it did not affect him as much as I wanted it to affect him and for him it probably I seemed like a wreck. I was always crying, I was always a mess and he was not used to that side of me. So it did take a toll on our relationship, but it was not one that we were unable to get passed but I do not know if it had not worked out.”

“It was so hard on both of us emotionally. It was damaging. It is a strain on my spouse and our marriage. We started to see a marriage counselor to help us through this process. I found it through our insurance company list and ironically, he and his wife were going through fertility treatments at the same time. It was a godsend, we were having these issues and he could totally relay. I felt like he helped so well with our communication, him being a man the same age as my husband, he could just relay. He was wonderful. We probably saw our therapist for a year.”

“When we were first diagnosed we pulled together and we really leaned on each other. For him, and here is another difference between male factor and female factor, for him it did not change very much. He wanted kids. He could not have his own kids but he can still be a father, but how we get there is a little bit different. That picture changed a lot for me. All of a sudden, I have to introduce at least a part of some man into our lives and our bedroom forever. It is not going to be I love you so much we created life sort of event. That whole picture of how we get from no kids to kids changed enormously for me and I was not the broken one. I was not the infertile one. He did not really get why I was having such a hard time with it. I was trying to be understanding and trying to get him into counseling. He said, “I am not my penis, really I am ok. It sucks but you know.” I felt that that was a very well-adjusted reaction on his part. But it took a while for him to really understand that just because it was him and not me that had the infertility problem does not mean it did not change dramatically for me. I have enough problems with men as it is, being a sexual abuse survivor, that he was a very rare specimen that I was attracted to at all, the fact that I married the guy was a big deal. I think in some ways I actually identified as a lesbian for a long time. I kind of acclimated myself. I was very familiar with all the lesbian conception drama and I thought I had put that behind me when I married a man who wanted kids. Oh no, this is

your path in life. It does not matter who you marry, you cannot take the easy way. Dealing with these things put a rift and the fall out with his treatment and all of the things that came up from that put more of a rift. Now looking at “if we do not have kids are we going to stay together?” That put more of a rift in there. The whole thing has had a very negative impact on my marriage. I wonder if we had not been infertile, would we be ok? Would we be better? Or where are all these underlying things? I mean there is no way to know.”

Not as invested or impacted as me

“It was just very uncomfortable. I launched very quickly into charting and he wanted more of a period of freedom, like let us just try naturally, which I regret a little bit. So I just thought “We are going to try to get pregnant. Well these are the things we can do. I can know what my body needs to do, how my body operates” and that was not his approach. So when time passed and it had not worked, I was in more of a panic mode and he was still feeling the loss of we never had fun with this. So it was a while before, after we went through a little bit of panic mode, that he said can we please just try to relax about it. So then I was like “Oh, Ok. Now I need to stop and slow down and relax.” It was stressful.”

“He was pretty supportive but also he did not exactly understand what I was going through, and I was more emotionally affected by it than he was.”

“There were the problems initially of not really feeling he was invested and then being scared to talk to him about using a donor. I did not like the whole thing with getting the actual donor.”

“It has been very stressful but not on our relationship, which I am so grateful for because I know it can be very stressful to all relationships. It has been stressful because you get into these discussions about the fertility treatment and it is hard to talk to him sometimes because he is male and he has no idea how it is to go through all this, to get stuck five times in a one day and to be poked and prodded. You feel you have no control over this and over all these drugs getting in your body. I had a panic attack when those drugs came in one big box, I could not breathe, I

was going to pass out and I could not control myself because all I could think of is, “all these drugs have to go in my body.” It is hard for him to understand that and he is not 100% empathetic. At times you have to make him a little empathetic. So that part has been stressful for me because sometimes I feel he just does not get it and never going to get it because he is not doing this. But he has had his fair share of let down with this whole process. He is really frustrated and bumped down about his sperm. I feel that it is way more defeating to a male that it is to a female to find out that you have fertility issues. I do not know what that feels. I can imagine, but I do not know. So overall it has been very positive between us. we have done some discussions, there’s been some tears or lots of tears. But, I do not feel it has stressed our relationship necessarily. He has been very supportive.”

“We are not people who want to talk about their feelings all the time or a lot. He was always supportive with whatever I would say, he was willing to do that, but it was not this very emotional sort of conversation. It was more practical. It was more like, “No we cannot buy the car, no we cannot go on vacation. We need to save the money. This is what this doctor recommends. I want to go ahead and do that.” I do not want to say there were not tears and sharing especially after the miscarriage. Mostly it was goal driven or goal oriented.”

Family

They tried to be supportive, but they failed miserably

“We are still working on that. They tried to be supportive, but they failed miserably, and that was hurtful to me. I knew their intentions were good, they would say hurtful things.”

“People either ask and you know how much you want to share and put yourself out there, and other people, other family members who are having babies, they do not ask. You know they are looking at you or whispering about it, “How come they have not had kids yet?”

“Not supportive at all. So first it was just my mother and her comments. People knew we were trying but no support. My spouse needed more support from family members and they did not give a lot of support.”

“They just all call my step mom and she will ask, “You are pregnant. Are you pregnant?” I told my dad, “S may be the only kid that I ever have” and he will just say “No” and I say “yes, it is ok, just say it is ok if I have one kid or no kid. You know I do not have to have so many kids.” And then my mom never wants to talk about it.”

They do not understand

“They do not understand and it makes it awkward.”

“They all wanted to be supportive but they did not know how. So they all had really great intentions. I remember my mom came out to help when we were through the IVF so that my husband was able to keep working while I was on bed rest. She came and she was so hopeful. At some point in time I felt asleep on the couch and she said, “Oh you are for sure pregnant. I just know it,” because I was sleepy and tired. I was like, “You do not know, how many drugs I am I

on. I just had a surgery and a procedure and all these stuff. How can you?” They did not know how dangerous it was to say those words. They were not realistic. I felt they were in Lololand.”

“I think of my mom in particular, she does not get it at all. She would want me to keep doing fertility treatment. She wanted to fly me to Korea because some of her friends had success there; women over forty. I just want to say, “They are using egg donors, they are just not telling their parents,” but I do not tell her that. When I talk about adoption she says, “Oh you do not need to adopt.” So she does not understand. It is cultural. It is just cultural.”

“My sister was great. I did not tell anyone else, because I did not feel I could share because I did not feel they could understand. So partly it was just wanting to keep it, it felt like such a personal thing, and partly was fear. For example, my parents would not understand, they are very catholic and IUI and IVF were NO Nos. My mom would not even trust me about birth control pills. We did not talk about that sort of stuff.”

“My wife’s brother has been kind of an asshole about it sometimes, not because he is mean, he just never says the right thing. Like my wife says, “Oh we have to do this or the other, and he would say, “Well, it took us three months before we had our first one when we started trying.” You just want to tell him, “Get the fuck out of here, I do not want to hear that.”

“It was hard. My family felt like pressuring, they were just waiting for things to [happen]. It is not that they did not care it was just a lot of pressure because neither of my other sisters are going to have kids anytime soon. Both sides of parents, they were waiting and waiting and you feel you are letting people down but there is nothing that you can do; I am waiting too.”

Some people were supportive

“I feel our parents were supportive of me. I do not really talk much with my mom and dad about it outside, “Oh, we are doing it again” or “This is what we are doing”. “Here is what we think we are doing.” They were there when I cried, when it did not work.”

“With the donor process it took a lot for the whole family to wrap their head around it. Also my parents would ask me when I was going to stop to do this to my body. They were very supportive and the communication was always there, but sometimes you may not want to hear what they are going to say. I understood where that was coming from, the cancer risks, the drugs, and the surgeries. Now being a parent I get it, if that was my daughter, but having been here I see both sides.”

“My sister has gone through it; my parents, her mother has been great. Her sister and her husband, they did something crazy like eighteen IUIs. But they had insurance pay for it. So they have an understanding of what we are dealing with. The only thing that is hard about friends and families is everybody knows we are going through this and everybody is going to ask in the next two weeks how did it go. On one hand it could be positive, but if it does not work, we have to go through telling everybody it did not work and dealing with walking through that many times.”

“I have felt a lot of support from people. When I shared about my miscarriage, my mom brought up when she had miscarriage and that was a really good bonding time. My sister is four years younger than me and she is not married. She is a college runner but her foot got injured and she could not run for several months. She was feeling her chances of ever running slipping away because she was aging and felt this powerlessness. She was trying things to make her body feel better, but it was not working. She was gaining weight and she could not control anything. So she really sympathizes with me because it is very a similar feeling, you are out of control and you are running out of time.”

“My mom is so supportive, she is helping us pay for it. His parents are really supportive they are helping us pay for it. My sister has gone through fertility treatment she did not do IVF but she is gone through fertility, so she is been very helpful. My family always asks how we are doing.”

“I would say with my family it was maybe good because they were supportive. It made me closer to my mom and my dad. They have been there for me. My dad, my brother.”

“My mom tried to be really supportive but she gets pregnant like this. She still has not gone through menopause. She tried to help.”

“Immediate family has been good, extended family expected to be so lovely. We are not even bothering.”

Do not ask do not tell

“Dad passed away last January, now that he is gone, last year I thought I had a family, and this year I do not feel it as much as a family. It is just my mom and my sister, I am not close to either of them really and I am not close to any of my aunts or uncles. Honestly, I do not feel really any pressure anymore and my husband’s sister has two kids, his mom got grandkids, so..”

“I am actually not super close to my family, and I think that was a little awkward just because I come from a large family, I have seven brothers and sisters, all but one of them, who is quite young, have children and my mother just sort of takes the fifth. It is a kind of “Do not ask do not tell.” I sense all of the unasked questions and the “Why have not they had kids yet?” but she never talks about it and I do not feel comfortable talking about that to her either.”

“In the sense that we kept it very private. We really did not want to get anybody else excited after we did go through this experience of knowing we were pregnant then we miscarried. So we really did not let them know where we were in any of the process for the sake of not letting anybody else down ever though we know we are letting our own selves down if that makes sense.”

“We kept a lot from our family. Now we share more but we were always very hesitant to share. It was rough, not being able to talk but also not wanting to talk about it. Part of why we did not want to share was because we do not want to listen to what they would say. Then suddenly my mom died and I never really gotten to tell her the whole story. I gave her only good news, I did

not want to tell her the bad stuff. Now that we have this good outcome, I am closer to my husband's family, her sisters has gone to appointments with me. We have shared with them and they have been very supportive."

"We withdrew from our families. We talked a little bit to them at certain points, but they did not know. So it is hard to blame them for this but her mom was kind of prying for information. We did not need to tell people about it because it was private information. We talked to my mom about IVFs, but if it did not work there is tendency of other people to say, "why did you do it that way?" being questioned."

My relationships have taken a hit throughout this

"I feel my relationships have taken a hit throughout this. The hardest one was my sister-in-law who recently got pregnant after only being married for five months. That was the hardest one for me. I could not see her for a couple of months and I know that was really awful. It is my husband's sister and she lived with us for a few months before she got married. We got really close and I really enjoyed her. She gets married and she moves away but we still continue to see them a lot. And then she is pregnant and it has like this is the baby that I should be having. I should be having the baby now, not you. It was really hard for me to face that sort of ugliness on myself, but I tried to power through and if I can handle it, I can just be happy when I am around her. I would bawl in the car, I would have to pull over because I was screaming. Obviously that was not a good thing. That is probably the person who was the hardest for me to deal with because she gets to give the first grandchild in the family when I should have given the first grandchild. We have kind of moved past it a little bit and I have been able to be not quite as close to her as before and I have been able to see her now without getting too upset. Still, I do not know if it has ever going to be the same until I do have a kid because now there is this whole part of her life that I cannot really relate to."

"I would say it has affected my relationship with family negatively just because I can be isolative and same things for friends and co-workers. I do not share much, and then when I do I feel I am

not understood, because they do not understand even though I try to share. I feel bad because they do not ask me anymore, because they know I do not want to be asked but I know that they still care. I only have another family who I talked to about this and who knows what we are going through right now because she did it.”

Friends

I just pulled away

“I honestly did not have a lot of interaction (maybe this is a male thing) with my friends on the process. They were supportive, they wanted us to have a child but there was not a whole lot of interaction through the process or even after the process with the outcomes.”

“I just pulled away and felt like I could not relate with anyone. Just feel so different and no one will understand. It is all you think about. But then if you talk about it they do not understand. So I pulled away, a lot, from people.”

“I do not have a lot of close friends, and I pretend to be pretty private about these things, so I did not feel I had a lot of people I could really talk openly about that”

“We did not tell much to our friends other than just one close girlfriend or two who might have known. But even that, I think my mom might have been the closest one who knew anything. But we kept it away from a lot of people. It was all in our end. No one did anything to us, it was us getting ourselves off.”

“There are very few friends I talk to. Even my best friend we are very different on that level. She already has a child who is sixteen, she had him when she was eighteen and she does not want anymore, so practically she thinks I am a crazy. But I know that if I called and I was upset they would be there for me. I just choose not to right now.”

“I did not talk to my friends a lot about it. The ones I did of course were concerned and sweet and one of my friends said, “Oh we have extra kids you can have.” Yeah, “We have a spare, you can have one.”

“People who did not know us as well would often ask “so when are you having kids?” and we would give some vague genetic answer “oh, I do not know. At some point, we will see.” because we did not want to share it with them what we were going through. We end up sharing with one close couple who had done IVF. And that was great. The people I share with I felt it was helpful and supportive, but people who did not really know, could ask hurtful things.”

“I have some friends that just do not get it at all. I have some friends with kids, I have some friends without kids, my friends with kids I still relate to them obviously. It is a pretty mixed bag but it has not been bad.”

“I do not feel I have a whole lot of other things to talk about besides fertility and I know that is probably boring for them, so I try not to talk about it, especially if they have not experienced it they do not know what to say or how to talk about it. I think it has impacted some relationships that I had for sure.”

“It really does impact your relations. Even my best friend once I threw baby shower and it was hard. It is so very difficult.”

“There are friends we stopped being able to hung out with because they had kids. I had to tell some of those friends, “Listen it is not you but my wife cannot be around you because it is too hard. You are pregnant and she is not. You just had a baby and we are not.”

“That was really hard, nobody understood. Our friends are all in different places in their lives. We told just two of our friends and whether you tell them or you do not tell them, you feel even more isolated. The things that are important to your friends, that used to be important to you, are no longer important to you. So I felt like while we were going through there was more of a wedge between us and our friends.”

“They definitely suffered the most. My best friend got pregnant and I did not tell her what was going on with me. I stopped hanging out with a lot of people, with the friends with young kids. I

did not have many friends to begin with and going through this I even had less but everybody has been really supportive now.”

“I did not really come out, so to speak, to anybody. I mean, I did, it is just, do you know how guys are? You are like, “You know I am going through this process.” and he is like, “Oh, that is a drag dude. Can you pour more coffee?”

“One question that would just bother the hell out of me was, “Why do not you have any kids?” I knew they were not trying to be mean, but it just came off as like, “Really? You are really asking me that?” She would get really upset too.”

I have supportive friends

“I only told my closest friend from school, we are friends since we are twelve, and he was supportive. When I think of friends in general I did not talk to them but that is not their fault. A twenty five year old talking with another twenty-five years old friends who are out of a bar about fertility issues they were “We are trying not to get people pregnant here” [*laughs*] “We do not want babies.” That was funny.”

“My best friend who is pregnant right now has done IVF with the same doctor and she is been supportive and I can ask her questions.”

“I made some great friends through this process, met other women who have gone through this and I have some great friends. The ones who I have known long I think that friendship has been strengthened through this process and they are all very happy for us.”

“People have been great about this. I have a lot of alternatively abled fertility people in my life. I know a lesbian couple and I have somebody very close to me, basically my spirit sister, I am godmother to her kids, her husband was wound in Afghanistan and he cannot have kids, so they outsourced for their sperm. I feel very lucky that there are a lot people in my life who have

alternative families and who have had other ways to do this. I talked a lot with some lesbian friends of mine and how they went about it. I was following their guidelines and what I read and what I have heard people talk about for doing jar and a syringe basically.”

Co-workers

I never involved them

“I never involved them, maybe I did not because it is a very gossipy place of work. There were some co-workers that asked, “You guys started” I was like, “Yes. We are going to start trying.” There is that beginning phase when it was fine to talk about stuff. Then years were going by and so co-workers were asking right there in the hallway, “so what is going on with this pregnancy?” It just made me realize, “I am not saying anything to any of you people.”

“I just pulled away, I felt I could not relate with anyone. You just feel so different and no one will understand. It is all you think about. Then if you talk about it they do not understand. So I pulled away a lot from people.”

“None ever knew. I have great relationships with my co-workers but this no.”

“I had a hard time with co-workers getting pregnant. There were some pregnant women in the office and I would just avoid them or you say the initial congratulations and you leave the room in pain. It was more like avoidance. I think I shelter myself a lot, just kept it to myself.”

“I did not tell my co-workers in my old job. I have been more open with these ones. I work in a church and so I feel that is more of a safe place to share rather than at a public school where there is a lot more people who care more. I feel there is always a dichotomy between motherhood and career. So I am pretty clear most of the time that I do not really care about my career. I care about my family, having children and even just taking care of my husband. At the church, no one cares about their career either because otherwise they would not be working two days a week at mothers’ day program. I feel that is a more safe place to share. I do not want to come off as judging anybody else’s choice to have a career at all. If that is what you want to do that is great. But it has hard for me to act I care about mine because I do not.”

“I did not tell anyone at work what we were doing and going through. I had that same general question of when we are going to have kids and I had the same general answer for them too. I am not sure, I do not know if they could be supportive.”

“I had one co-worker who I unfortunately confided in early on and she kind of let me down, but I did think she was a friend when I told her.”

“Coworkers did not really know what was going on with the infertility. I did not share. I was not too close. They are my scientist friends. There was not sharing with them, not sharing about our personal lives too much; at least not that type of thing. I did not want to tell that I might be trying to get pregnant. My boss, is not known for being supportive of women being pregnant as a lot of bosses are. So I did not want that to get out. I just did not tell anybody at work.”

“Yeah, there was that one coworker that I had shared it with who got successfully pregnant on her own. I did not really talk about why I had to miss so much work with my boss but he does not ask questions like that.”

“I have not shared it with them. I did not tell my co-workers until we were going through the treatment just because at school with children around and everything it was hard. I kept people in the dark”

“I am not going to tell them because they are not going to get it. I am not going to waste my energy telling them how sad I am and have them go “oh you will be fine.” Because that is more hurtful than not telling them anything.”

I shared with few

“If any at all, the only one I had was with my boss because he had an adoption agency and we looked into adoption. When he went overseas he went and looked into the office prior to us

getting there which was nice and helpful. So that was a positive experience from one co-worker. And you know there was also another co-worker who had gone through the IVF experience. She helped”

“For most of them I just kept it a secret. I only told my boss and one co-worker that I am really close to. The rest of all I just hid it from them.

“I do not like to share but I talked with my boss - I work with predominantly women. The group that I work there are 10% of guys. So, I Work with a lot of women it is like “This is how she feels. What shall I do?”

“I have spoken to my boss a little bit about it and she had her first son at age forty-five and then twins at age forty eight, she thinks that it is fine and it will just happen when it happens, when you are ready and I am like, “Ok, but it just happened for you! You were not even trying and it just happened for you and that is great!” but she does not understand at all.”

“I have a co-worker that I talk to. She is a little bit older and it took her a little bit longer; she did not go through all this stuff but just took a little bit longer to get pregnant. So I trust her and she is a little bit older, she is almost a little bit motherly. It is helpful to have someone who asks, is nice. Then it is kinds of, “Someone is asking, yes I want to talk about it, but it is still a co-worker relationship.” So, how much do you want to share? You know, kind of like that boundary of how much do you share about yourself at work. There have been days that she will ask a question and you just start crying then you think, “Oh my gosh now I am crying at work I am sorry.” She is like, “No it is fine.” We are social workers, so she wants to be supportive but at the same time you are like, “Ugh, I am at work.” It is a double edged sword. It has been nice to have someone who would actually ask.”

“There are three people in my unit that I am really close with, so the day when we could not do the IUI I sent a text to one of them, “Will you bring me some donut?” She did. It is great to have those people.”

“My co-workers have been really good about it. I told my boss and then one other co-worker who I see every day.”

“I work in a small office and everybody knows that I am going through this and they ask about it. So that is good. They were just wonderfully understanding and they were just great.”

Support Groups

A life saver for me

“They really helped me around.”

“That was very good. It was helpful to have people going through it. It is not help to talk to someone who has been through and was successful having a baby. It is the people who are going through it right now, those are the people that are most supportive.”

“Both of my wife’s involvement and my brief involvement with support group that was positive. I wish I could go more often.”

“That is been a life saver for me for sure. I started going to the resolve group here. It is pretty good.”

“I was not always the most active. It would be in and out of the support group. When I felt I needed the support I would go to the meetings, and when I was there, I was getting support and information. They were really helpful for me.”

“Support groups were very positive, once I found them and I could share, I felt so good to be able to talk to people about it. Even the support group that was not much of a support group, but the doctor’s nurse, that was still great because I got one on one chance to ask anything I wanted to ask. So support groups were wonderful once I finally found them. I just took me a couple of years to get that point.”

Support group should be diversified

“It did not exist. To my knowledge there is not a male infertility’s group.”

“I am not active in any of them, but I have been to a few. I do not really use it because so much of it is not really applicable to me. Most of the people in support groups are way far in the process and me I am ok with not having kids, but a lot of them are willing to go further than I am and I feel a lot of it is really helpful if you are in that position, but I do not really feel like I am.”

“The one I went it was very positive and I got a lot out of it. The only thing I wish they had, it was more support from men because it would have been really helpful from my partner to go. Even if he is not the reason you are being infertile, he has to live with you, and it is stressful for them and to have the room full of men to ask that would be helpful.”

There are things I like and there are things I do not like

“There are things I like and there are things I do not like. I really do not think it is convenient for me and sometimes even then if I am emotionally exhausted I cannot handle it. If there was a support group that was more with women like me, with male factor infertility, I would be more likely to go and probably find a more positive experience. I like having people there who understand emotionally. That is very useful. There is a lot of crying and a lot of frustration and even though we are sympathizing with each other and providing information back and forth maybe there is not a whole lot people [who] can provide me with information besides basic nutrition support and what we can be doing to boost up infertility anyway. There is not a whole lot of that information to share with me.”

“That helped. The support group was really helpful. Sometimes I feel the support group is really helpful and sometimes it was really terrifying. I would go to the meetings and some of their stories were so heartbreaking. They had been trying for so long. Sometimes you just feel like, “That is my future” and that is terrifying, “I do not want to be there, but this is where I am going to be if it does not work.” Some of the women had just been through so much. In the group, everybody had different issues, the unifying thing being you all have that feeling of... You know? I feel most of the women that went to regularly had been going through it longer than I

had been going through it; they just had been on this journey longer. That was the place you could be open about feeling like crap about what you are going through and everybody understands because everybody knows what that feeling is too.”

Medical Staff

Some are good...

“Last doctor, who I cannot say enough about how positive and very supportive and accessible he was, he would text you or you could text him late at night about some questions, he would call you at night with some results. He got the blood results he had call you at nine o’clock at night as soon as he got it. Also just very supportive.”

“Especially the last group we worked with, we were sad to leave them. We felt we had a real relationship with them.”

“I got to know the doctor really well. The nurses in cycle, it is really good to know them”

“I had good relationships and bad ones. Our doctor has a close relationship with us. Over the years she actually had me talk to other infertility patients of hers. She would say, “You just kind of have it together, and this person is just really having a hard time.” I have talked to three or four of her patients. I met with two of them somehow regularly. And so we keep in contact. But even with all that, you can always get a better doctor. Does that make sense? You are always going to think that.”

“[The doctor] bedside manner has always been over the top, he is kind. The nurses knew me every time I walked in and obviously after the history with the surgeries and all I have with them, I feel I am more than just a number there. I have paid for a lot of their bills.”

“My doctor was great. She was really sweet and so was the one nurse from the support group was. The other medical staff was not so great.”

..and some are bad

“They added lot of stress that did not have to be there had they been more compassionate, had they been more organized and more helpful and be more thorough.”

“You kind of want there to be a relationship, but there was not one. I cannot say there was not one because there were at least discussions, they followed you, but it was cold and sterile”

“I do not really have an ongoing relationship with any. A lot of people talk about how they love their nurses. I do not, they are fine but they are the medical staff and I do not have a personal relationship with them.”

“They tried to help. They were sweet. All they deal with is all these people who are infertile, so it is just very limited.”

Emotions

Emotions describes the possible range of emotions felt during the Fertility Treatment Experience

- | | |
|-----------------------------|-------------------|
| ◆ Anger | ◆ Depression |
| ◆ Frustration | ◆ Sorrow / Grief |
| ◆ Anxiety / Fear | ◆ Hope |
| ◆ Stress | ◆ Love |
| ◆ Isolation / Lonely | ◆ Excitement |
| ◆ Insecurity / Self -esteem | ◆ Happiness / Joy |
| ◆ Jealousy / Unfair | ◆ Acceptance |

Anger

I did not experience a lot of anger

“I knew what is there to be angry at; there are some things that we cannot change. I did not experience a lot of anger. I am not quick to be angry. I am not a particularly angry person. I do not really get angry like, “Oh injustice of the world!” That is not really anger. You know. That is just like, “seriously!”

I am angry about the unfairness of the whole situation

“I felt it. I still feel it. I am still angry. My son is going to have a lifetime of having to deal with this... my son is not going to be my son in a very small, but also important way in that at some point he is going to have to go through his life knowing that he is not our flesh and blood and that the entire thing is not fair. I am angry about the unfairness of the whole situation.”

“I would say situational. I get angry why me, what have I done? I have a very hard time with this most recent thing where we have had to delay our transfer and for this I go to therapy. If one negative thing happens everything snow balls. I get angry at why do I even have to go through this. I get angry at society as why people who do not deserve to have babies get to have babies. Pretty bad about the whole thing.”

“I felt angry. I would feel angry because I was gaining knowledge and taking care of myself and all the diet and the exercise and all the self-improvement and stuff and it just was not happening; we were not conceiving. Angry that I had to do all this research and angry that I had to be the one to keep insisting on things with the doctors and angry at my family for not being supportive enough or caring enough.”

“I had a lot of anger throughout this process. Just overall. I was dealing with a lot of emotional mood swings as a result of the treatments and the hormone pressures and so really quickly went from sad to mad to angry.”

“I do not know who I was angry at, God, me, my parents. I do not know who you blame. You are who you are and we were asking the doctor if this was genetic or if it was something that I did early in life. He was, “It is just you” there is nothing genetic about infertility, so they say in my situation. I was angry at myself because we had been married for a year before we started trying and you say, “We should have tried right away, or I should have frozen my eggs when I was thirty, and why I did not have my hormones tested when I was younger?” Every woman should get their hormones checked at thirty-two just to know every year. I did not put myself into staying negative and emotional for very long; I would give myself a day or two and then I was, “Ok. What are we doing next?”

At doctors and staff

“I felt angry with the doctor who took a stand off path that we should not have been on in the IUI process where the doctor continued on and on, and when I later found that was a useless experience, I was extremely angry with that doctor.”

“I absolutely experienced anger. I think I was very angry especially with endometriosis, which was not diagnosed for so long. I felt like I am really self-advocated and they were not listening. And so I was pissed off. I was mad.”

“There are moments when I got angry. I think that is frustration boiled over. There were times when I would say we needed to do a couple of things differently here and then repeat myself repeat myself, and I finally get angry and say this is stupid. In general I get angry for a minute versus just want to punch a wall because the IUI did not work but you do not punch a wall, you figure it out.”

“I do get very angry with medical staff and that is really the only thing. I get angry at the hospital practices and I take it out on the staff because they are not setting this cost process, they are not making these ridiculous fees but I feel like a scapegoat. Yeah, so I get angry that I cannot buy medical care like I can buy everything else, if I am going to be charged for medical care, I want to research it just like I research anything else that I made my money on and I cannot and it makes me really angry.”

“I definitely felt anger, not with myself or my husband, just how difficult it is and in our society, you do not really talk about it and that the medical science is not where it should be. My lowest point is probably with the Doctor that screwed up the test. That was probably the angriest I ever got.”

“The loss of control over things makes you angry. I got really upset that time at the fertility clinic with the rude medical staff, because I expected it to be in an environment where someone is going to be supportive. I remember thinking “gosh. I came in a really good mood, what is wrong with this person?” Just anger at the out of control feeling with everything.”

“I was part blaming it on the medicine I was on. But I was very frustrated with this whole process of whether do a hysteroscopy or an HSG and going back and forth. I was nervous because I was spotting, maybe you should do a hysteroscopy and not just another HSG. But then there were new discussions on cost. During that time I was on a medicine, Provera, that you took for a little while before to get your cycles to start, I remember getting very angry and I was very frustrated with the nurses and with everybody. I had a couple bad days. I was kind of flipping out.”

“It was more situational, like when I had felt doctors who had wasted my time or posed to being the more expert than they were. That is when I would get angry.”

“Of course I have experienced anger. I probably experienced it through a whole lot. I think the main times I experienced anger was when I would ask, “Is there anything else we can test? Is there anything we can look at?” And they say no. Then you go back and ask the same thing and then they say, “oh we can look at this” it is like why did not they just start there? That angered me because I felt I was extracting things from them. Why are you making me work for it?”

At my husband

“I have been very angry at my husband. I am so incredibly angry at him. I have been ready for kids. I think maybe six months after we got married I started feeling the itch and we had agreed to wait two years after getting married. Two years came and I said, “alright let’s get ready” and he said “Oh no. We are not financially ready to start trying for kids.” I waited another year and a half until I was super ready and really angry that we were not trying. So we did start trying. And then it has taken two years longer. And that has made me furious. I just cannot cope with how angry I feel a lot of the time towards my husband for making us wait. I feel it is his fault that we do not have kids now even though we were probably infertile after two years of marriage. I feel maybe we could have had a baby during that year and a half that we waited. I have also been very angry at God; extremely angry at God, I cannot even handle it. I started my period on

Christmas day and I had to cut off my Christmas visiting with people early and come back to get a sonogram. I was really excited because we were going to start a medicated cycle. We had already stop before because I had a cyst and because A was out of town and so I was very excited to finally start. But I had another cyst. So I was really angry and we have not been back to church after that and this this is the only time in my life I have not gone to church. I have stopped praying and I have stopped reading the Bible. I am just really angry. I feel I am going to give science a chance because God had two years to get me pregnant and had two miscarriages instead. So now I am giving science a chance and if I get pregnant doing these cycles, I do not know if I am going to be ok with God again. On the other hand, I cannot imagine raising a child without God. How do you explain things to them? How do you give them any hope? I do not understand why God would do this to me. Temporarily angry about that and I do not know if I will ever get over it fully. Maybe when I have kids. We will see. And everybody says “God can handle your anger. He is bigger than you and it hurts him that you are angry at him.” So that is been the biggest loss.”

“When I felt my husband and I were not on the same page made it me very angry. I felt he did not have the concept of the biological clock, and he would make aloof statements like, “You know age does not really affect it. My mom’s friend got pregnant when she was forty one.” That is an exception that is not the rule. I feel he did not get it. And because his personality is very nice, it is hard for me. Some guys are just jerks, he is not that. It is a side of him that I have never seen before, I am not used to it and that makes it worse.”

At Unexplained diagnosis and failed treatments

“When I go to doctor and he said I have unexplained infertility, I get angry because I do not have any answer.”

“I would say that anger and frustration, yes both of those two have been high but it is certainly situational. For instance when I found out that I had the antisperm-antibody, I was really upset not that I had it, but upset that I did not know I had it until this late in the process. But as far as

dealing with each individual thing, I do not really get too angry or frustrated about it. At first when I found out my sperm count is getting low and low every time, I definitely was frustrated. But that is also like “Hey my hair is falling.” I will probably have to shave my head in the next ten years because all my hair is going to fall. It is like “Hey you are getting older” that kind of thing happen. So I will relate it to that.”

“I was very angry because so much is unexplained and so much was out of my control. I think there were times that I was angrier than others, so I was not always angry. Anger and frustration probably did occur later on as more treatments failed. At the beginning there is a lot of excitement. In my case we were finally going to do this, my husband has agreed, he is onboard; we are going to have a baby together. So I was a little bit more hopeful at the beginning. I really think the anger and the frustration happens later on. I would say anger and frustration were pretty similar. I think I was angry because I was frustrated.”

“I did not have anger in the beginning. I was happy when I found out what was wrong with me. I experienced anger with the failed in-vitro with my eggs. I had spent a lot of time in Peru with God, probably the closest that I have ever been and honestly it just felt like it was going to work. So, the disappointment made me become angry with the whole process. A lot of that might have been because I was on Gonal-F for so long too. I am not sure whether all these emotions were drug induced or natural, but I was angry for quite a while after that first failed IVF. That is one of the reasons why we had to step back and did not do anything for a year and a half. I had to get my body and my emotions back in track and it took a lot to do that.”

“Sometimes it comes out. When it did not work I was definitely angry. I was a little angry about the egg donor situation when she was not taking the medicines right. It was not really anger, it was more frustration because we have been planning to do it and now it is going to be pushed back another two months.”

At people's attitudes

“I was very angry, sometimes more than others. I think a lot of that was I thought people were so ridiculous because of things that mattered to them. I am like, “you have no idea what other people are going through, and the thing you are asking me to do or criticizing is so stupid because you just really have no idea.” So I was extra sensitive too. I was very *very* angry.”

“I felt that every day and it was very high. As far as you can go on anger, that is what I had. It was not why me. It was not at God. I was not jealous of other people who had babies. I did not feel any of that. I felt angry because I did not feel understood and everybody else did not have a clue what I was going through and how easy they have it. They are all idiots, they do not have a clue how easy they have it. They just take it for granted and they cannot fathom what it would be like. So that is why I was angry.”

“I have anger, definitely when I get my period and it is gotten better than it was. I have been going through it for so long that now I kind of expect it. Also just being with pregnant friends or women who have children that are friends of mine or even my niece just had a baby. I was there this weekend I had peace by just holding that baby in my arms it was wonderful. I got angry sometimes at some of the things that she would say when she was pregnant. Very insensitive comments made by her, “We were not ever trying to get pregnant, I was using ovulation kits to not get pregnant and I got pregnant.” Saying that to me when I have been struggling for five years to get pregnant? Where are you coming from? That definitely was frustrating.”

At abusive parents

“For while I worked with child protective services. I have seen people who hate children, they abuse children, neglect children, they are drug addicts and they are with children. this really ticks me off.”

“I am not usually a very angry person. That was probably the angriest time of my life. Even my husband would be scared of my reaction to people. It sounds terrible, but I teach in a low income school and a lot of the parents there have children that they cannot take care of adequately. I would watch that and it would made me so angry. I feel I was always angry because every time a kid was neglected it would make me angry, because they were able to have these kids and then they could not take care of, my anger would spiral. Even if I would be at the grocery store and see a woman slap her child my blood would boil. I would see her with three children under the age of four and she is pregnant and she seems so angry with her children, I would tell myself, “I am so angry with this woman that I never met before.” Every time somebody was pregnant I was angry with them and they did not do anything. Angry was definitely an emotion that I had never felt before.”

Frustration

You work hard, but you do not necessarily succeed. It's out of your control

“Frustration because nothing was working. Seems like you try and try and try and you try to fix things and nothing ever gets fixed. Usually, the harder you work the more you can succeed. This is one of those you work harder and harder and you do not necessarily succeed.”

“Very high. Because nothing I can do about it, is out of my hands. It is so frustrating when it keeps not working and not working and not working and you have no control over it. What is more frustrating when something is not working and you have no control over?”

“Certain occasions. Throughout the whole process I was pretty mellow, but it is when you feel you are trying to go in a certain direction and then it did not work. Ok, now I am pissed because you got your hopes up and you are frustrated.”

“That is been pretty high. Things are completely out of my control, like growing cysts. It is really frustrating to me because there is nothing I can do. For my diet related things, well, I did not do the diet, so I cannot expect to have the results from it. So there is no point in getting upset about that. But with the cyst, there is nothing you can do. It just happens on it has own and that is really frustrating.

Throughout the process

“You are frustrated that you are going through it. As a guy, you are frustrated that there is really not much you can change, frustrated that things that you are trying to change are not always the way you want them to be, frustrated that you are not as emotional generally as your partner, frustrated when it does not work, frustrated when you have to write that six thousand dollars check. I think that happens more often.”

“The process of going and the first initial four years with the OB/GYN doctor going through the IUIs that did not work, or the failing end results, or not knowing what was wrong with me. Frustrated with the cost. Frustrated that you are talking seven years’ worth of time.”

“I am verging on that all time frustrated with it mainly because it takes so much. Personally I hate how I take so much drugs and so much time and my body does not cooperate. That is why it was so upsetting this past week that I am already going through IVF, can I get a break? Why cannot it be an easy IVF if there is such thing? I feel everything I do even with IVF, which is already such a challenging process, is a challenge. Like it takes more drugs to get me to ovulate. I am going to ovulate I have got to take these extra drugs take extra estrogen to make my uterus lining grow. t is Everything about this challenging process has more of a challenge for me for whatever reason. So that is really frustrating for me.”

“I cannot say I did not have frustration because I did. There is so many times where you are disappointed and you have done so much.”

“I would say very high all the time. From the very beginning.”

“It was all the time because I was constantly pushing the pedal in the meddle trying to solve this problem, trying to find a solution and trying to make it happen, make it work, check everything off the list. I was frustrated because nothing was working. We were running out of time, running out of money, it is eating us alive. We have no friends. It is a wholly frustrating experience from start to finish.”

“Well, every consecutive event might have frustration attached from scheduling to transportation. What comes to mind it is trying to keep up my sweeties bio-rhythms became kind of an archivist for her chemistry. That got a little frustrating, having to mark her mood because I kept track on my cell phone. Like “have you been to the bathroom today and when?”

“I would feel frustrated a lot that the timing was not working or just frustrated at the scheduling and the rigidity.”

Every failure

“Of course I get frustrated every time I get my period and it is like: - I knew it was not going to work anyway and of course it did not work! Yeah, there is definitely more of that. Definitely the last two weeks of the cycle would be more frustrating than the first two weeks.”

“A lot of times you are on the wait and see game. Like, “Hey you have twelve eggs, ten of them fertilized, that is great!” Then you get to the embryo stage and only two are viable or three are viable. A lot of times we would have six or eight viable, but three or four would be high quality and then we get to the last stage and we would get pregnant, but we got the miscarriage. So frustration was more situational.”

“I kept thinking that the IUIs would work because they worked for my daughter. Going back I wish I would have researched a little bit more about the premenopausal, but I just kept thinking the IUI would work also because is the less expensive option. I was on Gonal-F at that point too. Every month [that] I would be on the Gonal-F I would develop a cyst, so they had put me on birth control, and after got off of it did an IUI. That is another reason why I did IUIs for so long, because I kept developing cysts in between and I had to get back on birth control. Then moving on to the next step was frustrating. You do IVF and it does not work and you are frustrated. Then the only option is to do IVF again, but we knew it was not going to work with my eggs and you are frustrated because either way it was not an option in mind to put my body through that again. So, you have to reevaluate.”

This is unfair

“We are frustrated nothing has worked and what we are doing right now I do not consider as being working. We have had three complete strangers come together and have a child for us and

it is not so completely less than ideal and I am so happy that it is working but I feel guilty and frustrated about that.”

“I would say that depending on the day. It is more like finding out someone else is pregnant or seeing someone else has a baby or people at work. When I covered the maternity leave for someone at work it was in the kids unit. This morning, I was over there covering for the pregnant one that had to go for her glucose test and so it is sharing her stuff and while I am happy for her, it is exciting, it is also like I do not really care, which makes me feel really crappy because I want to support my friends and coworkers. So it is probably triggered by the presence of other peoples’ pregnancies.”

“I was really frustrated by this. Just trying to figure out what the problem is and what exactly is going on, it is very difficult to get to the bottom of it and then very difficult to get answers on the best course.”

“For me it has been mostly some delays in the process, with relationships; just different things that I have done in the process but frustrated more with myself; with choices that I have made.”

“Really frustrated by having to do this extra things. Some people get pregnant so easily, so high frustrations with that.”

“That is a more accurate description of my emotion. I feel it crops up a lot even when I have got a good handle on things like, “Ok, we are going to go forward with this, this is good, and these are my options.” Then I will have that moment of, “Why I am I having to deal with this? This is not fair. Why? This sucks.” I will have pity moments that creep up on me. It will get triggered by people on Facebook announcing their pregnancies or somebody in the store talking about their fifteen year old who is pregnant again, or people in the store who are ignoring and neglecting their kids or expressing that exasperation and frustration. I know parenting is not easy, but sometimes that will trigger me and I will be like, “Do you have any idea how much I would give to be in your shoes right now with all of it?” I hear people saying, “We want to have kids, but we

will wait five years and this and that. I have got plenty of time” I just want to be like, “You do not know that, it is not guaranteed that you have time. You say that thinking you will get pregnant within a year and there is no way to know if that is true. Do not take it for granted. Do not ever take it for granted.” So when I see people in my life or people I encounter taking it for granted, I get really *really* frustrated.”

Anxiety / Fear

Fear of doing something wrong to cause it

“Yes, I felt that. It would be of the unknown and not knowing what was going on and not having a clear diagnosis and just afraid that I was maybe causing it somehow because I was not opening up to enough people. Things like that. So just a lot of anxiety about what can I be doing differently?”

Losing the pregnancy

“My anxiety would come with my pregnancies. I did not want to be too excited because of what happened in the past, especially on my third one. Then there was a fear, when is it going to happen.. all my miscarriages were when I went in for a doctor’s appointment and there was no heartbeat, so going into my appointments for just ...”

“From the time we found out until we got pregnant; the whole time I was terrified, “What if it did not work?”

“A little bit of the fear that things would not succeed. It is usually that moment of waiting on pregnancy, more than anything, so the rest of it was more anxiety or hope.”

“I have a fear that I am going to lose it again. Since I still do not know what happened the first time.”

“It had been very high for each pregnancy. Not the first one, but after that, the anxiety and fear was very strong.”

There is a lot of anxiety about the future. Is this will ever work?

“I had a lot of anxiety. You know they say the difference between anxiety and fear is that fear is in the moment. So if a spider or a snake falls from the ceiling you are scare right away. And anxiety is looking more into the future and I think the future is really scary. There is a lot of anxiety about the future when it is so uncertain. When you are dating someone, you look into the future, you picture getting married and that is comforting. And then once you marry you think down the road, you picture your lives in five ten years. When that is totally unknown as far as family goes, kids, if you are going to be able to do treatments, how long are you going to be doing treatments, can we afford to do these treatments, that is keeping you awake at night.”

“Definitely during treatments and also whenever I think of the possibility of not ever getting pregnant. I have the tendency to have a lot of negative thoughts. I have to really make an effort to combat those thoughts because they will just creep in like at the grocery store or wherever. So anxiety and fear are big ones.”

“Lots of anxiety and fear that this would never ever happen, ever in my entire life, no matter how bad I want it and every cycle you are, “Ding, ding, ding. What am I going to do?” you are too anxious and you think I am not supposed to be. I should just forget about it, nobody can do that.”

“I do not know how much fear; I would not say there was any fear. Anxiety yes, just the unknown, not knowing what the outcomes would be.”

“I do not really know if I would call it anxiety. I am afraid that I will never have children.”

“My husband experienced things with more anxiety than me. There is anxiety during the two weeks wait; you are waiting to see if it worked after the treatment. But you do not want to be anxious so that kind of makes it worse.”

“We had a lot of anxiety when we were waiting for answers”

“I experience it maybe a little bit. The most is that waiting period to knowing if it works or not. It is hard to focus on anything because your mind automatically goes there.”

“Probably more anxiety than fear. You feel anxious every time you are waiting to see if you are pregnant. Yes, that is really anxiety provoking. Also anxious to get it done. I am just anxious to do this transfer and to be pregnant and move on with this.”

“That is been mostly during treatment. You go through that period when you just do not know if it works; if it is not working. Am I wasting my time, money and resources? I am I doing the right things for the baby?”

“It is more like, “Gosh, will this ever work?” I think that is probably the most, the main anxiety, “How long do you wait? Are we ever going to have kids?” So it is more anxiety about kind of the unknown of what will happen in the future.”

“It is keyed in with my PTSD sexual abuse stuff, I think. That gets in there, and not just the feelings of “what if this does not happen?,” but also all the things that come bubbling up when I am dealing with it. Like the first time, we talked about it for months, got all these things together and we were ready to go. I am holding this jar and I am just like, let us go back to the beginning and deal with this again because I am having so much anxiety about having part of some other guy in my body. It does not matter if it is separated by a wall, a syringe and all these things. It is all of the anxiety and panic. That is not something that is constant but when it spikes, it is fairly debilitating.”

Big risk

“I took probably four of the largest risks of my life, while we were going through fertility treatment, which is a risk enough, itself, so I had a lot of anxiety throughout of that.”

“I worry about things not working or all the money we were spending. I was not as afraid of the treatments. But I had a lot of anxiety.”

“I had a lot of anxiety during the IVF with my eggs. It might have been the sheer magnitude of drugs in my body but just the anxiety about the amount of money that was going to involve, and the hope that it would, and the fear of it not working knowing that the next stop was probably going to be donor, which I was not 100% comfortable with. So there was a lot of anxiety and fear with the whole IVF. The one thing looking back on it now, I am thankful I got only an egg, and that is probably where God became involved, because if I had not gotten that egg I would have done the whole thing over again. So, we put a stop because we knew that my chances were slim on IVF. At that point when we got the statistics we said, “Let us just get a donor, they are doing us a favor financially too.” This is a great deal of money. From the estimated twenty five thousand, when the medical expenses kept popping up higher and higher, we went ten or twelve thousand over what we had budgeted. That just adds to anxiety and fear.”

I went on medication

“I went on anxiety medication. When you go through such a long period of frustration and loss, it is inevitable. Everything makes me anxious. What if it does not work or what if we do this, we do that, it is just so hard to make a decision and it is the only thing you think about.”

“I am medicated now. I went to see the psychiatrist about my depression and she diagnosed me with anxiety. The medication makes me feel like I am numbed. I love Christmas. No one visited my house because it looks like a freaking psycho winter wonderland person lives there. I barely mastered the energy to get out the nativity scene that my mom gave me. Our tree was not decorated until the weekend, Friday before Christmas, when all my nieces showed up and I made them do it.”

Stress

One of the most stressful things that I have been through

“All the times. I felt like I was on my max level of stress that I could possibly handle, and then it would get even worse during treatments or during negatives. Yes treatments made it even worse.”

“It is one of the most stressful things that I have been through. Now it is less because of this decision to stop trying and just let it be like it really helps.”

“I get stressed out very easily, I internalize my stress and when I get stressed all my body systems go haywire. That will shut down my ovulation and it will shut down everything, my appetite and everything. It will be a lot more stressful if I was going to the doctor’s office for IUI. Not only the cost, but that was another reason why we decided to try at home insemination first, because it is at home in my own space. It is less pressured, I do not have to worry about appointments and all these other things. I was hoping that would be an integral component to keep my stress level down; would be beneficial to doing that. I have become very adept at learning good stress management coping skills. Part of it is distraction. Part of it is giving in and letting myself feel things, just forgiving myself for whatever I am feeling even if it irrational. There is tea and bubble baths. Or saying yes I can have wine in the middle of the afternoon.”

You are stressed financially, emotionally, and physically

“Stress is a big one definitely. Just because infertility is the first thing that I think of in the morning when I wake up and the last thing I think about before I go to bed at night. It is always in the back of my mind; it never goes away.”

“Well, going through all of this, the financial stress, the physical stress because I over stimulated constantly. Plus taking the shots because I am petrified of needles, now I am not, but at that time... My husband did them for me and then eventually I felt bad waking him up so early all the times, I started doing it myself. It was just very stressful. It is a different lifestyle that you did not ask for and you get thrown into it. So I felt a lot of stress at times. I mean I tried to keep it calm, cool and collected but when you are going through the IVF process that is where a lot of the stress is; is IVF. IUI is nothing, take a few pills then show up. I could do that. It is the IVF that stressed me up the most.”

“You are stressed financially, emotionally, and physically through the whole process. Trying to recuperate from surgeries and deal with the family and the job, life goes on! Your life does not stop just because you are infertile; you have a lot more stress on top of your regular daily stresses.”

“Stress was high, It was stressful talking to my husband about it. The money, paying all that money was stressful. And just coordinating all the medical information that was very important and I have to be on top of it. That is kind of stressful. During the process itself probably like maybe the waiting. Waiting is very stressful.”

Throughout the process

“Trying, the scheduling, missing work, lying you know, a lot of trying to get things done without one knowing. That was stressful. I guess with not knowing what is going to happen in your next appointment, or there is going to be many follicles growing, how many eggs I get. With the process a lot of stress. I would see it was a little more stressful doing the IVF but then it is always with you. But it was more then, because there was money invested in it. Something was happening and you need it to go right. So I felt more stress and pressure during an IVF.”

“It is just a very stressful process in general. Definitely when something did not work and then you have to gear up for the next step and what to do next. “

“I had a lot of stress. The highest stress was at the end of the month when it did not work. I would be bawling and wondering if this would ever go to work. I was stressed somehow during the process, but at least I was hopeful.”

“The two weeks wait was stressful. I had a lot of external things in my life that were stressful; that made it very hard and added stress. The experience itself I have tried to keep my mind open, so it was not terribly stressful for me. I did not mind ultrasound.”

“When we were actually doing the IVF was the most stressful. Those shots every night and then the waiting; there is a month period when you are doing the shots and then you are waiting, that month was a torture. It was hard to keep your mind on anything else.”

“More in certain occasions. There was a constant level of stress during the whole time because you are monitoring your fertility. You have to have sex on a certain day and then you wonder if it is going to work; and then you have to do the whole process again, so there was probably some constant stress.”

“I think more of it just came with the process itself and going through the treatments. And then the time that it took to do it, then waiting.”

“The whole thing is stressful because it is all a numbers game with them. Attrition all along, so you are trying to get as many eggs as possible, and they are trying to get as many retrieved and then as many as fertilized, and every step of the way the number drops. Stressful every time I had to go with timing the lining. I was so stressed and worrying about going overseas if my lining was bad again. I felt “oh my God we are not going to be able to do this or going overseas.” So there is a lot of stress involved and I think when this is your focus and you really want this to happen and people are telling you to be relaxed, you know what, you have to be stressed. And so everything is making worse.”

“There was a considerable stress. Well, no there was a constant hum of stress. Yeah, something involving the pairing, my wife and I, there were some features that were created by this process and those were abrasive.”

“Stressed I will say all the time because my job is really stressful too particularly right now. So my stress level is abnormally high right now. And I stress about being stressed because I feel that is not going to help my chances of getting pregnant.”

“It has a little bit decreased now with not going through treatments. Going through treatments it was probably five all the time because of two week increments. Two weeks is not terribly long and you are waiting to ovulate and then you are waiting to see if this worked and then you get up a period then you are really stressed. I think it decreased because we are not as focused on that, not going through treatment, but I think it is still always present in your mind. If we start to talk about it then it is more stressful or if I get my period then I am like afraid to tell him because I know he is going to be upset and then I am really grumpy and stressed out.”

“The time stresses. Making sure that everything was exactly on the right time schedule. I think the time schedule was a very stressful thing, having to plan your time around schedules. Again the big stress on what the outcome was going to be was a big stress because if there was going to be a negative outcome it was going to be very depressing. I would say a very high stress”

For the relationship

“It is stressful when we have to do the whole testing with the sperm count and that is stressful but it comes and it is gone and you are over with. We experience that but it is as stressy as it is like having sex when you are not really feeling it. “

“Very stressful trying to calm my wife down, being in her shoes, she is upset and knowing that there is nothing I could do. It was very very stressful knowing that I could not do anything. You cannot just say, “be patient.” You cannot say, “it is going to be ok”. Those things do not

accomplish anything. So it was more stressful, I mean that is the stress that it put on our relationship.”

Around pregnant people

“Being around pregnant people probably the most stressful. If someone is pregnant at work, you come home crying. Also trying to combine work and treatments and all that. It is a stressful process, the decisions you make are stressful.”

“It was pretty much all the time mostly because of my job. Working in labor and delivery got to be so hard, my stress got greater and more constant just because of my job. To work around laboring women all the time and so many of them you think “Why are you pregnant? You are not going to be a great mom!” It is hard to have that constant reminder that this is an easy biological process, people get pregnant every day.”

I could control it

“It is stressful but I think I can control it pretty well. I read, watch TV, go for a walk.”

“I do not get too stressed out about it working or not. I want it to work, but it does not really weigh me down. I was certainly emotional last week when my wife was feeling really bad. But I guess I was feeling more stressed o because she was feeling bad, not because we had to push it out one week.”

“I have taken steps to make my life less stressful like cutting out work and cutting out seeing people when I need to. So I feel like I am managing the stress.”

Isolation / Lonely

It was pretty lonely

“It was pretty lonely for us, just me and my spouse and I do not know whether I expected something different or not. But that was definitely an experience we had. There was not a lot of friends and family around. Some of that was by design. In case you have to go through the same process and before you get everyone excited about it you would want to believe for a good outcome. So some of it was by design but some of it was just because that is what happened.”

“So isolated, so lonely. Just cutting yourself from people and not talking about it.”

“We did not want to go anywhere doing anything and every restaurant there are million kids and pregnant women and then the girl shoes store. I mean like basically I have to go to work, and that is where I will go, but we were on it. You know, on and off a lot.”

“Throughout, once we realized how much bigger problem we had when our first IVF failed so completely, it started to feel we were completely starting to be shut out or we are shutting ourselves out.”

“I did because I think there is a certain amount of this process that you just do alone and I could recognize my wife parceling off and emotionally isolating, so yeah that was a big player.”

“I definitely isolated myself a lot. I do not feel like myself. It has been five years now, but over the years it is gotten worse and worse to where I just get really anxious thinking about it. I am an introvert anyway and some of that comes from my personality type. It is easier for me to have one on one, but when it is the groups, especially now, it gives me anxiety. Like this weekend we were going to this “all cake hold down” it is all you can eat pancakes and square dancing, and I

am kind of terrified. We invited our friends that are recently pregnant, and so it is going to be all kind of terrifying but I am going to go... and there is no going to be any alcohol.. so that makes it ever harder...”

“We do not talk about it. Those of us who are going through it do not talk about it a lot. There are those moments even as people are talking about, “oh did this and that.” I am Like ok.”

“I did not feel it that often but I did feel it after the failed IVF. I think that was the lowest point for me emotionally. I felt very alone.”

Until I found the in person support groups

“I felt some of that in the very beginning. I had that friend who I have known since I was twelve and I have my best friend who I have known since high school. I remember she did not know what an IUI was. She did Clomid but she did not know what an IUI was. That is when I joined the support group, I had to meet other people really quickly who knew what I was talking about. So I was able to come back to other people.”

“I had a lot of that especially before I found the support groups. There is all these people having kids, all these pregnant women and what is wrong with me? I did not realize that other people also had to go through the same thing to get pregnant, until I discovered that one friend couple. I had some comfort in reading online message boards of other people experiencing infertility. I still felt a lot of loneliness and isolation until I found the in person support groups.”

“Not too bad on that. I think it helped being with the support group, with other people who were going through it.”

“Just, “Why is this happening to me? I do not know anyone else who this has happened to.” You just start to feel like you want someone to go through it but you do not, because I do not want to wish this on anybody. Finally when you find those people, you really understand, “This is not just me and how can I get something out of this.”

Not a lot of people who get it

“That for me was the worst part of all the infertility because I told my husband I can go through anything, I can handle anything that life throws at me, but it would be nice if somebody was there to support me. Anything, any acknowledgement other than pretending like everything is normal and OK because I will tell you that is not normal, it is not OK. You need support. It is impossible to survive alone. Everybody carries its burden alone. You lean on your husband and you know that you are leaning too much on him. I actually put together a list and sent it to my friends and family and they did not really respect it. It is like, “oh I did all I can do. Then do not talk to me. If you cannot follow these rules, then just do not talk to me.”

“Even with my partner until he had gotten his own labs back, he did not really get where I was at with it. Finally, when he got his first sperm results back he broke down and he was crying and was really upset and I thought, “Now you get how I am feeling and how it sucks, does not it?” but until then I was just that crazy girlfriend who cries and is angry and spends all day in bed. I do not think even I knew how much support I would need. It was not just that he was not supportive, it is that you have no idea how much it was going to take emotionally out of it.”

“I think more just that not being able to talk about it and not having people who get it.”

“We were kind of in the middle, it depended on what it was. I think there is not too many people that you can share the dirty details with. That can make me feel lonely but I did have my husband by my side and one good friend that you could tell everything good or bad. And I felt that is of all I needed at that point. And actually the support group was great once we found that.”

“A little bit. I tried through the process to stay the strong and silent “I am here for you when you are sad” but I did not want to get upset a lot around her just because she was already upset, which is a flaw of mine. I do not have many friends that I want to talk to about it. That is personal to look at it in a more introspective way.”

“I do not have a lot of close friendships or a lot of support. I am very close to my husband but you need more than that, you need a wider circle.”

“I felt that a lot, a lot of times in the two-week wait because the whole waiting and the time taking would be on my mind. When it did not work I felt that my husband was not aware of my cycle and he was not aware that I was going through that and so that was kind of ever present. And also just not having friends to talk to about it.”

Insecurity / Self –esteem

A man perspective

“This was in the sperm count issue for me, low self-esteem when such a major part of you does not work well. So low sperm count caused low self-esteem for me. Insecurity is not knowing if it is going to work or not.”

“I think the whole sperm thing was embarrassing that I do not have super sperm, but I cannot change that. I got over that quick. You get twinges of insecurity when my cousin who is pregnant said “Hey, why do not you have a baby?” and I thought, “you do not know what is going on, stop pounding me”. But I am more open about it I think that she would want me to be, so I do not feel insecure at all.”

“As a man when you learn that your sperm count is so low, it is like “oh that is a real bummer” but then I just go about my day and forget about it. That said, again it is situational, it is not something that I think about all the time. I was a little bummed when I first heard about it.”

“Well, that might play back in the fact that I was unable to produce good sperm, but truthfully it kicked a couple out. Even if I had not, some people got it and some people do not; that might be one tag in my self-esteem I can think of and it did not really have any effect at all.”

What is wrong with me?

“Probably more self-esteem, wondering “What went wrong with me?”

“It wears on your self-esteem, everyone else can get pregnant but I cannot get pregnant what is wrong with me.”

“I definitely experienced a lot “what is wrong with me, why cannot I make this work?” I would feel pretty down about myself especially during that two-week wait or right at the end when things had not worked.”

“I did wonder what is wrong with me, but it did not consume me.”

“That is huge. That is very high. It has made me very insecure. It has affected my self-esteem. It just wears me down, and it makes you feel like you are not the woman that you could be.”

“I cannot bear a child, here there is this man that I love and I cannot give him a child. It just make you feel insecure as a woman.”

“It goes back to the anxiety of, “Will this ever happen or what is wrong with us? And why is this not working? Is it me?” I do not think neither of us blamed the other or really we do not blame ourselves, but I think that you inevitably have some self-blame because something is not working.”

The extra weight

“It is low, because I still have the baby weight. I still have most of the baby weight on me and it just does not come off. So that makes me feel not as attractive to him”

“My self-esteem was very low. The drugs made me gain a lot of weight, so physically you are not feeling like yourself. They make you fatigued, so you are not exercising. You are not wanting to do anything. I think you definitely become depressed. And so the psychological pressure of not wanting to do much and you feel you are not totally a woman because you cannot get pregnant. It was never the way my husband judged me. I never felt he ever looked at me that way, but my own personal self-esteem was very low.”

“That is about the effects, I have gained some weight through it and that does not make me feel great. I am afraid when I do get pregnant I am going to blow up like a house. That is going to be fun.”

That it has not the one thing that defines me

“I think there are some and knowing how many women I have talked to about this in support groups and women I have met, but I think a little bit differently than they do. I have never thought less of my body because I cannot carry a child. My friend said to me, “I do not think I will ever feel truly a woman because I could not give birth.” I remember thinking, “oh, I do not understand that.” But that is how she feels. I remember when she said it I was kind of shocked, because career wise I have accomplished so much and travelled the world and done several other things that it has not the one thing that defines me.”

“I know a lot of people feel they are less of a woman because they have struggle with this and I never really have it at all.”

“A little bit because you used to be in control of your life and things to fall in place. With this you think they are going to and instead it is a big setback. But I have a pretty high opinion of myself.”

“I do not feel like this is something I do wrong.”

“Women at the groups have talked about it effects how you feel about yourself, but I do not think I had that.”

“I do not think much. I feel very different than other people, but what I struggle with is me being angry at them for not realizing or recognizing.”

About the feelings I have about my husband

“If I had to describe my husband’s sexuality I would say he is pretty asexual. I do not know if that is because of the fertility problems or just his personality. Before we got married he did not seem to have a lot of interest and having sex was an issue, sometimes he was not able to or maybe it is a good ”catholic boy” thing. He just has guilt over it and I thought if we got married it would totally change. So we got married and everything was good. He got on medicine like Cyalis and did not get better. Then we started trying fertility wise and you know it was like, schedule those sorts of days when we have to do it. So I do not know if his lack of desire is because of the struggles that we have had or if that is how he would be anyway. I do not know. But I was a very sexual person before. This is the rest of my life, less than once in a month, like seriously? He is on the computer and I think, “I wish I was a computer game so you could pay more attention to me” I do not know if my low self-esteem and insecurity is because of the fertility much is just his lack of desire. I am like, “Will anybody ever find me attractive again?”

“Minor but present. Mostly in judging myself about the feelings I have about my husband, and that feeling of ‘nobody wants to have a baby with me.’ I found the man who does, [but] he does not make sperm. I have friends who are like, “I will make a baby with you.” I am like “Yes, but I do not want to make a baby with you. Please stop, stop offering. You are a perfectly nice individual, but the thought of making a human with you makes my ovaries recoil.” I feel I have to honor that a little bit. It is like, “Yes, I know that you have good sperm and you are a decent person, however there is something about you that just like my nose goes no.”

Jealousy / Unfair

We were not even trying... oops!

“People with children. We had friends who I talked a long time ago not wanting to have children or not being interested in having children and they are having children as well having to hide those things from my wife. I would find out and I would have to hide them from her, not tell them to her or destroy things we got in the mail you know.”

“Definitely with people who just say “oh, well, we were not even trying but we just oops you know.” So yes, I feel jealous of folks who would seem so easy for. People who got married after us and have already had two kids and that kind of thing.”

“Some of my co-workers, a couple in particular, one of them was always saying “We are never going to get pregnant; my cycles are so messed up! It is going to take forever.” And then boom! She was pregnant and she said, “Yeah, we went on vacation and it happened the first time we tried.” So, that was really rough and then, for another co-worker friend of mine it just seemed everything she planned happened. When I started work there she had been together with her fiancé about a year and she had the perfect wedding and then she planned to get pregnant at a certain time, and her best friend wanted her to get pregnant. They planned it out, each of them could take care of each other when they were in labor, so one of them would get pregnant four months earlier, so they would be back to work by the time the other one had the baby and it worked just like that. I thought that was not so fair. Everything cannot go what you plan at some point you will have something in your life that does not go to plan”

“I felt that a lot right after she [the baby] died, but it is kind of gone away you know, very low now. But I did right when she died because my cousin announced she was pregnant and she had just told me at Christmas time that she did not want another kid. They said “no, we did not want

any more kids and we are not trying”, but she got pregnant like when I lost it. And that is not fair. You do not even want another kid.”

Seeing others pregnant

“I had several friends who had one and then two babies while we were trying and just seeing a lot of people get pregnant at work. So yes, I would feel it just with people. Friends; close friends I was more ok with. I guess because I had a personal connection.”

“Yes anytime we would see somebody get pregnant with no problems there was jealousy. Even up to now when we see people get married and in a couple of month they are already having a child or pregnant. And unfairness we are a great couple, successful, nice, all the above, great features... Extremely good looking, ah ah ah very smart...so yes, but the one thing... It is extremely unfair.”

“Yes, lots of that, all the time, with pregnant women. I could not go to baby showers, for years I could not go see friends’ newborns. Still, still to this day. Last week I went to a birthday party for a friend’s two year old, and the girl is pregnant, they are younger than us. They did this whole thing, which is a revealing, all these balloons out in the park. All the grandparents were crying. I wanted to go punch her face off. This is disgusting. It was like a joke. We watched. Ridiculous, yes. Probably six women there were super pregnant, and one was going around saying, “whooh whooh,” like she cannot breathe. I am like “Gosh, I am going to be pregnant?” Tons of pregnant ones and those infants. Where did all these come from? We went to this kid’s birthday a year ago and she has all these mom friends from the fun group and I do not know if we are going to such parties anymore. The moment we walked in, there were children everywhere, and there were pregnant women everywhere and then the balloons. I was pushed over the edge.”

“People do not understand that when your best friend gets pregnant you can feel two emotions. You can feel massively jealous; unfair wise, but you are also happy for her. I do not want her baby, I want my own. I think you can be very happy for them but at the same time you are

jealous and you might not want to hear the details. I remember telling my mom that if my sister got pregnant before me, I do not know if I could talk to her about it, Maybe I could go to a shower or I could not talk about it. And my mom flew off the hem. She was like, “How could you not be happy for her during that time, that is so wrong and you cannot take this out on other people.” They just do not understand that there can be two very different emotions in the same space.”

“There were times when I was really jealous of my friends able to have babies normally; I could have 60 thousand dollars in my bank account and play with it! That would have been fabulous, but it is what it is. The jealousy is fleeting in ten seconds, when it is like “I would love to go to Hawaii and instead I have a baby”, so you cannot get too upset about that for too long and I knew that things would ultimately turn out ok.”

“Yeah. It definitely happens when I am with my friends and they have got their kids.”

“Definitely very jealous. It was more jealous of pregnant people than people with babies. I am still jealous of those people but it was the pregnancy that upset me more. I struggled with that, I thought that would be an issue with surrogacy but it has not been or not yet. Hopefully it does not. Inducing lactation because has given me some control and I feel like I am doing something.”

“I have been dealing with jealousy recently because of my good friend that is pregnant right now through IVF and I love her to death. They are our best couple friends. I am more happy for her than anything, but I am so jealous. And that is with the whole thing, everything is a struggle more with us than anybody else. I feel that their process through IVF was practically seamless. She has had the best situation of her insurance covering it I think they paid like less than \$5,000 for IV. She is pregnant after her first transfer. She got four embryos just like we did, but everything has been falling in place for them seemingly. I know it has been so hard for them; it is been just as hard for them as it has for us. I am sure. But nonetheless I am just jealous about it. It has been seemingly much easier for them and now they are pregnant. I could not be happier for them, but I am also so jealous at the same time. And I definitely feel like it is unfair.”

“One friend I had was not there for me when I needed her, did the exact same procedure and got pregnant the very first time. It just felt so unfair. People I knew were getting pregnant left and right. It felt unfair. It was really difficult.”

“Sometimes it was high, at other times it was not. In the very beginning when you find out and all your friends are getting pregnant there is a hint of jealousy, but I was always able to be say, “It is a baby, it is blessing, there is no reason for me to be jealous” After the failed IVF there comes unfair feelings because I have put my body through all this.”

“Especially with friends and family that are pregnant or new parents. It is just always hard.”

Unfairness more than jealousy

“I never wanted what anybody else had. I wanted what I wanted, and I did not compare the two. It was more like you are an idiot and you do not have a clue how easy you have it, you do not have a clue what I am going through.”

“Absolutely. I mean that just goes back to my faith; unfair that it happened to me. But I had no jealousy at all. There is nothing in terms of that emotion, but unfair absolutely.”

“Some things would be unfair. I know people who would never want to go to baby showers. I could do that. I missed a good friend’s baby shower and I was supposed to be hosting only because I was going through the miscarriage, but if it had not been that period, I could have done it. So I was not trying to avoid people with kids, but I did sometimes have feelings of being unfair. It does not help that I work with teenagers or people who are maybe not going to be the best parents. What upsets me the most is when I hear a news story about somebody having done something to a kid and you think somebody like that can be a parent and I cannot.”

“This was not throughout. There were times where I would just look at friends or people with kids and think, “How can you?” It was frustrating because he is cheating on his wife or doing things like this and he would have two or three kids and he would not be paying them any attention. I would give anything to be... you know?”

“That was another thing that influenced me to quit my job at Headstart. A lot of the Headstart families were perpetually in crisis and they would have three kids under the age of five and then get pregnant again with another one. And if there is a good and loving God why is he giving these families more than they can handle and withholding from me what I could definitely handle? It was getting really hard being around these children that were not getting the care and attention I could have given them and just having to send them home with their families everyday where their next meal was going to come from or did not know whose house they were going to be sleeping. So that was something I had to take into account.”

“There were a lot feelings that this is unfair. I work at the hospital, so I see a lot of crack heads with babies trying to get rid of them unsuccessfully and you are like, “Just give me the kid. I will take it.” So not fair.”

“That is the one that everyone has. Seeing this person strolling down the streets and dragging a child. That is unfair or during fertility treatments seeing women with the big belly walking in the street was very difficult.”

“When I see lots of kids who resist taking care of their kids having kids, I do get jealous. I do think it is unfair.”

“One time I had an episode of jealousy. About two years ago one of my older cousin (she is a year older than me) was pregnant for her third time, the third father and she is having twins, a boy and a girl, and my mom calls and tells me, I hang up and I was just crying. I have never done that before. I was angry and jealous because she is in no position financially to do this and here

she gets two at one time. I was jealous and that happened once. I was pissed, I am not that type of person. I have an episode and then I can calm down.”

“I never felt jealousy, but I did feel at times unfair especially when I saw girls on drugs getting pregnant. I was not jealous of them. I just felt that it was unfair. When I saw pregnant people or I would hear about pregnancies, the first thing that would come to my mind was “Gosh you are lucky.” I do not feel jealous because I always felt that that is their path. That is awesome. Do I want something like that? Yes. Do I want their path? No. Do I want my baby? Did they take my baby? No, they did not take my chance. I know going through the yoga fertility support group, that there is a lot of anger out there. People that cannot stand seeing a pregnant person, but I was always indifferent. My best friend got pregnant with twins. I was fine. Yet when the girls were bonding it was hard because I really want that. I was so happy for her. And my friend and I were close enough that I called her one day and said, “This is really hard for me.” She would say “No, this is hard for me, I want this for you more than anything.” I am like “I know you do.” But on purpose, she and I continued hanging out with each other even with the girls to where now they know me and all is well and I do not feel weird around them.”

“There is not a lot about that. It is just those moments when I see people who take it for granted. It just seems unfair.”

“Yeah, there is always the feeling that it is not fair. I do not understand why I have to do all of this when nobody else has to.

I felt it all the time, that was one of my biggest feelings, “That is not fair” and then you get upset with yourself and think, “that is how things are, things are hard. It should not happen to people who do not treat their kids right or who do not want kids.”

“I had moments of that and it would be when one of my friends would be pregnant without not even trying, she is forty-one. Yes, but it is definitely internal, I would never lash out, I never withdrew from my friends. I am happy for them, but still I had moments by myself that I thought it was just unfair.”

“The situation is unfair. At people who take their kids for granted I am being incredibly jealous. I have people in my life who announced their pregnancies and I am nothing but happy for them. I do not have a problem. I had two friends who both got pregnant within a week of each other. These are of my innermost *innermost* circle. One was my friend getting pregnant with a second baby who had to outsource for sperm. She had a miscarriage between the two and I was with her throughout all that. She was nervous about having another miscarriage, she could not be excited. I was like, “I will be excited for you until you feel safe to be excited.” At the same time, my other friend got pregnant on accident without trying and she had never wanted kids. She has always been so vocal about never wanting kids and she does this “Surprise! I am pregnant, it is great, we are really excited. We were not even trying.” I was like, “I cannot even look at you.” I have yet to meet her baby. They are five months old. I cannot even be in the same room with her.”

“Probably relates to other people’s pregnancies. Really with probably, go back to younger kids who get pregnant or teen moms and they are like, “Oh, I did not even mean to.” His goddaughter graduated college and she got pregnant. They told us right around when I had the hysteroscopy and surgery, so it was very frustrating. We had to go to her graduation while in pain from balloon shunt and all that, and having her talk about the pregnancy, what they are going to do, and plans with this boy. I was like, “Ugh, I do not want any part of this conversation right now,” People who are young and not trying and the unplanned pregnancy it really feels unfair. Even here, I work in a mental psych hospital and so we get people who come in with mental illness who do not understand the pregnancy and they are not taking care of it or they are abusing their kids. They are doing dangerous or risky behaviors around their kids. I am thinking, “You are not even good parents, you need to appreciate you kids. Or you had eight kids” you know kind of that unfairness there. We are old enough, we have the money, the support, and we have a house. We built a big house because we wanted kids and now we are living in this big house all alone, and so that all goes back to the unfairness.”

Depression

After failure

“I felt down after the IUIs did not work because it was a big deal working on those. After that we are not going to go right into IVF because my husband was not even onboard with the path up until that point. So it was just like this kind of big time change”

“I was definitely particularly towards that last month. I thought I might need some sort of professional help. I would feel depressed and down every month when it did not work, but as long as we are going into the next treatment I had hope. I could keep going. So when the IVF did not work, I wanted to know how soon I could do next transfer. I would not focus so much on did not work, as long as we can try something else.”

“After getting the results that it did not work. That is also when I felt the sorrow and grief.”

“I typically did not experience it, but after the failed IVF I did.”

“I would probably feel a little bit of depression after each miscarriage and the DNC. The week time when I knew that it was not working I would go through pretty severe depression with the crying and all of that.”

“I know I am definitely depressed but I do not think I was ever scary depressed. Definitely after a loss and then the decision making time of what do we do next. Also watching tv programs, there are a lot of shows that I stopped watching because one of the characters got pregnant. That would always bring me down.”

“I think more through the IVF process and afterwards I do not know if I could pin as to what it is. It could be a lot of things.”

“Just over the event. It was depressive, whether I was made depressed by it might have been another factor; I can get glum.”

On and off

“Depression, I would say some days I feel it and some days I do not.”

“That happens but that is mostly just related to my hormonal cycle. I get pretty midgrade depression every time I get my period, so it is just a recurring thing.”

“I tend to get mild depression and there were good days and bad days”

“It kind of depends on the day, or the week, what is going on. The last bad depression I had was when the placement hold started with the foster care. I saw my doctor and she started me on antidepressants, because it was getting really really bad. I was having panic attacks, just feeling that the world was working against me. I know that is not true and what happened with that baby is horrible and it has nothing to do with me. I know that intellectually, but it felt like all the doors were closing.”

No matter how much work I put into it, it does not matter

“It was a kind of low degree of depression for about a year. Just enough that it was not a concern but I it was there, I was always sad. Overall realizing that everything else in my life I can work really hard and do it and do all the things that you are supposed to do and then it is done; but this is not that way at all, that is not how it works. It is sad to realize that no matter how much work I put into it, it does not matter.”

“To some extent depression and frustration were the same in this scenario for me. There was ongoing frustration that nothing is working, which caused as an overall depression that nothing seems to work.”

“Just situational. We were a little depressed that it did not work, but you try to pick yourself up and move on.”

I struggled a lot

“That was sort of a thing with me anyway but it has definitely seen an uptake. I did hit another suicidal depression this past winter after the fallout with our donor. 2013 can go suck an egg. There were so many things, not just this, but so many things were just awful. There were some seriously legitimate reasons for feeling glum on top of my, what do they call it now MDD? [major depressive disorder].”

“I was struggling with severe depression. I remember being so mad at my husband and it was the day I was going to ovulate and I would tell him days in advance that this is going to be the day. I remember specifically two or three times when he chose to go out with his friends and his brother rather than wait the ten minutes it took to try and get pregnant. I remember being very angry about that and feeling he was not invested. I remember wondering if he even wanted a child. Lately it is more apparent that he does but the first two years I was wondering if he wanted the baby at all. And so that hurt our relationship.”

“There are moments that felt pretty hard. Before I was able to start doing fertility treatment, I had resolved into this lifestyle of be just single; so will be single and will be childless so go and enjoy the world. I did that for a while. I remember I would go to these beautiful places, nice beaches that kind of thing. I would sit in my hotel room just depressed. It was not until I really started making efforts to moving forward in the right direction, whether it happened or it did not happen, it was just the fact that I was able to do something, I did not feel so hopeless. That

moved me out of it, and until that point, there were some serious doubts where I was completely depressed about the whole situations.”

You get on

“Yes, lots of it. situational. But you get to the point where it is, “you are in it.” And I took more medication for that.”

“If you sit and think about it for too much, then you sit on your pity pot and feel a little bit worse for yourself. But going about my daily business it is not as consuming”

“All this stuff is very depressing but I do not feel like I want to kill myself or anything. It is nothing crazy drastic.”

“I definitely was not clinically depressed, but I was going to a therapist that helped me get coping skills and it helped to talk about these things. But I think there is a lot of symptoms of depression that as you are going through infertility pop up at different points and time. I am sure there is a lot of people understandably get clinically depressed.”

“it has hard for me to know what exactly that is. I have never been depressed. So I do not know exactly how it feels. Sometimes I have wondered if I am depressed because it is hard for me to get the motivation to do things. But again I think it is my exercise that keeps me from getting chemically depressed. I feel my emotions are depressed, but I do not feel my body is depressed if that makes sense. I feel like it is all situational because I feel this is just normal situational response to what is going on with your life.”

“It does not impair my life.”

“Not so much for me, but I swear this past week is probably one of my lowest weeks. I felt like I got hit. Normally I am really a positive happy person. I saw a therapist during IVF and she would

tell me my thinking is different from other patients because I knew I always wanted to be a mom. So it did not matter: adoption, biological, anything that was guiding me forward. But we had an adoption scam this past week with someone faking her pregnancy, that made me feel really low. But besides this past week, the most depressed I got was after the first IVF did not work, so I thought that was clearly the magic bullet.”

“I definitely was not clinically depressed, but I was going to a therapist that helped me get coping skills and it helped to talk about these things. But I think there is a lot of symptoms of depression that as you are going through infertility pop up at different points and time. I am sure there is a lot of people understandably get clinically depressed.”

“I do not really get depressed. Same thing with grief, the sorrow and coping. Those are emotions that I have experienced going through this it is situational. But for me it is mostly about how my wife is feeling or what she is going through because I do not have to. My body is not changing fundamentally, I am not doing all the shots and things like that. I learned when we are going through this situation with her dad, is that I cannot make her happy. What I can do is be there for her and let her cry, complain, grieve, yell, whatever she needs to do to get those emotions out. I think a lot of that becomes an act of listener as opposed to just letting her talk and ask her how she is feeling and let her get it out. And then other simple things like hey let us just go and take a walk and talk about it or let us go ride our bikes and you get out there. We are pretty active people and so that is something that can turn around a negative situation pretty quickly. So it is a matter of trying to do things and have fun, even just simple things like that.”

Sorrow / Grief

The grief of this not working time and time again

“I never really stopped to feel the sadness and the grief of this not working time and time again. So I really bottled it up for a long time, for years.”

“When there were probably failed IVF cycles and all these were really painful. And on the birthday, Getting older, yes there is lots of other triggers.”

“I felt sorry I could not change it and I felt bad every time it did not work.”

“There was probably grief throughout the whole thing.”

“Each cycle I was kind of grieving that it did not work, during the month I would talk to my baby grow and then at the end of the month there will be nothing.”

“After getting the results that it did not work, that is when I also felt the sorrow and grief.”

“Probably when a period comes. When I am having a conversation with my husband and he is not open to pursuing any more fertility treatments. If we are not on the same page or the placement hold will not happen.”

“I grieved a lot. Just every time. Especially that one time I was on Femara and I was a week late I really thought I was pregnant but I was not. It is really devastating and then losing my relationship and going to the grief of that has been hard.”

Loss of fertility

“When we got the diagnosis, I definitely had a mourning process, because you have envisioned your life a certain way and then you find out that it is not the way it is going to be, and you have to cope with that. It is almost like losing somebody.”

“I have after the last time when they removed the last tube, that moment when verdict was in. That week after I got out of the hospital, going shopping and everybody was pregnant. Every single one; every man, woman, child, pregnant trees. Everybody was just pregnant. I remember getting home, I was trying to be tough. I am handling this, I am fine, and my husband said, “You need to just cry and get it out.” This is like seven o’clock in the evening I started crying, and the whole night, that hold for like two days straight. I just do not think I have ever felt that kind of grief before. I had fallen from the sorrow in the grief but I knew at that point that was it. You know, it does not change.”

What could have been

“It has the grief in the morning that gets to me a lot. I remember very clearly lying in bed probably about six months ago and just thinking about the kind of family I want to have. I want to have four children like my mom and like A’s family. I want to home school them and I want them to all be close in age because we were all two years apart and that worked out really well and we were all really close together and we were very proud of Czech-German heritage. So I want my family to be all these little Czechs running around all close in age. I think my husband and I have really good genes to pass on. We are really smart, we value family. So I want to have genetic children and I want them to be close in age so they can all be friends. But I was thinking of the actual realities of that happening given my age if every child takes three years to conceive. So just thinking of the actual realities of being able to have the kind of family that I always thought I could have it felt like a sword in my stomach, just like a sharp *sharp* pain. And just feeling that like grief and mourning. I do not know if it is ever going to be ok.”

“That is high because is just hard. You have sorrow for what could have been, thinking about that. You know all of those things.”

“Just sadness for the fact that you lost. In my head, I could have lost the ability to have our family or we did not know how it was going to happen.”

“I think it is important to mourn the loss of those dreams that we had and to get yourself off of that. That was undervalued in our culture and I really wanted to give myself space to feel that. So I felt it, but I do not necessarily think that it was a negative thing like I should feel that and make room for that.”

“Just talking about things he will come up with, “You know if we had a baby, she will be this old now.” A couple of weeks ago I thought, “Geez it was two years ago today that we had surgery from miscarriage.” It was kind of anniversary, birthdays, being around my friends’ kids who are the same age, or even just being around kids. Not kids, but like friends who have kids. I love kids and I am happy for my friends. I want to play with the kids and I love them to death. But it also feels very empty that you do not have that, or friends posting funny things their kids have done or they dumped flowers what a mess. I think, “Gosh, I would love to have a mess.”

Every loss

“Numerous occasions we lost a child and that was very depressing very great sorrow, great grief and there is just no getting over that sorrow and grief that you feel when you have a child and then again that causes more depression and that happened on a number of occasions.”

“Very high after every loss, but still a little bit now. I still feel like I am grieving a little bit even though I know that is inappropriate. I feel like the anticipation is tireless, some are treasured with that grief and that is wrong. I feel guilty about that.”

“Well, close after certain episodes: the tubal, the miscarriage.”

“Because of the miscarriage. That was a rough time.”

“Even if it is early in the pregnancy a loss is a loss, and that is always a grief and something that you are going to remember that there was a child.”

Coping

Not afraid to ask for help

“I think we did a really good job of coping. For living I work with cancer patients, young families and I teach them resiliency, coping and self-care. And my dad had cancer when I was a teenager. Working with teenagers of parents with cancer every day I was able to easily remind myself of the things I needed to do to take care of myself. I was not afraid to ask for help and get a therapist. There were no stigmas attached to that. My husband was around when my dad was diagnosed, when he died. We had been through that as a couple. My dad died six months before we got married. We had already been through really difficulty together as a couple, and kind of had worked through a lot of our crooks, so we were not afraid to ask for help or to realize we needed vacation from med or let us get a massage; just a lot of self-care. Communicating was hard but we at least realized we needed to do it even though it was not the easiest.”

“Normally I am good about coping. I saw some of the IVF therapists in the beginning. I did meditation and relaxation techniques, which are actually still in my mind. One of those meditation techniques was to stop repeating negative thoughts in my head. Doing that was kind of amazing. It was a breakthrough. I do not have to think about it that way. But I have not done meditation in a long time and it is getting a little hard because if we had already adopted by now or if the surrogacy had worked, I think I would be in a different place now. I am still in that boat of if the surrogate starts cycling in June it is still going to be another, another nine months before a baby, or what if it did not work, So I am like, “oh another year ticking by.” So that is the coping part that is getting hard now. I just decided to go see an infertility therapist here. They turned us into small groups; some are meeting next week with. She was highly recommended by the resolve group leader and a couple of other women in the group are seeing her. So we will see how that goes. But I have not done any infertility therapy since the early days of it.”

“I do not think I am the best at it, but I do not think I am terrible at it. I am going through therapy to help me cope. I am trying to do all those other things like meditation, yoga and acupuncture. So I am making effort towards being better at coping.”

“I did a lot of distractions like finding hobbies and I never found a hobby that would sustain me through a long period of time, but I would find hobbies that would occupy enough of my time. It was mostly distracting techniques like breathing exercises. I did some meditation, meditation was good. It was time commitment so I have not done it in a while but it was good for helping especially with the anxiety.”

“I feel like I am doing ok. Seeing a couple of therapists helped a lot. She was really helpful, she had gone through infertility herself, which is how she got recommended to me. The massage helps a lot just for the stress. When I switched from acupuncture to the massage it was no longer so sad when I was not pregnant because I could go to get a massage. So it was, “Ok I am not pregnant but I can get two massages this month instead”, which is good because you cannot have a massage when you are pregnant. That really helped, to have something to look forward to even if it was not a baby.”

I do not let things affect me too much

“I am doing ok. Obviously it is hard for me but I do not go through everyday thinking about it. The whole thing for me it is thinking of all of the things I can do because I do not have children and all of the things that I can take advantage from and all this: - Look at this study this is a couple happier without children – and you are like: - Well...[laughs].”

“Overall I think I am a person who handles things well. I am an optimist, very easygoing and I do not let things affecting me too much. I just do not worry about things because I am not going to change anything by worrying so I do not let myself do it and it sounds very easy to say but I think it is just a character trade of mind and I find it easier to not worry.”

“I think I cope well. I stay busy. I stroll myself with friends. I have a lot of interests. This was a big focus, but it was not my sole focus all the time.”

“I coped well. My coping would be communicating and holding.”

“I think I am pretty good at coping. Just spending time with my husband, going on trips, trying not to think about it and live your life.”

Have some support

“I am really good about coping. I talk with my husband. We have a great relationship that helps me through the process. So without him I do not know if I could handle part of or any of this process. So my coping is pretty good.”

“I had my wife and it is easier when you have somebody there with you. At times I would think about a single woman having gone through this, that would be so hard, granted she would have support groups through online or she may have some friends, but they can only do so much if you do not have somebody really there with you, I cannot imagine that.”

“At first we would all have longed to finding a donor and finding a way to make it happen. Now we are a little bit more reserved after that first fall out. There are tools available even if they do not always feel exactly the right tool and the right fit for me. I have people in my life I can talk to, so that is pretty great.”

“The coping got better when I had other people to help at the support group. That was definitely the best way. One way was keeping things going. But really finding the support group made a huge difference for me.”

“I think the support group helped me so much, and the fact that they were strangers and they opened up to me and I opened up to them. I did not take any friendships away from it, but to be

in a room with people who know exactly what you are going through, I would come out from there feeling better every single time.”

“Either than that IVF, I was always pretty good at coping. Thankfully it did not take me that long to get pregnant with my first daughter and I remember sitting in the fertility doctor’s office, and see the anxiety and despair on some of the women’s faces and me just thinking, “Thank God I have my daughter.” I was always able to cope because I had her. Not to say that it did not want a second child, but I always felt very blessed to have her, so I was able to cope with everything just knowing I have one and that is a my blessing. So she was always able to help me cope.”

“There is good days and bad days. Of course I am doing so much better now that we are going to do IVF. If we would have had this conversation a month ago I would have not been in such good spirit. I like to get outside, walking, I go down to a spot I found by the river. I have a Godson. An old friend of mine I recently came back in contact with, we knew each other ten years ago. She has a two year old, she is single parent and she really has a hard time, life circumstances has not been easy for her. She has depended on me a lot, which has been a good thing because it is given me a way to get out of myself and help her and her son. I have spent a lot of time with him and she was so sweet and asked if we could be his godparents. I had him this weekend and we just get along. Spending time with him has been a huge joy. I have talked with other women who have had struggles with infertility and for many of them being around children is difficult. I can understand that. For some reasons with him we have this connection, he really clings to me and that feels really good. It would probably be different if the kid did not have such positive feelings for me. But he really likes me, sees me as his second mom in a way because we have been around them so much. That has been a real good positive thing.”

My emotional reserves are depleted

“I was pretty good at coping with things that happened. I never had to deal with terrible things, but stuff happens to you. You do not get the grade you wanted. You do not get the job you wanted. Your grandparents die or something like that. I feel I was always able to cope with those

things pretty well. With this I feel my emotional reserves are depleted. Everything is a bigger deal. It feels like everything that happens with infertility is a huge deal and it is the end of the world. My emotional reserves are very low. I would say, I am not doing very well with coping.”

“I feel I am not coping even with the medicine. Today I just told my endocrinologist that I am less hopeful. It just made me cry. I am seeing a psychiatrist who has given me a list of therapists but I have not contacted anyone. I did do a little bit of therapy, that ended right about the time I went to the psychiatrist, but I felt that the therapist was not helping me. I could share my stories and we could have a good time but I felt it was not helping me, I was not getting better. We could sit and we could talk and I could tell her everything that I was feeling and experiencing or refusing to do like I did not go to work two days just because my stomach hurt. On a scale of one to ten, a one but I did not go to work, ridiculous thing, and I was not getting better.”

“The therapist said I need to let her go because I am like holding on to her and she is not here. Acupuncturist told me the same thing, That I have blood stagnation in my belly like I am still holding on. So coping...And coping every month, that does not happen, it is like it all starts over again. It is hard for all the same emotions that cycle around. So coping, I am trying to cope. I am trying to focus on other parts of life that do not involve getting pregnant.”

My coping skills were not the best

“That was hit or miss. I would say my coping skills were not the best. I do not think they were healthy coping mechanisms. I would usually drink wine as soon as I found out it did not work, or I would go get a big mocha latte or get something that I had been starving myself for. I did not have too many people I was sharing this with except for my husband and my parents, and my husband was not always there. So coping was not very good. I did not cope very well.”

“My mechanism used to be to cry. I would let myself be in that place for a while and then my husband and my family are good people and they would talk to me. I process a lot inside. Coping is important.”

“I feel like probably I did not do a very good job.”

“Boy, is not coping just surviving, like the energy to survive? I was able to cope with bad results. Like ok, that is the result, move on, next step, come on. That is the only way I was able to cope.”

“Some days it is harder than others. So I think overall we do OK. Probably nothing healthy. I isolate myself or I sit on the couch, watch mindless TV. I probably should work out and lose some weight. I do not want to talk to people because I have talked all day. That is what I do all day and so it is more of just kind of isolating myself, doing nothing and zoning out. It is probably not terribly healthy. I am sometimes an emotional eater which is not helpful if you are gaining weight either. You kind of eat better and in healthy way it all binds, ties together. I read a lot.”

“I did not cope really well. I mean, I went back and forth. I had all the time coping at work. Before I started fertility I was just a rock star. And things were going great, make money and all that. I just was doing my job all the time. All the infertility just happened. I just was not able to give it when I did, and it was just, yah. You put everything on hold for this.”

Keep busy

“The other thing that I notice about us, when I say us, I am speaking about women who are dealing with fertility, is that we get really good at throwing ourselves into other things, work, books, whatever. I was working many hours just for the fun of it because I did not want to have to come home to myself, even talking to my husband. Yes, you can come up with ways to cope through it. Then I have a really supportive family. So that is been helpful.”

“I felt I coped pretty well even though a lot of it was me on my own, which was not the best. I do some journaling and also probably maybe keeping busy. I just start to exercise more and that seemed to help; doing something positive and dancing. I like to dance to cope.”

“The frustration is you do not have much control. That is the problem with coping. Coping in my scenario was more about almost passing time and trying again, more that it was about being very proactive and doing things to proactively impact next go round...so coping from my personal experience, maybe not from my spouse was more about hanging on and trying again.”

Hope

False hope

“I was hopeful that it was going to work, some of that could have been driven by the doctors prognosis. He seemed like he was hopeful too. Though as it got worse after the lining and all that I felt I was wrongfully hopeful and I was pretty torn.”

“Lots of hope on the entire process. Some was a little bit of false hope when the doctors would say keep going, keep going. But hope nevertheless. Also as you try to change from one technique to the other, you go from IUI to IVF, there is an additional hope because this is the next level, the next best opportunity and then you hope the transplant succeeds in a successful pregnancy.”

Losing hope

“With each miscarriage I just would lose a little hope, you just cannot help it.”

“It depends on the day. I think with the treatments, even though they were not working and that was really frustrating it was hopeful that potentially it could/might work. This might be our time. There is sort of that hope every month that this could be it. Now without treatment, there is still some hope that something could be working, but I also feel it has been two full years and so it is probably not going to work on its own. I think I have less hope doing nothing. We are doing nothing to not stress about it, but it is a little but more stressful to have less hope, so it is little bit counterproductive too.”

Afraid of being hopeful

“I am losing again actually I am starting to get to the point where it is probably not going to happen so I need to focus on how my life is going to be without another child. So my hope is to get this grief out and move on, but I am kind of losing hope on having another baby.”

“We had a lot of hope early on during the process. Then after the second IVF, hope was out of the window. We were still trying things but I every time we felt hopeful, it felt like we almost immediately got punished for that. I would lie to myself each time she got pregnant. It was like ok, this time is going to be different, and you start to get excited and you start to make plans. You start to look up daycares and then it did not work. And you feel like well that was my fault because I thought good thoughts about it and we started to get ahead of yourself. that it is probably one of the most painful parts about it. We are very hopeful right now.”

“I tried not to get too hopeful but it was definitely out there. And then it goes away.”

That is a roller coaster

“It has hard for me to have hope. I feel when you have hope and it does not turn out right, then you are a fool for having had hope, joke is on you. So when I do feel hope I try to squelch that because I do not want to be proven a fool. It has hard for me to have hope. “

“That is a roller coaster. Sometimes you are very hopeful; I cannot say that I was hopeful the whole entire time, but I think we always had it; like it never went away. Had it gone completely we probably would have just stopped.”

“There were definitely some very non hopeful times. I just felt like this is never going to work and only recently we have been more hopeful.”

“Hope is something that I am struggling with. I have some moments where I am very hopeful and excited, like two Mondays ago when I thought I was going to do my transfer and I thought I am going to be pregnant in a week. But 90% of the time I am anxious and stressed. I try to focus on those positive moments, but I feel that we are keeping defeated. But then like we have four frozen embryos. That is really positive and very hopeful.”

I had lots

“I had lots of hope. It was tempered by facts but no, I had hope.”

“I remained hopeful while putting my body through it.”

“I do have hope. It is not a constant feeling.”

“I definitely have hope for the future, I can envision a life for myself without children, it is not necessarily the one I would have picked but I do not feel I will be unhappier for it, I feel that it will just be different than just the one I was expecting.”

“It is easy for me to be optimistic and say, “It is going to happen sometimes. I feel like it is going to happen.”

“I am pretty hopeful. It is weird, every time we get pushed out, I am still hopeful that the outcome will be great. I think it is easier for me because there is that part of me that is pretty hopeful that we will have a great life without children. So I am hopeful both ways.”

“I am hopeful that maybe one day things work out either way and I am going to have kids, they are just not going to be mine.”

“High because I know 100% it is going to happen with adoption. We are on this track no matter what. I have decided if something does not happen in the next year and a half I will try again with a facilitator or possible lawyer.”

“I think it was probably the sixth month after the IUIs. It was a pretty low point and that was the time when we were going to try just relaxing. Then I did say to my husband, “I am going to take my temperature. Now we had to keep knowing what my body was doing.” So I was letting him more into the process. So even though I had reached the lowest point up to the IUIs and I was pretty drained from it all, at the same time I was trying to get hopeful and wanted to try something together. And I was in therapy and my therapist kept trying to give me tools to make me realize that I was doing too many things on my own. We worked a lot on that, and that I would include my husband.”

Very low

“I am still in denial about fixing it, that a miracle could happen. I can hope still, but it is pretty low.”

“It destroyed my hope. I’d say it shattered my hope.”

“I did not have very much.”

“I would kind of lose hope at the end of each month, but then if I had another treatment coming, then I had hope that that one was going to work. So that would keep me from getting too low. Also, when sometimes during the two-week wait I would have a lot of spotting, I would lose hope halfway through and I will be like “well, it is not going to work again.” I also was bad about taking home pregnancy test. So even before I got the official No, I was already in my down negative moods. That was when I would feel the most. So that last probably the last week of my cycle when I was either sure it was not going to work or you know when I knew for definite it cannot work.”

“I have cautious hope. At this point, I am just thankful for having the opportunity to try. I did not think that would even be a possibility. Even if at the end there is not a little one of us running around here, for me I just feel blessed to be able to try it because a lot of people do not even get this far in the process.”

“I feel I did not have hope and I did not think it could work, but I am one of those people that looked to the worse like, “Ok, this is not going to work this time. What are we going to do next?” I was always thinking about the negative side of things because it is really hard to think that is going to work and then not have it work.”

“Like I said, there is sperm everywhere. If I really wanted some, I could get it. But my dream is never going to be what it was. Even if it is a really close second there is no guarantee that it is going to be that close second.”

Love

Pretty strong

“I mean just spending time with my family. I feel a lot. It is pretty strong.”

“I think our relationship was really strong. I think emotionally the only thing that kept us going was our love for one another because we were so strong. We knew that when I was having low moments then he would take it on and vice versa.”

“I love my husband. I felt like it was comforting that we were on the same page and we have the same values and the same level of commitment toward the process. I feel like if I had been super insisting about IVF, he would have supported me; I do not think there would have been any problem. It is just that so happens that, we both feel the same way, we are willing to go to this point and then we are evaluating going further when I am a little bit older and we do not have a window opportunity anymore and we have to decide.”

“Overall I felt so supported by my husband, and we are in it together and we knew that whatever the outcome it was not going to change us.”

“High because during all this time even though the other five girls had their babies now, like just for valentines’ day I send all the babies little packages and stuff like that.”

“My level is very high. I know that my husband loves me and I love him. We will make it through this if we do not get a baby, but we do get a baby it will be amazing.”

“I feel pretty loving all the time. Even when we hang out with our friends that have small children, I love hanging out with them. I think it makes me stronger.”

“I felt I love my wife even more going through what we have gone through.”

“Love is tied into so many other emotions. I loved my doctors at times. I felt they were helping me and I was really thankful for that. I love my husband for doing this and my parents for supporting me. So it brought out a lot of love.”

“It got us through it all.”

“I have a lot of people that care about me and I care about.”

“Yes there is lots of that.”

“Luckily even though my husband and I were not necessarily able to grieve in the same way or deal in the same way, our love for each other was not affected.”

“I always knew I had love around me. My husband, no matter what we were going through, I still knew that he was there, and friends.”

It tests you

“You do this because you want to have a child and you want to love it. Continue to love my husband, but it is hard, this it would test your strength.”

“Curious. I feel like I always had so much love to give. Even though I hated people passionately like everyone, I still have love too. I still had love.”

“Highs and lows. *Highs and lows*. I do not know. We went from feeling lots of love and support for the people around us and within our marriage and really leaning on each other, to feeling there is a lot of distance, just a lot of distance.”

“We have love to give to children that we do not have, sort of like unused energy. But no space to put it. So it is just kind of bundle of energy, cells that you cannot designate. I think that at the end of the day it probably brings us closer because it is such a difficult thing, it is like this unresolved grief that you cannot resolve. We were able to talk about it and help each other and support each other, I feel we are not blaming each other and I think that is a big piece. I think it has maybe brought us closer. If we can do this, I mean nothing else could be this bad.”

“Love. This is kind of interesting because I think it does somewhat bring you and your spouse close together. You love her more at the same time all the frustration and depression that goes in there kind of drags that down a little bit as well.”

Focused on the outcome

“I think you are going through the process you are focused on the outcome, at least that is how I looked at it. “I love you but we need to do X, Y, Z and Q” and that is probably something that I could have improved upon.”

“It was not very high just because I was not feeling the best about myself. I felt a lot of love from my husband and a little frustrated with him and us.”

“Love does not fix everything.”

Excitement

Lots

“I think there is a lot of excitement building to this, because doing all these different procedures felt hopeful that this could work. I would definitely try to embrace them. So I tried to get behind everything we were doing.”

“Yeah. It is exciting to do it because you think it could work. It is your best chance to carrying a baby. So yeah, definitely.”

“When you get a positive test result, a positive pregnancy test, it is exciting but we are always very cautious. Never got too excited.”

“I have moments of excitement. Definitely excited at the opportunity and excited about getting pregnant. But there is always this “if”. The “if” is big for me.”

“It is pretty high, I am hopeful but I am also still a little cautious. I try not to get too excited. I definitely get jazzed up every time we hit a milestone or every time we start a new cycle, but I try to keep it contained a little bit just to not get overly excited.”

“I was pretty excited at the beginning and at the beginning of each procedure. For the last IVF I was also very excited.”

“We were excited by the process, it is really thrilling.”

“Yeah when you find out you are pregnant you get really excited, so it is very high when you find that out.”

“There were times when I was very excited like when ovulation, testosterone, and everything seemed right. Yes we are going to do this and we found the right person and this is going to be great. It has been a while since I felt that excitement but, there was at one point.”

Wears off

“Yes, very limited occasions when the pregnancies came back as a successful pregnancy. Extreme excitement, extreme elation during those periods. Unfortunately that did not get to last for me. The excitement about keeping going and continuing on with the process, there is a little bit of that at the very beginning but it wears off very quickly after about the third IUI treatment.”

“Obviously now we are super excited. But I do not know that in the mix of it that there was that much excitement. I think maybe in the beginning the thought that this could work, we are actually getting help, but that faded very quickly.”

“It is really hard to get excited about things even when I was pregnant for those couple of days I did not allow myself to get excited because I knew that the chance of miscarriage was pretty high. And then I was glad I had not called everybody and I did not buy baby clothes and such. So I was actually glad that I had tempered my excitement.”

“I was excited the very first couple of IUIs where I thought this was going to work. The doctor thought she knew what was wrong and this was going to work. But then with more treatments you are not excited it is more the stress, the fear, the anxiety than the excitements.”

Ups and Downs

“It is like almost an all or nothing thing because your ultimate goal is to have a baby and it there are all these huddles you have to go through and it is like, “Oh got through that, got through that, got through that. Bam! You are back to here.”

“When they retrieved twenty-two eggs and that sounded so promising, that day I was really excited. The next day when only one had fertilized, I was not so excited. So I had a lot of ups and downs.”

“I kept excitement on reserve. It was exciting to know that we had a frozen egg. It was exciting when we did the frozen egg transfer and the eggs bore well. It was exciting to see that I had nineteen follicles but it was very disappointing to see that we end up with only one first one and the unfrozen one. So you get your excitement. Right you go up and down, up and down constantly.”

“You have good days and bad days, not let your mind go to the bad place, you have to try to stay positive. That is the only thing that helps me just be hopeful and praying that it is going to work. You do get excited sometimes, now I am excited thinking that it is going to work. The donor started her medicine today. I started my estrogen patches about four days ago.”

Low

“Excitement I would say low, nothing really exciting you know right now.”

“That was tough.”

“No, I do not think there was a lot of excitement. I did not feel like it was a fun process. At the same I do not worry and I do not put a lot of stock to it because I do not want to come crashing down.”

“None of this was exciting. I did not feel any excitement. I guess in the very beginning when we started trying I envisioned that everything would be fine but none of them worked.”

“Not until we got the good news.”

“I just did not get excited about anything working. I could not.”

“Oh gosh, hat is so little excitement. There was nothing to be excited about. There was only sorrow.”

“I feel like it is hard to get excited about things. You are just kind of in this perpetual state of blah.”

Happiness / Joy

Not much joy

“I do not have much of that lately.”

“I would sometimes feel happy but not like I would have before.”

“It is hard to separate where we are now from during the whole five years compared to these six months. These six months it is been huge but as a whole there is not much joy and happiness. Even though there is lots of love and there is lots of support from each other, there is not much joy and excitement in the relationship and the marriage.”

“Throughout the whole process as you look at the entire thing, there is just not much happiness about trying to go through this. The happiness and joy of the IVF working was a five, everywhere, but the process, not knowing what your outcome would be keeps it pretty low.”

“I think we were probably ten week when we let ourselves experience any joy. And if there is any joy in non-fertility that was always hard, like am I allowed to be joyful.”

“I have been able to experience happiness with some other things that is been going on in my life. So it has not completely gone.”

“I would not say I experienced that until the very end when it finally actually did work. But along the way there was not really too much, so not until the very end the happiness and joy.”

“I have low moments with this experience. I am not saying that I am not happy overall, but with this experience is not a lot of joy quite yet. Hopefully soon.”

“I do not think there was anything that was about happiness or joy in that other than when I was pregnant the first time. But then when I miscarried it was like much worse than happiness.”

“Lots now but as far as the infertility experience... It is just tough. For lack of a better word, it is just a tough experience.”

“Well, it never worked. So for me I really never had that.”

“Everything that could be construed as positive news to me needed to get tempered by the fact that this is just a linear part of the process, the end result tells the tale and so I just refused to get too excited or too happy that would ring as a bell, that strikes a tone at me until such that time that was proven out.”

“Not regarding this experience.”

Find it in other things

“I have had some really great moments of happiness and joy during the time we have been dealing with this but none of it was directly related. It was more like I was happier and joyful in spite of dealing with this.”

“I think we always relate it to how much happier we think we would be with children.”

“Probably when I am not thinking about infertility, when I am with my godson, when my husband and I are having dinner. We have been watching different shows and being with each other and just kind of have a normal life.”

“Overall I am pretty happy but it is hard to be super happy when everything that is going on is seemingly negative. So, I am generally pretty happy. I get a lot of joy and happiness out of each step. Like when we retrieved I have many eggs, that was happy. That was a joyful occasion.

Then we made for embryos, that was pretty awesome. We have not had some of the super negative experiences yet as far as an embryo not working.”

“You know there are a lot of things that I find happiness. Like with the foster kids, when they are around, you feel joy, very happy. You know I have had a lot of blessings.”

“I think the process was not fun, but we tried to live our lives as normal as possible through it. We have pretty happy lives.”

“I continue to try to stay engaged and notice the beauty of the world and everything.”

Acceptance

No acceptance yet

“No. I still try to get there. You think, I would have accepted it by now.”

“At some point you have to accept where you are at and I think I have accepted or very close to accepting the fact that it may never succeed. I guess the good thing is it takes away some of the stress. The down side is it kind of allows a little more depression and insecurity to set in.”

“I am working on that right now. Accepting that it might not happen.”

“I feel like I can accept not having kids.”

“Not really because it happened so fast. I think theoretically I was saying, “If it does not happen I will be ok with it” but practically I was not there yet.”

“I am not very good at acceptance. When I found out in January that she was pregnant I thought surely I will die, I will just lay down on this floor and I will die of grief and sadness. I refused to believe that it is happening and I am just going to lay here and die. I was actually really surprised at the end of the month that I did not die; that I was not dead and not that I was in any danger of harming myself. I thought that I would literally be unable to exist in a world where she was pregnant and I was not. Amazingly I was able to exist that specific situation.”

“There have been a few good things, like sharing with other people. But by large it has been a negative. You know a lot of people say that they got a lot of good things out of their struggle with infertility. They got closer to their husband or they gained a greater understanding. I do not feel I have gotten anything out of this. I feel it has been nothing but *crap* [sic] the whole time.”

“I accepted that I had this problem and I wanted to treat it. I still was not at the point that I could accept that it was not going to work.”

“Maybe because I was not that accepting of the situation is why I kept going. The fact that I had been pregnant when I was young, I got pregnant on IVF cycle, I kept producing a lot of eggs, the doctor’s prognosis was good. Because all of that maybe I was not so accepting so I just keep on, and there was a part of me that was wondering why they call this infertility. Why do not they just call it fertility? why do not they spin it?”

“That has been really hard for me. I felt it was hard for me to accept that it was not working because all of the test results indicated it should be fine. So it was hard for me to accept this possibility of chance and circumstance. Even though that is the case, I just was having a hard time accepting it.”

“I struggled with that sometimes. When you keep getting negative experiences and there is negative pregnancy test, and having to be on birth control knowing that you are stagnant and cannot do anything, and accepting things have not control over”

“That is a hard one for me. I am still trying to come to terms on what is acceptance.”

“No, I did not have hope but I was not ready to accept what we were going through, I do not know if that makes sense.”

“I feel like with each other we are fine. I think that that is probably a pretty frustrating and I do not think that we have ever fully accepted why.”

We have accepted it

“I think we completely accepted our situation. I think it helps that we had the diagnosis. I cannot imagine when it is unexplained. It will be really hard to accept that. For us I think it is different

because there was a very clear diagnosis, a very clear medical reason why this was not happening. If you accept it, then you accept what treatments have to happen. If it was, “we do not know. Just keep trying” probably it would be different.”

“You cannot change it just because you accept it, it does not mean you are going to be infertile all your life and not have kids just because somebody told you. You are infertile that is just a diagnosis; there are ways around it.”

“Along the way, you accept the failings of your body, but it is not an easy thing.”

“There are some positive. I think I am a better person from having gone through this but it is not something you ever want to go.”

“I think, I have accepted the fact, that I have this issue. I am still frustrated that I had to do this, and we have to go through this. But there is really nothing I can do, it is something out of my control. I think it will be another hump if we do not get pregnant having to accept that.”

“I have accepted we have been doing it for so long and it is just a part of our schedule; almost our routine.”

“You got to have that. You got to have a lot of acceptance.”

“That was the hardest part, accepting. I am fine now, but for four years I was like, “This is bullshit! It is going to happen.” Now I have accepted that it would be a miracle if it happened without treatments. I have accepted what is going on.”

“I have accepted where things are and the whole process and where has led me to be as a person and how I grew from it.”

“It took me a lot but I did accept my infertility and we were going to do the donor egg. Once you accept it just the way to lift it off your shoulders. Then we decided not to have kids and that was just another way to lift it off. Yeah, I have accepted it, eventually.”

“I have accepted it, but it is still, I still have this, “This sucks. It is not fair.”

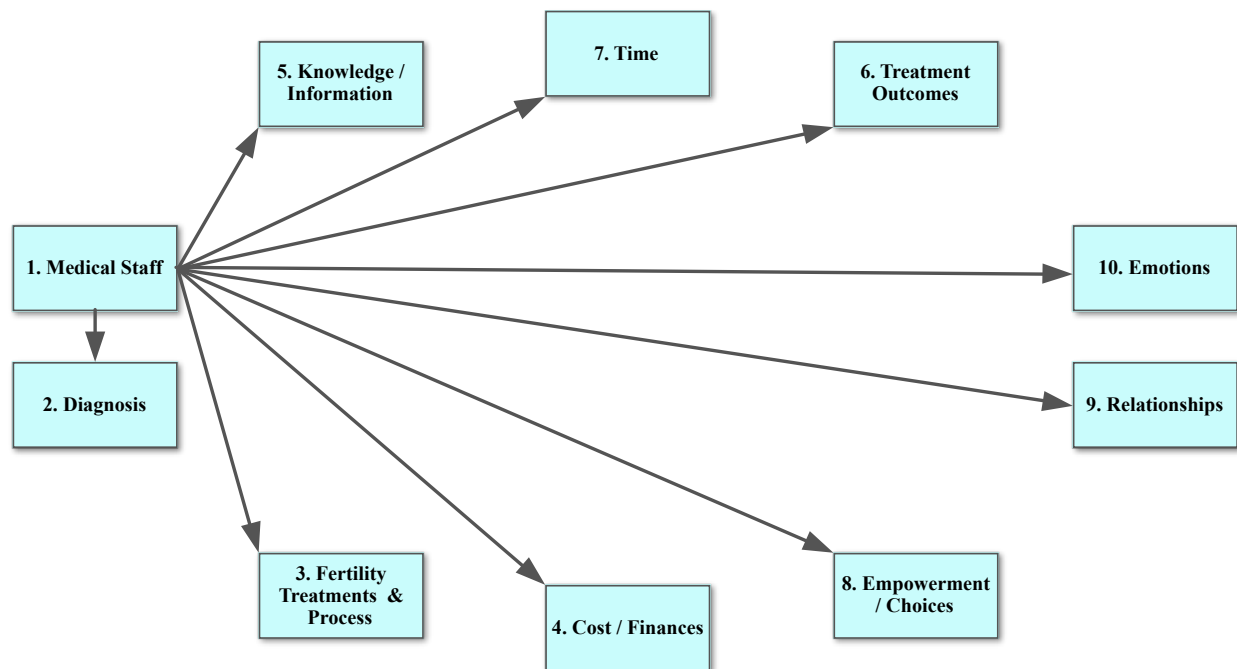
“I was able to logically accept stuff and do what I had to do to go to the next step. I think acceptance on an emotional level is something that takes time, so you just repeat to yourself, “Ok, it did not work out. We did IVF and we got a negative.” You have to understand that, you got to accept that it did not happen.”

CHAPTER 5: ANALYSIS OF THE INFERTILITY TREATMENT EXPERIENCE SYSTEM RELATIONSHIPS

In the previous chapter, the researcher conducted Axial coding to pair quotes across participants with the themes. In this chapter, the researcher conducted Theoretical Coding in which participants were presented with each possible pair of affinities and asked how they are related to each other. All quotes about any particular affinity pair were grouped together into common tables. This table was then used to create the System Influence Diagram (SID).

The System Influence Diagram (SID) is a visual representation of an entire system of influences and outcomes. In developing the SID, all of the affinities are arranged according to the Tentative SID Assignment chart and created with a flow chart or “mind-mapping” software program, such as Inspiration. The researcher began by placing the affinities on the screen in order of driver (most important cause) to outcome. The first version of the SID contains all the quotes even those that are redundant as well as all possible relations among themes and so it is referred to as Cluttered. The redundant quotes are eliminated and only relations among themes identified by multiple participants are retained so there is a clean diagram.

Medical Staff Influences



Diagnosis

“The diagnosis is dependent on the medical staff ability to analyze the information. The more knowledgeable the staff is the more they are in tune with who you are and your relationship, who you are and where you are heading, the better diagnosis they are going to give. They were the ones telling me what I should do and what information they needed to come to a certain outcome. They were the ones looking at the test results and doing the different tests. Through the exams, through the labs, that they had to administer to understand what is wrong with me and then give me a diagnosis. So they had to be a big part of administering the process to get to a diagnosis. Had the doctor not ordered the right test, we would not have known that my husband needed treatments. Medical Staff are the ones that decide the diagnosis and you have to decide if you trust the medical staff. Here they did a stellar job, we were not concerned that we were going through endometriosis. They had it figured out, they knew what they wanted to do and we agreed with their plan.”

“Because we went to multiple doctors, the diagnoses are a little different from each doctor. I feel there is more than just their opinions that are driving the diagnosis. Doctors have different opinions and an example would be the medical staff not diagnosing my endometriosis. That was huge. I believe if I had had a different medical staff, we would have been diagnosed a lot sooner. I have the poor medical staff that gave me the bad diagnosis.”

Knowledge / Information

“A lot of your personal knowledge [comes] from the medical staff. It just depends on what information they give you. How much do they share? Some are much better than others. The most information I got is through the medical staff. Depending on what staff or what nurse you are assigned to [that] can affect knowledge and information that you receive. The nurses are better than the doctors [and] I think that is one place that they can change. We go to doctors to get that information, we are at their mercy. You might do information seeking on your own, but whatever they tell you, you are going to go with that. I just do not know why we did not do more research on our own. I think it is because it is medical and maybe it is a societal thing where you trust the doctor because they are doctors and went to med school. All I know came from the medical staffs.”

“Much information is sought from the doctors. The doctors are the ones who share information with me about what is going on and often that gives me a starting point to look for information on my own. Because they plant the seed and then tell me everything they know and I take it upon myself to seek more knowledge. They have all the knowledge initially. Until you know what is going on, you can research anything, but you do not really have a way to know if it is applicable. They provide you some of the knowledge and answer the questions. I felt they had the information and I had to go and ask. You ask what they know and they tell us. For example, you go to your doctor and you ask “This is what we are facing, tell me what I need to know about it. What can I do to improve our chances?” They impact how much I would know about what was going on with me. They were a big provider of my knowledge, diagnosed me with endometriosis

and telling what that was and that is why I was having the pain. They would give me this statistics or this percentage of it working.”

Fertility Treatments & Process

“The medical staff recommended the fertility treatments, they conducted them. It is one of those things where you show up and they tell you here is what we are going to do and not necessarily why. You are at their mercy, whatever they suggest you do. Because they are calling the shots! They are the ones who decided the treatments and which protocols to use. They were doing their job, fertility treatment is their job. They have the technology, they have the insight, they have the tools and the equipment. There are some things that this doctor’s office has been able to do just because he has a really strong network.”

“They are the ones recommending treatments or processes, or telling you what your options are. They were the ones who were orchestrating it, they have to sign off on it. So your relationship with your medical stuff and what they provide you determines your options for it. But they certainly outline the steps and the treatments. They make the recommendations and decision basically on what you are going to do next. Sitting down with the doctor we drew out a plan and we knew what our treatments and our process were going to be. They tell you where you are in relation to the process, so the medical staff tells you, “Ok this is your status quo, this is what you can do and what is happening and what you need to do and then that is how you go from diagnosis to treatment.”

“It just depends on whom you are seeing, what their mode of treatments are, and what they feel. For example the doctor just outlined everything and said, “I see this going and this is what you want to start with.” Obviously he knows more than I do, so that affected what we chose. All the fertility treatments that we went through are based on the doctor’s recommendation. They would give you a few options once you were diagnosed, I could do a surgery and then starting off the Clomid or going straight on IUI, so I was always given as many options as possible with most of my processes. My reproductive endocrinologist would tell me my options, you can do IUI or if

you try IUI only try so many and then we recommend you do IVF. They would give me the options and then they do the treatments.”

Time

“They are always working on time frames. It is not always about you. As far as scheduling, it is very time oriented, so it is time sensitive. Everything they dictated, the time, the schedule. We were oftentimes dealing with the schedules of clinics and the doctors and when they could fit us in. It depends on how busy the clinic is and when they can schedule you. If they run a good shift it is more efficient, which affects your time. You feel if they are effective and efficient and they care, they are not going to waste your time, they are going to try to make it efficient for you.”

“Depending on how aggressive they are, when they are performing the treatment. If you are seeing a reproductive endocrinologist who does IVF it is going to take more of your time than say somebody who does IUI. Our doctor with the surrogate wants to go soon, but I want to do one extra round of testing. If the medical staff does not make the right choices, then it is going to take you longer to get pregnant.”

“The medical staff makes you wait. They wasted my time. It was bad at the OB/GYN’s office, not as bad at the RE’s office. They would have some control over how long it takes you to get or to do the treatments to get results. Because I knew better than to have me to come in on every stupid little thing, they wasted far less of my time, but I could have seen that eating up; times and times of going in and hear no as an answer and sit for an hour and half to figure out one word. One time a surgery took longer than expected and I had to wait 3 hours before they wheeled me in for my surgery.”

Cost / Finances

“The hospitals policy drastically affects cost and finances. The more surgeries I had, the more doctor bills were meant for me. The doctor decided to do those two procedures, which drained our flexible spending money and \$1,000 of our bank account money, and they found nothing.”

“The medical staff sets the prices for what they are going to charge you to do things. I am sure they all try to keep the cost relatively similar so that it is more competitive in regards to personalities and locations. That is why I was saying that the medical staff I feel has all the control over finances. That goes back to even the OBGYN. I think they are sometimes interested in making a profit versus really helping a patient. There is a lot of cost involved and not realizing it. You have to have a sonogram and take it for granted that insurance does not cover it, and they expect me to be here every day to do a sonogram for five days; it costs two hundred and thirty dollars apiece.”

“I definitely think it affects the cost, maybe sometimes the quality of carrier getting IVF. Depending on the medical staff, depending on the center or whether it was an OB/GYN or a [fertility] doctor, it affected how much cost it would be. If you are seeing an IVF specialist it is going to cost you more money. They have decided what they are going to charge me. I remember stressing out about that and even asking them when I did my second transfer why do I have to do the transfer in this expensive extra six hundred dollar room when it seems like it is not any more complicated than the IUIs you do in the office. These people were expensive.”

Treatment Outcomes

“That it is a science, but it is also an art. For me what I appreciated was that the doctor was familiar with this art. It is like he knew minutes. Like this one is working good and this one is not going to work good. Let us make these adjustments here, let us not make these adjustments here. Dr. decided because I hadn't gotten pregnant in 7 months on my own that I may have

endometriosis. So he talked me into the procedure of hysteroscopy. They are not going to know what to do next without these treatments outcomes.”

“They had some control over the treatment outcome. They can suggest or initiate treatments, but your body is still the determining factor. They set up the treatments to the extent that the treatments could possibly be successful that was originated with the medical staff. Outcomes ultimately were not as a necessary reflection of the medical staff, but it was dependent on them. Some of it is my body, but they would have some control. Depending on how qualified the doctor was if the odds of it working are higher. I felt if I chose what I thought would be the best center, the best lab associated with it they would give me the best chance of a better outcome. I am seeking an IVF to up my chances of getting pregnant. So hopefully I will have a better outcome if I am seeing a more specialized medical staff. If you have better doctors, you might have better outcomes. I feel I had bad doctors, so the outcomes probably jumped to be bad. You have to have a good doctor in order to have a good outcome. Without them you will not have outcomes, so you need them. We went to this fertility clinic because they had the best outcomes in the area. I know there is still a chance that it will not work, but they have good stats

Empowerment / Choices

“I think the medical staff could have empowered us more. I do not know how much more choices we could have had. But they could have made us feel a little bit more involved in the process. I felt pressured to start immediately and did not really give me any other options. Usually you do not want to make choices against them. You feel you need to listen to what their recommendations are because obviously they should know more than we do. I did not have a choice, I do not know if that was not an effect. Being rushed, the managed care, they do not make you feel comfortable you can ask a bunch of questions, or if you have a bunch of questions you are bothering them.”

“Not so much with empowerment, but at least with choices, getting the diagnosis helps make the choice, you get the diagnosis from the medical staff. They provide you with information about

what you need to do. You take information from the medical staff but ultimately it is up to you, they can make you feel either more or less empowered but it is really up to you. If you have a good staff they would empower you as a patient to make choices. At the OB/GYN I had a certain amount of choices. The fertility doctor allowed me a different amount of choices. Just the difference between the two fertilities treatments that I went through: fertility treatment one was more this is what you need to do, come back and do it. The other one was more, “These are your options. You can look at them this way it will get you this way. If you look at this you are going to get through it this way.” So I felt more empowered at once.”

“It depends on the staff themselves to give you the choices and how they frame it. They outlined the choices for us. My doctor drew me this table or chart showing IUI. Here is Femara and IUI and this is the chance of success and cost, here is IUI with injectables and the treatments and the cost. I felt she empowered me to make decisions over my treatment by taking the time to explain the options, cost, rates of success.”

Emotions

“Medical staff affected my emotions for sure. Based on how they handle things, how they deliver the news. Medical staff can influence emotions just with the experience you have and the knowledge you got. If you have a doctor that encourages you to feel in power to make your own choices, you feel better about the things you do. The good doctor gave me positive emotions. They were sincere, sympathetic and positive. Initially when you are getting results or you are going through it and you can get something positive or a little bit of hope that can help you. Telling you things that you need to hear but that you do not want to hear. Also they help cope. Recently I went to the OB and she gave me bad news. It made me an emotional wreck for a week. The doctor was understanding and accepting of my emotions, but also helped keep things in perspective.”

“Medical staff can make your emotions better or worse in the sense that they were positive and caring and they did not look at it like just a technical, “I am here to get your money.” If I see

them looking stressed out or fearful about something, it causes me stress and fear. If I see that they are handling it well, they say this is not a big deal, it is a big deal with me but not a big deal with them, then I can try and calm down and it relieves my stress. How they are treating you during the treatment day definitely. There were times in Minnesota where we would leave and my wife would just be crying, because we could not really have very good doctors.”

“What they did would definitely lead to emotional way. Sometimes the way that we were handled by medical staff, for instance the doctor telling us that we were in the clear and we were not. Then our subsequent pregnancy, first the doctor told us that the pregnancy was not going to work, then the numbers started getting much better but we were still two or three days behind where we were supposed to be. She kept saying, “Listen, I am sorry. It may have been too early for me to say that, but the medical literature does not support a pregnancy like this happening.” She was right, it did not, but it kept going on for about two weeks. So a lot of emotions came from how we were treated by medical staff.”

“One nurse who I felt was a little snippy increased my anxiety. Sometimes if you feel the nurse did not listen to me you take it wrong. They pissed me off. Maybe like talking to my doctor about not finding anything on the test and just how frustrated I was. Not getting or feeling that you are not getting your needs met at appointments or you are not getting a lot of questions answered; feeling rushed through questions, that influences how you feel about the process.”

Relationships

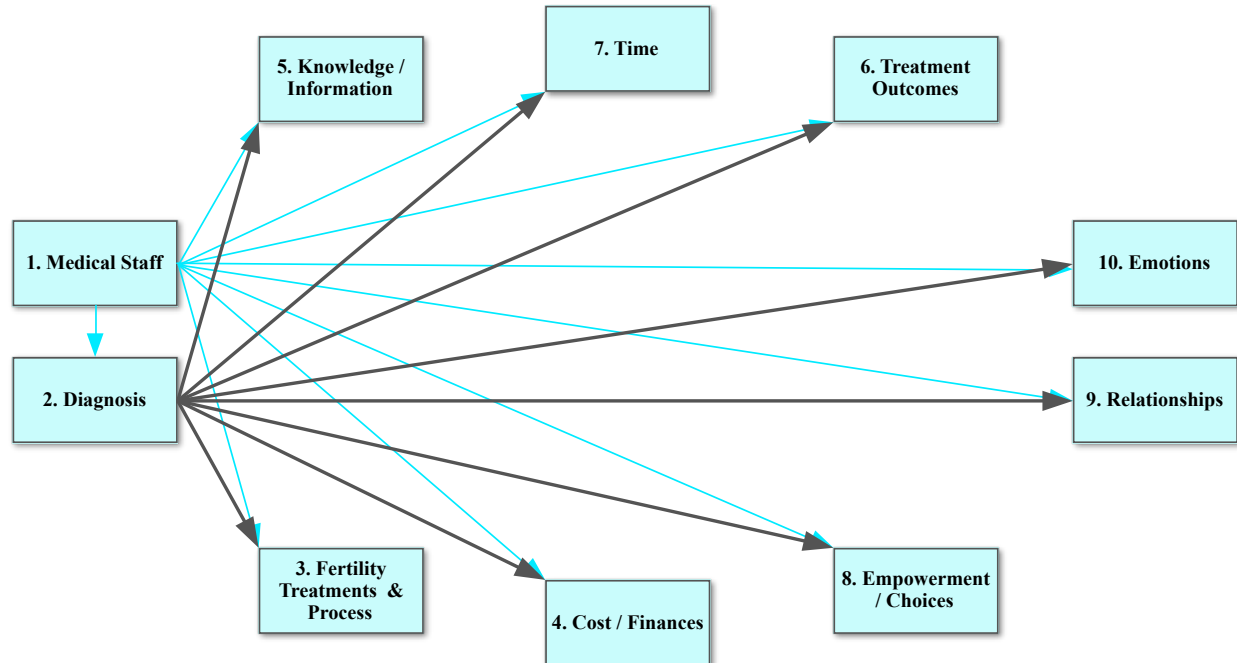
“Their personality, I would say affects how your experience will be and how the relationship will be. For instance when that doctor blew off my symptoms, which made me not want to go back to them. So gave me a negative relationship or idea of them.”

“Medical staff made me hopeful and affected all the relationships that I had. They have to be invested in your care. The doctor and his clinic was very good about making me feel included. I

went in with my husband to his appointments and they could have said, well, you know it is not her body, it is not her issue.”

“I am not going to form opinions of people based on what they do, it is how they stand in front of me, so the medical staff drove the relationships individually. I felt it was pretty good with my RE, not as good with some of the nurses. I think it is about different personalities and how informed they are. Things like that kind affect your relationship with them.”

Diagnosis Influences



Knowledge / Information

“You educate yourself on whatever the diagnosis is and you are not an expert on it until you have been diagnosed. Once you are diagnosed with something that is going to directly affect the knowledge and information that you want to get about that condition. Much information is sought after learning diagnoses, to determine next steps. Knowing what we have gave me something to search for as far as options. After being diagnosed with Hashimotos, I started a yearlong research about the disease. When you are diagnosed with something that is all the information you seek out. You do not really seek out anything beyond that. So you kind of get in this weird vacuum. Since I was going to have to go to IVF, I was researching IVF. I was not even looking at the other options.”

“I was diagnosed with unexplained infertility, went home and tried to get as much knowledge as I could on that. It made me look out there for what other things it can be. You seek more information once you know the diagnosis. Since I was unexplained, I was always trying to figure out what it would be. I was trying to get more information and knowledge about what infertility causes might be. If you do not know what you have, then you do not know what to look up. I do not feel there is very good information out there, at least on the diagnosis. I just felt there was not much information out there. Because it is unexplained infertility they did not have as much to talk about whereas if it was because of a specific reason, then maybe they would have more specific literature or something that they could share that would bring impact.”

Fertility Treatments & Process

“The diagnosis dictates what kind of treatment. When you know what is wrong you are able to treat it. With my husband’s situation knowing he needed to increase testosterone he was treated with Clomid. The diagnosis determines what you do. If my husband’s diagnosis is bad sperm, then we are not going to try surrogacy because that is not going to matter.”

“My IUIs did not work and I had very low reserve that determined what treatment and what the next process would be. I had diminishing ovarian reserves so my only odds of getting pregnant would be IVF. Just them saying that it was an egg quantity issue, there is not a lot they can for that other than IVF. If I had something different I would imagine my treatment to be different. If you cannot make your own eggs they decide the treatment they have outlined for it.”

“Once you are diagnosed you have to figure out what process you are going to take, whether they are going to do IUI or IVF, or do donors, and if you are going to have the surgery first. When we found out we had endometriosis, it was “What do we do with this? Let us just do IUIs and be done with it.” Based on my diagnosis there is a surgery.”

“When they said it is basically unexplained but these are your options, these are what we usually try with unexplained. I was told I have unexplained infertility. So I started the process for IUI.

For us because it was unexplained and because I was thirty-four at that time, we did not rush straight to IVF. We waited. We did some IUIs. They were unable to point to either her egg or my sperm, but those theories pushed us towards the use of donors.”

Time

“If you do not get one [diagnosis] you are waiting forever. The lack of diagnosis meant more time. I went through four years of treatment that were worthless because I had the wrong diagnosis. Depending on what diagnosis is it will determine how aggressive you have to be. So it is something you can spend some time trying.”

“Without a specific cause, it may take forever before something happens. If there is a specific thing we could address it and potentially resolve it quickly. The diagnosis of unexplained affected the time I spent in treatment.”

“The more severe the diagnosis, the longer it is going to take. It will take time going through the process of IVF. Certain diagnoses require more time commitment. In my case, it did not require too much time but had I been diagnosed with something different it would have taken more time.”

Cost / Finances

“The more severe the diagnosis the more cost you are going to incur. Some things cost less than others to fix. For us especially with having an actual diagnosis like the endometriosis, there were more treatments. More cost associate with the surgeries and the treatments on top of the fertility treatments. The miscarriage was extremely expensive for all the ultrasounds.”

“Mine was pretty cut and dry, so I knew upfront that this is what I am supposed to do. If they had said both tubes are shut, IUI will not work for you, that would have increased the cost because I could not do IUIs, nothing else was going to work, we had to do IVF. We had to go through the

IVF process and spend the money in order to get what I wanted to get. IVF is more expensive than IUI.”

“Each diagnosis has its own associated cost. Without the diagnosis, there would be no cost. Anything we did was based on the diagnosis at that point. In terms of insurance, your diagnosis absolutely affects your cost. If it is for a specific problem you insurance will cover it, but if it is not, if it is for treatment or resolution of an issue... It costs money.”

“If it had been unexplained they would have tried a lot more things. Toward the end it became clear to me I am definitely ovulating and I can throw all this money at it, but the problem is that I just have a limited time. That is what we figured out from the diagnosis: I do not have forever. I am not going to be one of these sixty-five years old women who is pregnant and says it has happened.”

Treatment Outcomes

“If you can get an accurate diagnosis then you should have a positive outcome that is my case. We were successful in getting pregnant through the IVF and that presents the outcome. If you have a hard diagnosis, it is going to be harder to treat. If you have something minor then it is going to be easier. Mine was not a great diagnosis, but there was still the chance to get pregnant. If you think of women in my group, awful eggs, a much lower chance that you will get pregnant with your own eggs. Depending on what the diagnosis is definitely affects your outcome, and some diagnosis means you cannot get pregnant at all.”

“We had unexplained diagnosis and we still do not know why the treatment did not work. My diagnosis is unexplained infertility; my treatment outcome is not pregnant. Unexplained is not really a diagnosis to me it just says we do not know, but with the outcomes we are not getting anything and so it is like, “Well we do not know what is going on, so therefore we are not getting anything.””

“Not the results I wanted because of that we did the treatments. In my case with my endometriosis and my husband having sperm antibodies we had to go through different treatments and moving from IUI to IVF with ICSI.”

“If you are being treated for your particular diagnosis, then obviously everything that follows comes from that. Because of his low sperm count we could do ICSI and that was more straightforward. Pretty cut and dry. We knew we are going to do IVF.”

Empowerment / Choices

“Finally getting diagnosis was a success such a huge deal and got us on the right track instead of continuing to do things that just never worked. I am like “Oh my God I cannot be anymore at all.”

Once you have the diagnosis, then you can explore your options. You can explore options without a diagnosis, but you are taking a step in the dark, at least with a diagnosis you can take an educated guess as to what you might try next. Your diagnosis with certain things gives you the power to say, “Ok, this is what I have and this is what we need to do.”

“I will have choices to make based on what the diagnosis would be. Once you get the diagnosis and you figure out what is going on, you get your choices or what you need to do. In our case the diagnosis left us with no choice, this is what we had to do. Unexplained infertility, my choices are IFV and/or IUI. Diagnosis affects whatever we wanted to do either stop or continue. You have to have the diagnosis first and then decide which treatment based on that. If I was diagnosed as infertile and not able to have children then I will completely feel I am unempowered.”

“When I was given the diagnosis of Hashimoto’s, I felt like I was forced to take thyroid medication. Almost like I had no choice anymore. It made me feel like I did not have any power over it. You cannot make these choices without knowing what you are dealing with and not having a diagnosis make you less empowered.”

Emotions

“When we got the diagnosis it was reassuring to know that there is a reason it is not working, there is a reason you have been trying for a year and a half and nothing has happened, so that was comforting. Diagnosis gave me a lot of clarity, not knowing is worse. Even in the case like mine where it was like, “Yup, nothing you can do,” well at least we know.”

“I can't even describe the emotions I've had since finding out I was "infertile" or "low ovarian reserve". It definitely struck a sad emotion that I won't be able to go through bringing another life into the world. For me personally just knowing what it was deeps into grief. It took control of my emotions.”

“Knowing that you have very minimal time left makes you feeling frustrated and stressed, upset. The diagnosis acts upon the emotions. I knew about it before we were trying to get pregnant and I think that fueled some of my anger because I could tell my husband I have an actually condition that might affect my ability to conceive. He said we do not know that it does not, and that was always his excuse.”

“Unexplained diagnosis definitely affects emotions. In the beginning happy; nothing is wrong but later, “why cannot they find out something.” You do not know what is wrong and so it is more frustrating. For me personally stinks knowing that something is wrong and you cannot do anything naturally without some sort of intervention. And it really affected my husband. It was a big disappointment for him to find out something was wrong with his sperm. It affected how I felt about things. If the diagnosis had been positive, I would have been happy. But when they are negative, I would be sad. Something you do not want to hear is not always nice. Finding out what is wrong and finding out that is why this pregnancy did not take, it is ultimately going to make you upset.”

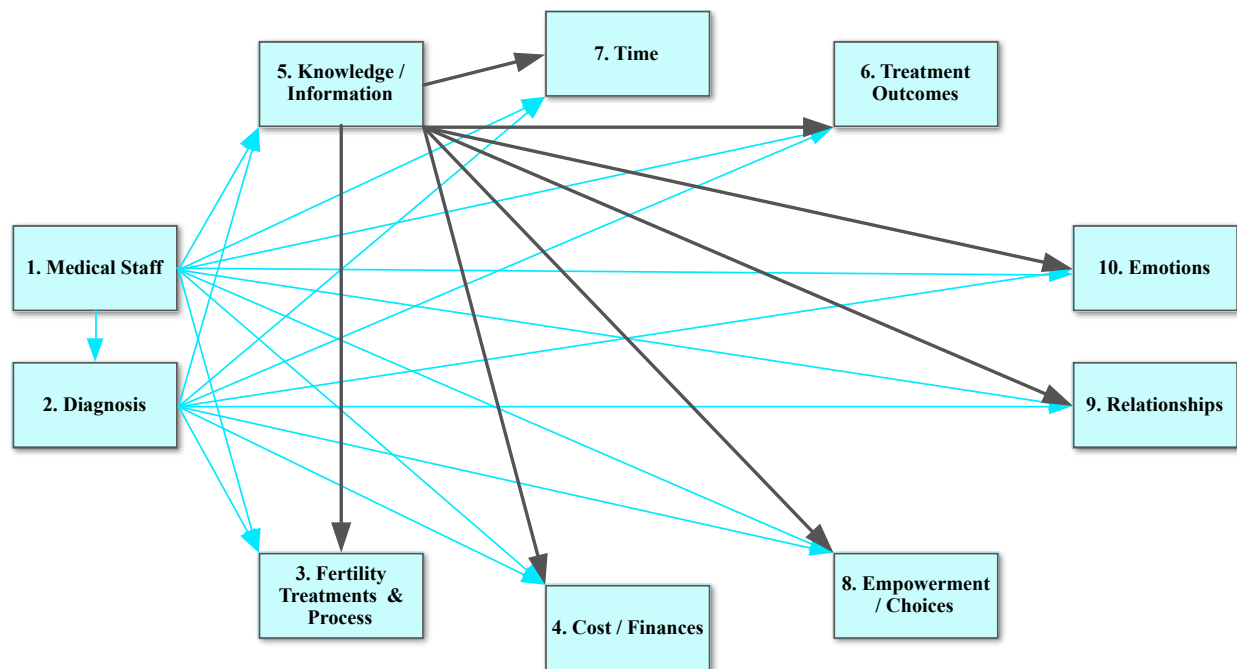
Relationships

“It is a circular conversation that I have with my husband in terms of, “What is wrong? Do you think the doctor was not telling us something?” and, “Maybe it is me” “it is not me” or, “If it is not me, then are you saying it is me?” We get frustrated with each other and we feel like one is blaming the other even though we are not. You are just kind of irrational. And the social relationships in general, the isolation. Diagnosis affected my relationship with my family and my friends. We could not have children and the relationships were wicker as a result. As a result of the diagnosis experience we began to withdraw from relationships. It affected my marriage; it affected relationship with my mom because she was given that drug and I think she felt really guilty. It was a good thing to finally know, but also was really awful and sad.”

“Our diagnosis is with my husband and not with me and that affects my relationship with my husband, not that he would ever let on or talk about it – Heaven forbid, but... Just like he got diagnosed and all of sudden all the issues in my marriage dealing with those things. Relationships are tested based on the diagnosis. You get a diagnosis, it is kind of a label and that label carries into the relationship.”

“Because my diagnosis was infertility, I had some relationships that grew out of that from people who had the same thing. I got some support from people. If I would not had been diagnosed with infertility endometriosis I would not have gone to the doctors, I would not have made those relationships. Had my diagnosis been different, I might have a different relationship with my friend who was not there to support me.”

Knowledge / Information Influences



Fertility Treatments & Process

“We ought to know what the options were before deciding on what treatments go through. The more information we had it affected the decision on what to do next. I do a lot of research about what can happen and what does happen and search those things out. That made the decision whether to continue his treatments, what treatments we would want to consider. We have a diagnosis we know what the issue is, we know it is sperm count and then we know like: - Ok, we might want to try this or that. That you are aware what your options are then you choose what you want to do whether it is IUI or you want to take the next step to do IVF.”

“We were acting on what we thought was the best knowledge to choose. Based on two bad IVFs with our genetic material we moved to donor egg and then based on the fact that we had similar results with that donor egg as we had had with my wife’s eggs then there was some idea that it might be my sperm. Then we tried IUIs with donor sperms.”

“You better research before you decide what to do. Knowledge allowed us a window into the fertility treatments to be more comfortable with. I would do the research and then decide which treatments I would want to do. I probably would not do fertility treatment if I had knowledge that my chances were 0.01% versus 75%.”

Time

“The more you and your doctor know the faster you can get resolution and get pregnant. If they do not have the knowledge you take longer and longer to get there. The more knowledge you have the more likely you are to pick the correct treatments options and process for you and therefore your time could be lessened in some cases.”

“Knowledge affects how much time you spend in the process. If I had known a little more about infertility, I would have not stuck with the OB/GYN as much as we did. We knew we need to do IVF before we are thirty-five. Do not just keep doing IUIs. If we knew back then what you know now, might have done something different and saved yourself time. Once I became more aware what I was up against, then it made the time more urgent or less urgent just depending on that.”

Cost / Finances

“Medication for example, you gain the knowledge in different ways it can help beat the cost. The more knowledge and information we had, it allowed us to find less expensive pharmacies and shop around.”

“The more I know about something is going to help determine how much I am willing to spend on it. Knowing about the different treatments; which ones are more expensive, what my choices are, I can choose something that is less expensive. If you do not have the knowledge the cost can get out of hand. You have to know how much things cost. For example, if you have four thousand dollars in your bank account and you decide you are going to do IVF, but you do not know that it costs that much you have just screwed yourself.”

“You would not just jump into something without having the knowledge. It made me wearier of picking very expensive options. I found, through the process of research different grants and other ways to do it. Like figuring out what it could be, how much we can afford, where do we want to look first and things like that. Doing a self-assessment and looking at all the possibilities, where we want to start and tackling it, how much do we have in the bank to do that. I was pulling a lot of information before we went to do that.”

Treatment Outcomes

“The more information you and your doctor have the better chance you have of a good outcome. The more knowledge we got, the better we could make a decision on what we should do next, which then affects outcomes. Knowing that I could try really hard and then finally coming to the conclusion that trying really hard did not affect the outcome. Knowing that my husband has sperm antibodies, so we had to change the treatment. We had to know what is the best way to use then starting to get the best outcome and to make sure you are not ruining its effect. So it is like, “Do not take this, do not do that.”

“Knowledge affected which treatment we chose, IVF versus IUI, how likely it was to succeed. So the information would then affect the outcomes. I think we tried a lot of other treatments that we would not have with all the knowledge that we had. Just being able to understand more about what the process was and what these numbers meant. It may not have changed the treatment outcome but it changed how I felt about the outcome.”

Empowerment / Choices

“Knowledge is power. I can make good choices if I know what I am in for. I needed that information first to be able to make the educated choices. Having the knowledge made me move

forward with the things we were doing. The more we know, the better choices we can make and the more control we can have. Definitely knowing more left me more empowered.”

“Researching and knowing which options, knowing that people try IVF for a long time. Having the knowledge of IVF might drive your choices whether you are going to do it or not. You have to be aware of the options to decide which one you are going to go with, you can do something about it. The more you know the more you can ask. The more knowledge and information I was able to obtain, the more it gave me choices and made me feel empowered. By researching other fertility places, I made the choice to go elsewhere.”

Emotions

“The more I know, the more sometimes I wish I did not know. It is extremely overwhelming, stressful. The more knowledge you have, then you can jump to the worst-case scenario, the big picture that you do not want to get, I think that deeply influenced my emotions. You can get really emotional about a diagnosis for example, and freak out. Your mind goes to all these horrible places but if someone was able to sit you down and really explain and answer all your questions. Sometimes the unknown makes your emotions go haywire. If you get some real knowledge and information at least you know what to freak out about as opposed to freaking out about everything. For me having more information was power and if you feel you have a little power, your emotions are not as affected. You could think a little bit more clearly.”

“Sometimes the outcome, the knowledge, and the information is just too much and it just wears on your emotion. The more I learned the more emotional responses I could feel. Sometimes knowing what all your options are but knowing you cannot afford them makes you a bit angry. Sometimes the more you know is not better. The more information I know, the more I feel less in control of things.”

“Information would affect my emotions; sometimes it would give me hope sometimes it would be frustrating. Sometimes the knowledge is negative and it would just trigger negative emotions. You know the hard truth makes you sad.”

“The more I knew affected the way I thought about it and even my emotional level. The more knowledge I have it affects my mood. Just reading all these stories made me a basket case. A lot of time the more knowledge I had, the more frustrations I had.”

“When you learn something new, you then react happily or silly. Lack of knowledge drives my emotions, not knowing the information frustrates me. Yes because of having knowledge, you felt good and empowered. How much I knew or did not know about what was going on or why it was not working. The more one knows, the more one is able to cope with emotions. The more informed we became the less stressed about some areas I was.”

Relationships

“With me, doctors worried about my particular case or that they listened to me affected our relationship. I would be really mad when they did not listen or understand. That was frustrating.”

“I am thinking of my knowledge of how important self-care is and coping skills in reducing stress in lives. Had I not had that background our relationship probably would not have been as successful during this. Maybe not as easy because if you do not put that at the forefront, it will be a lot more difficult. More knowledge and information I had improved the relationship with my husband because we could talk about it. Also it affected the relationship with my medical staff and the doctors because we had educated ourselves on everything we could.”

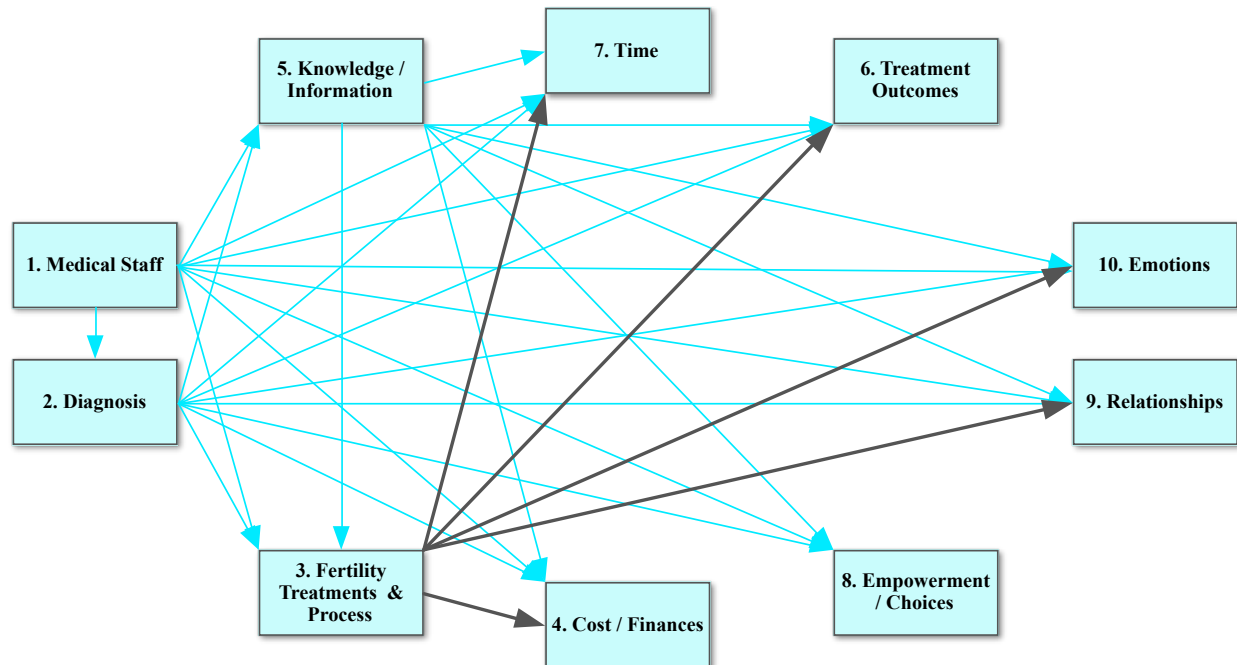
“My husband is normally the researcher; but when it has come to fertility and babies he does not so much and I stepped into the role he normally is in. It made me feel he was not in it as much as I was, so definitely affected the relationship in some ways. It kind of places blame. For me it is a

very empowering thing but could be too much for my husband and his parents and our relationship with them.”

“The more information we had, that changed how we related to people. Hard knowledge about what we were going through affected us emotionally, but also [because] people did not know but we knew that affected our relationship with those people. Not knowing how much support I needed, not knowing all the pieces and not knowing that hormones almost made me crazy. I did look at some things online about relationships and how they are affected.”

“The more I knew the closer I was able to grow to my wife. Being able to make informed decisions with my partner about which ways and how we were going to do it; being able to share with families, it created a different level of sensitivity. I think it kind of brought us all together.”

Fertility Treatments & Process Influences



Time

“It takes a long time to know. It is not something that happens overnight. The length of time it took was dependent on the treatments. IVF takes way more time because of the different schedules and cycles. Each of those treatments in their own took three or five months a piece to set up and execute. As you went through treatments you are turning around your life, your travels, money. So it affected how you used your time long before you could do something else. The more treatment you do it definitely impacts all the time that it is taking.”

“If we had time, if we did not have time, time as limiting factor. It takes time away from you. Treatment had an effect on my sense of urgency and time. We have to wait and see if it takes and that kind of thing. There is time involved with each treatment whether it is the surgery just being a day and then there is the recuperation time, or the whole month going to a cycle to get pregnant.”

Cost / Finances

“The fertility treatment [is] pretty pricy. Longer the process greater the cost. We have not gone that far, but the further we go we will have to start making more decisions based on cost. Which treatments you are doing definitely affects the cost. Depending on the treatment, the cost is different. IUIs are less expensive than IVF. Knowing that we needed to do IVF affects whether or not we are willing to invest the money to do it. Upfront it was outlined to us how much all those things would cost and we knew going into it.”

Treatment Outcomes

“You have to have a treatment before you have an outcome. We tried things and they did not affect the outcome but they might have. For us we did the wrong treatment and then finally doing the right treatment affected our outcome. With IUI the outcome was not getting pregnant. So the different treatment will drive different outcome. Going with IVF treatment would have a higher chance of a better outcome. IUI is 15-20% chance and IVF is like 40- 50% chance of getting pregnant.”

“I think that we can credit taking Clomid with the miscarriage. Yes I think it affected it. Perhaps if we had done the sonograms early on, it may have affected treatments outcomes. You try something and you would either be pregnant or not. Once you have identified what it is and they are moving it forward with that treatment and process, then based upon how they do in those processes, your treatment outcome will either be positive or negative. The treatment was what caused us to get pregnant. We have four frozen embryos, so, we have seen some great outcomes from the treatments and the processes.”

Emotions

“The treatments affect your emotions in very real way physically and emotionally. It is all I had to go through physically and mentally. It causes a lot of stress. Then on top of it you have got this added fake hormones pulsing your body. The medications affect you, then emotions are stress and everything. Clomid makes you crazy. The drugs make you a little cuckoo.”

“I did not let the emotions dictate what the process would be. We tried to be objective about it, but definitely once you are in it, that affects your emotions. It was each treatments and their success or failure that caused us to be hopeful and/or despondent. You have a roller coaster emotions going on high, low, like hope for the best but prepare for the worst, right? It is really stressful and frustrating.”

“Certain fertility treatments were not as difficult on my emotions as others, like IVF was more difficult on my emotions than IUI. You are always in the moment of figuring where you are with what has just happened. Just the IVF and just the frustrations, time and efforts involved in all that. Getting upset if we have to push a week or if we are not making eggs or if we do make eggs and then embryos, the emotions are much more positive.”

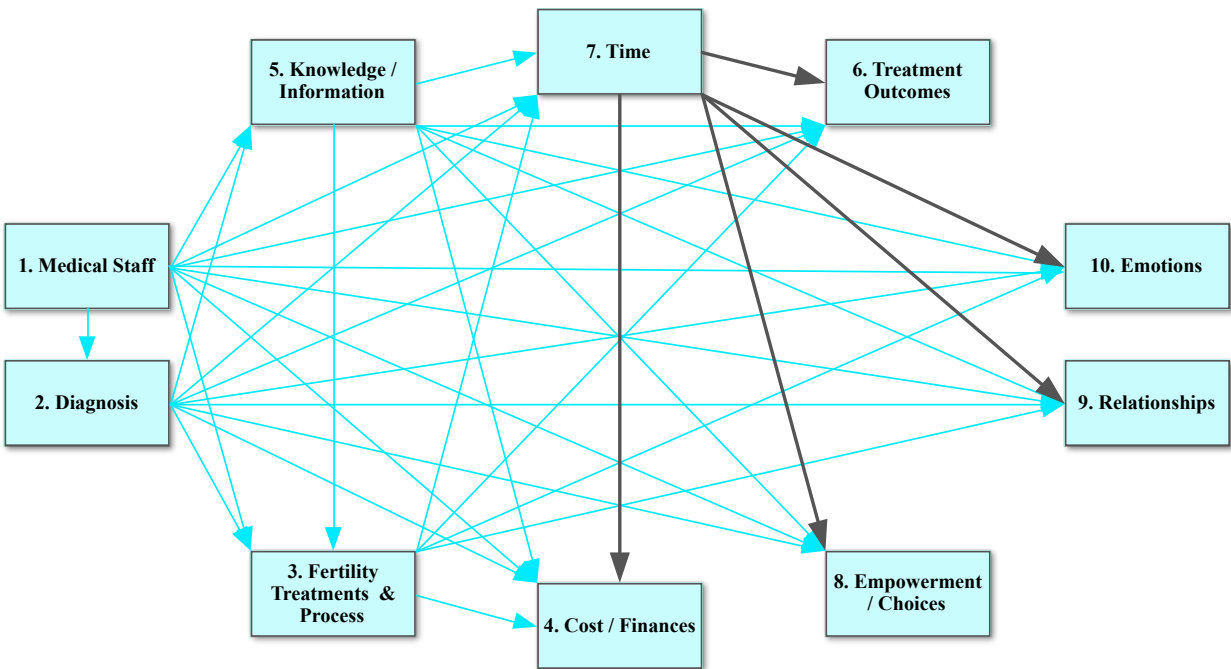
Relationships

“If it does not go well I am not going to be happy with them. It affected how close I was with my doctor depending on the treatment I was given and also the relationship with my husband and my friends.”

“Going for treatment is stressful and can negatively affect your relationships. One of the main ways is the hormones that they are shooting you up with. There is no way that cannot affect your relationships. Mess with hormones you mess with people.”

“While we were going through this, it affected all our relationship with other people. You are on medications and drugs and you get emotional and hormonal. The emotional baggage and the stress that impacts the relationship while you are going through the treatments. It is just emotional. I think it goes back to the isolation, puts stress on the relationship.”

Time Influences



Cost / Finances

“As I was willing to be in the beginning pretty aggressive, and come up front with a lot of money, I felt like time was ticking away. The older you get they may cost more and the more you have to do, the more meds you have to use, it might have cost a lot anyway but. So time affected cost in my case too.”

“If you have to do ten treatments it is going to take a long time and it is going to cost a lot of money. The more time that we are spending trying, the more the cost goes up. The more time I was required to be there, the more it cost because of the treatments but also because of loss of work.”

“Sometimes you have to wait until you get the money together in order to move forward. So time is affecting your ability to get that money. Yes our years of saving. It takes a lot of time to save

enough money for the treatment. The more time we wait, the more money we have saved up but the more time we wait the less time we have.”

Treatment Outcomes

“Because of a biological clock. Time is the thing that makes me need the treatment results to work. We would keep just rolling into the next IVF, not take a break and wait two years. We just keep going IVF, IVF. The longer you wait the less desirable outcome you will have.”

“It does take time and you have to be patient. You have to wait. You hope is that if you spend more time the outcome is going to be better. I had to wait one cycle to the next to see if any magic happened. A month feels like forever. In our case time led to better outcomes. For us it was just time and timing and all the months of waiting, it definitely influenced it.”

“It is like you are wasting so much time and it is making the outcomes poor. Sometimes it is good to step away and give yourself time to consider what is going to happen. It just takes me a long time to get pregnant. Longer than most.”

Empowerment / Choices

“It is so timely, it has to be done at a certain time. So, you do not have a whole lot of time to make a choice. The longer you are doing it and the older you get you need to make the right choices. I think that affects what you do. The longer you go, the less empowered you feel.”

“Timing drove the choices that you did. We are always working against time and so sometimes we try to take what we thought are the most experienced paths. I wanted to have another child within this year, so if nothing happened in the next month, we were going to start IUI.”

“When you choose to go through, it has to be the right timing. Being worried about not having enough time for it, made me rush a lot more and be more outspoken about what I wanted to have

to work on this. Time has taken away some of our empowerment. Just because of that number 35. Your clock is ticking and you are getting older and you are high risk; feeling we have less choices and we have to be more proactive, that we cannot sit around and wait for very long.”

Emotions

“It is a rollercoaster, I am sure lots of people describe it that way, and the longer it goes the more you wonder if you are ever going to get off that rollercoaster.”

“The more time we spend on this the higher the emotions are. As time passes you get more and more depressed that everything is passing by. Every month is a chance to be sad that you do not have a baby any more. In some way it is time that wears my emotions because the closer I get to 35 I get more anxiety. The presence of urgency creates stronger emotions. Just the worry not to have long time to spend on this, I have to hurry. There is so many options and ways of going about it, stress and sadness.”

“The longer that things took, the more anxiety, the more stress. The waiting was big source of the stress and anxiety and frustration. The waiting... the frustration with having to wait. The two week wait makes me think I'm wishing my life away. The longer it took, the longer we dealt with it, the more stressed and emotional I got.”

“I would become stressed because of too much time spent on this process. It is just so much time you are spending on it; it is ridiculous when you think about it and it can definitely play with your emotions. The more that goes by the more that it causes an emotional reaction in terms of suffering for so long and going through this.”

Relationships

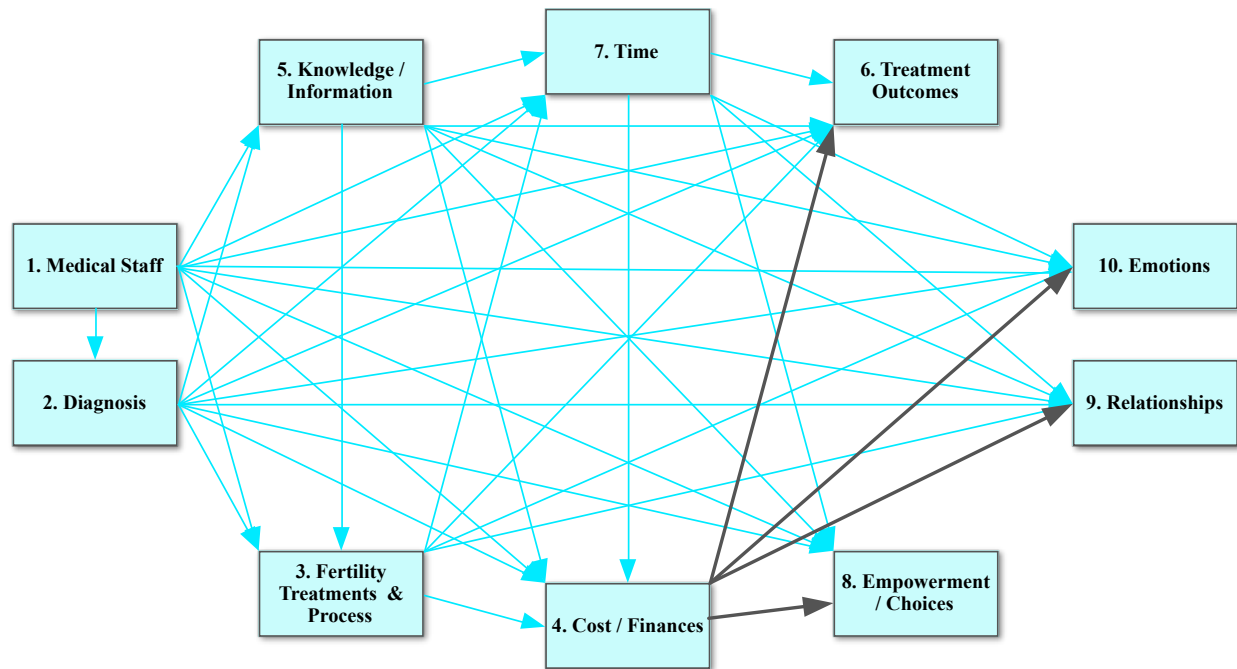
“The more time you spend coming in the office, the more relationships you feel you have. The better I got to know my doctors and the more, in a way, my husband and I bonded because of it.”

“The longer you are going through the treatment it can put a lot of strain on all relationships. The more time it took us the longer we felt we were socially retarded, we sort of entered into a limbo where we were looking forward.”

“Time puts pressure on the relationships, because I always have in my head a running account of how many months it has been and that is not helpful for my relationships. The longer you are at it the more it wears on you. It is like running a marathon versus a sprint. Ours has changed over the course of the fertility treatments. Not gone bad, just different.”

“The whole time aspect affects your relationship whether it is just trying to schedule the appointments or the time waiting to figure out an outcome. It takes such a long time to do this; it is a lot of waiting. The more time you spend doing something the less time you have for the relationship.”

Cost / Finances Influences



Treatment Outcomes

“Cost does drive the quality of your treatment. If I were in some small town I would not expect to get the same good treatment. I would want to be where there is more knowledge. So, I think sometimes if you pay more you get a better outcome. Like the clinic I went to in another state is expensive, they really have high success rates and I know a lot of girlfriends who got pregnant there. So I think sometimes spending more you get more.”

“The more you pay the more likely the outcome that you like. If you spend a lot on IVF it might not work, but there is a much higher likelihood that it would work if you do it than if you do not. If you have unlimited funds and you are able to pay for IVF versus IUI, then your outcomes there is a greater chance that it is going to be positive. The reason why IVF is more expensive and your chance for an outcome is better is because there is so much more involved and a cost to that. We did have results and we had to pay for it. In the sense that we had to pay for the babies.”

“The cost would dictate if we decided to do it or not. If cost was not an issue you would pursue treatments faster and more aggressively. If I could afford to go to the best clinic in the country, I might be more likely to have the best outcome. The more you spend the greater likelihood you might have of having a baby. I truly think if we had spent more the options would increase. Ultimately we had decided to stop not due to some psychological barrier that we hit or some realization of a factor that had not previously been considered like age or relationships. No, if it was free we would be probably still swinging at it.”

Empowerment / Choices

“Sometimes you feel you have no power when it comes to cost. Cost is the number one thing for us. I felt we had no choice because we financially could not afford IVF and that is what panicked us. Your choices are limited by how much you can afford and how much you are willing to spend. I knew how limited we were and how much we could do and that really tied our hands.”

“We have been empowered by the fact that we can afford to do this and that is an incredible thing. Cost influences how empowered you feel, if you had more money you might feel more empowered. You might feel you could do more. You have choices but what you can actually choose or that you have the power to choose can have to do with the cost. Cost/finances drives one's ability to make choices. If you have the money and the finances, you have the choices. Choices get limited if you do not have; or having your salary to blow on one cycle. The cost limits your options and you feel less empowered. Because if it is too expensive I cannot do it.”

Emotions

“If it sounds expensive it is stressful. That was the number one thing for us. That is when the emotions come up in the relationship. My husband is the one that takes care of our finances and the one that is making the money, the primary breadwinner. Not that he ever would be like, “I do not want to pay for this.” He was just more strategic. I was willing to go into debt for it. He was

like, “We cannot do that; we need to think of the long term.” That is not easy to hear when you want something as badly as a child. Then you got the biological clock on top of that.”

“It is hard to put a price on a baby. Cost is part of the decision-making that would lead to stress, because even though you feel you are advantaged and can afford it, you still feel this could be a terrible waste of money. And you feel guilty for being able to do it. I can afford to do this more than a lot of people and kind of mess with your emotions. “I should be able to at least conceive for free, right? Even if children are expensive, that is the free part.”

“There is a lot of anxiety. It is because often the bills were presented to me, so it was like a shock. The expense of the miscarriage makes me angry; over \$1000 and we're back to square one. Every single month you are trying something, it is more money than you have paid, so I just adds up. It stressed me out thinking about future cost of it. There was just a certain level of stress and sacrifice when you start thinking about that cost and how you are going to take care of it all. That takes you through a whole range of emotions at any time.”

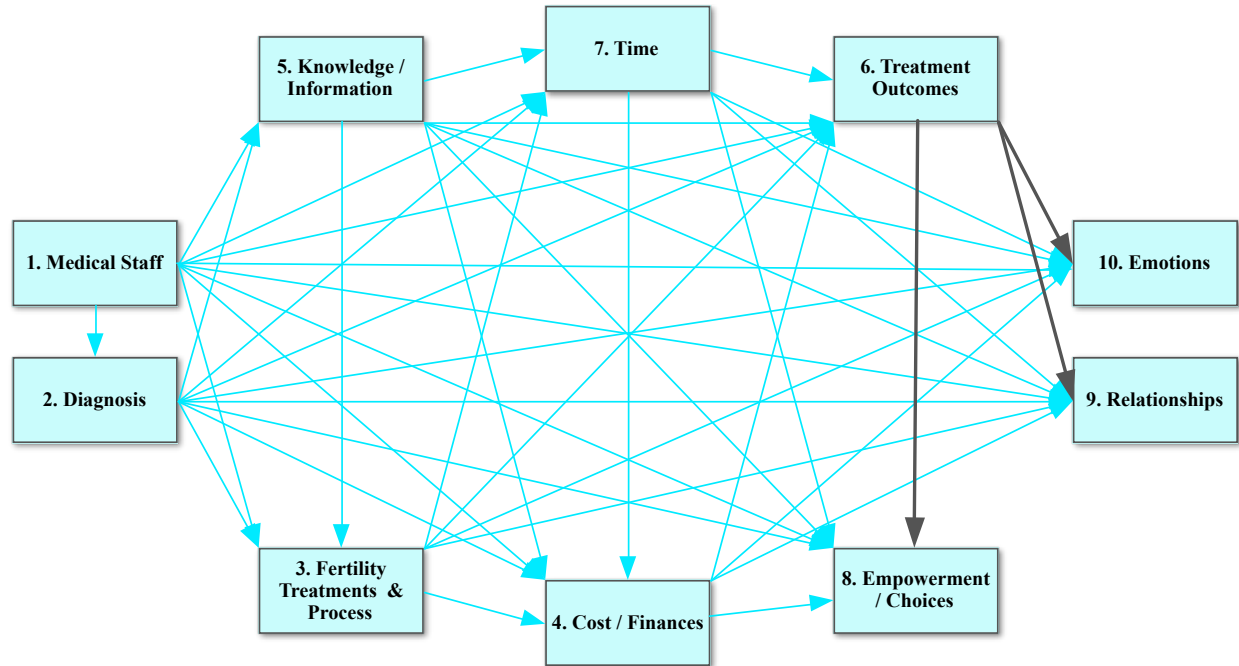
Relationships

It is stressful figuring out where you are going to come up with the money. It is a stress having to take the money from somewhere. And you know getting money from your family is very complicated. Like when our first IVF did not work, you feel so bad because your parents are going to pay for it and it just complicates things a lot.

Finances are not a fun thing to talk about in any relationship and I think most couples will bite heads. You know the wife is going to want to spend a little bit more for that finished kitchen or the luxury car. I think women are one person in that relationship going to say I am willing to spend a little bit more when you come down to something as life changing as a baby, especially if you have a more maternal instinct. That is not an easy thing to discuss. Making the choice about spending all of our savings.

Money is always the biggest thing and ruins most relationships. Money is a strain on any relationship. The cost that we incurred added to a lot of stress to our relationship. I am like, “Oh my God, look at how much money we spent today”. So that was my gut reaction like, “Oh my God, I would not be in this financial hole if it was not for you.” When he will not take it seriously I would say, “I am wasting all this money and you go like eating cheese burgers and smoking pot. What are you doing?” This is really stressful.

Treatment Outcomes Influences



Empowerment / Choices

“The treatment outcomes eliminated choices for us, in the sense that diminished the amount of choices or made the choice for us. Every failure you had you had to make another choice. The outcome had control on what we did next, it affected my feelings of empowerment. Not getting anywhere makes us feel like we have less control.”

“Treatment results influence what choices I am able to make for the next time depending on whether a cycle works or whether it shows that I ovulated. That is going to influence what my next step will be.”

“When I got a negative outcome, I would just move on to the next thing and I felt I could control that. Like for my miscarriages I was, “Ok. Let us get through surgery and then what do we do next?” so, I was ready to move on.”

Emotions

“There are a lot of different emotions that would not have happened if we did not have those treatment outcomes. Treatment outcomes 100% affects your emotions if it is a negative or positive test. You are going for a test and you hope you are going to get a result and it does not really. I do not think that I have met anyone that is not affected by a negatively outcome emotionally. Good result will resort in good amount of emotions.”

“Treatment outcomes affected how I was feeling. I feel upset when they do not work out. When my IVF did not work it definitely affected my emotions. It is so sad and so defeating when it does not work. In my situations all treatment outcomes were negative, so that would be a bad day for emotions.”

“The result of the treatments affected whether I was upset. A lot of people think emotions affect treatments outcomes, but in the reading and in the studies I did, yes stress and depression might affect the treatment outcomes, but that random chance is more of a determinant and that the emotions are a direct effect of the outcome.”

“The outcomes led to an emotional set. It stressed me out. Definitely surgery, being under stress and having to deal with not working out and you are disappointed.”

Relationships

“Treatment outcomes are hard on relationships. Every time that something fails or that a cycle fails or that it does not work out, I feel angry and I my first line of attack is to blame my husband. It does not have anything to do with him but that is what I do first.”

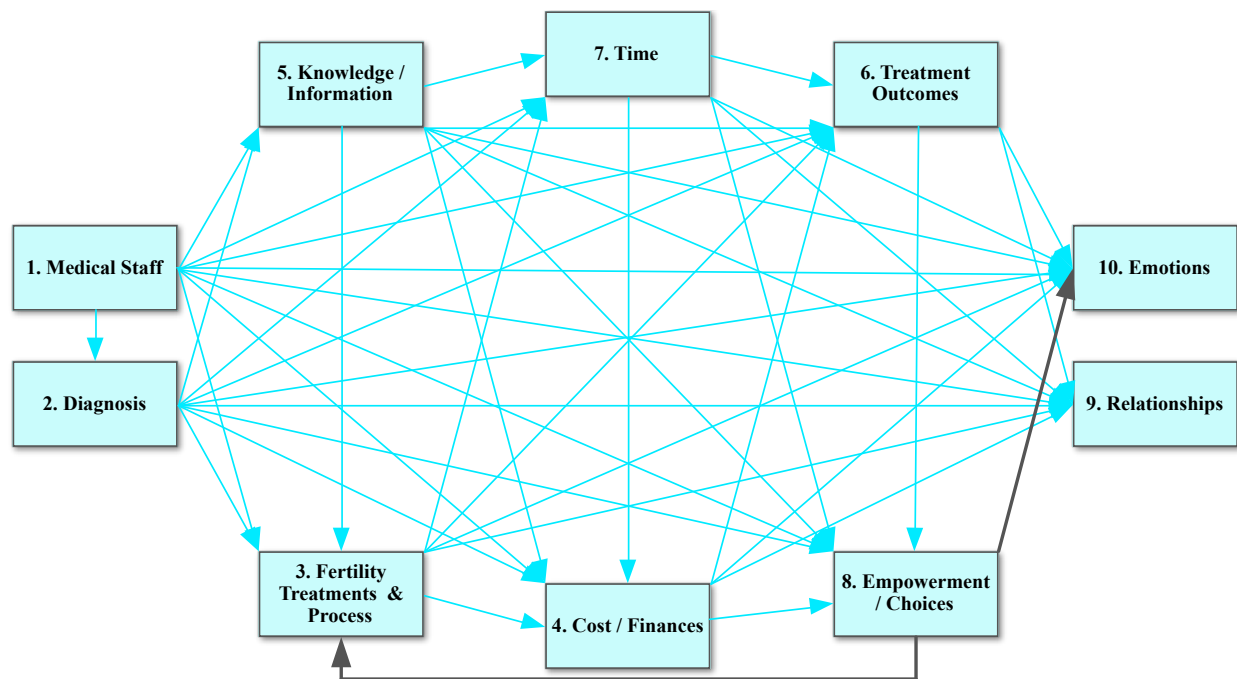
“Outcomes affect relationships; makes them more stressful if they are not successful and very happy if they are. It added stress every time it did not work. It did not affect mine negatively

necessarily but it definitely stresses them. It is hard sadness you go through together. Bad outcomes may drive becoming closer with relationships or may drive some apart. The miscarriage brought my spouse and I closer together.”

“In my situations all treatment outcomes were negative, so that would be a bad day for our relationship and also for emotions. Every month when you go through another failure you know you are a little more irritable with each other or a little bit more isolative because we need time alone to process things.”

“Surgery was a stress on our relationship. Me being down for a week and my husband having to pick up the responsibilities of my daughter.”

Empowerment / Choices Influences



Fertility Treatments & Process

“Treatment is always at my pace, not the doctors. . . for better or worse. It is your choice to go through with the treatment. I decide if I want to have it done. I usual feel this is what we want to do and we are taking a step forward knowing exactly what is going on. Ultimately it was my decision to go forward.”

“The choice you make or what type of treatment you want to take and what process you take. I made choices where I went to, what doctors I went to for what treatments. We went into it by making our own decisions and creating our own process and your plan, your map.”

“I had some say in terms of what fertility treatments I did. My sense of choices and empowerment led to the fertility treatment what we explored, like we had to go into it with a really open attitude to get something out of it. The more that you feel comfortable saying that I

have read, I have seen or I have heard about this other way it may change your fertility path. Knowing what our options are and what we can do has affected what we have done.”

Emotions

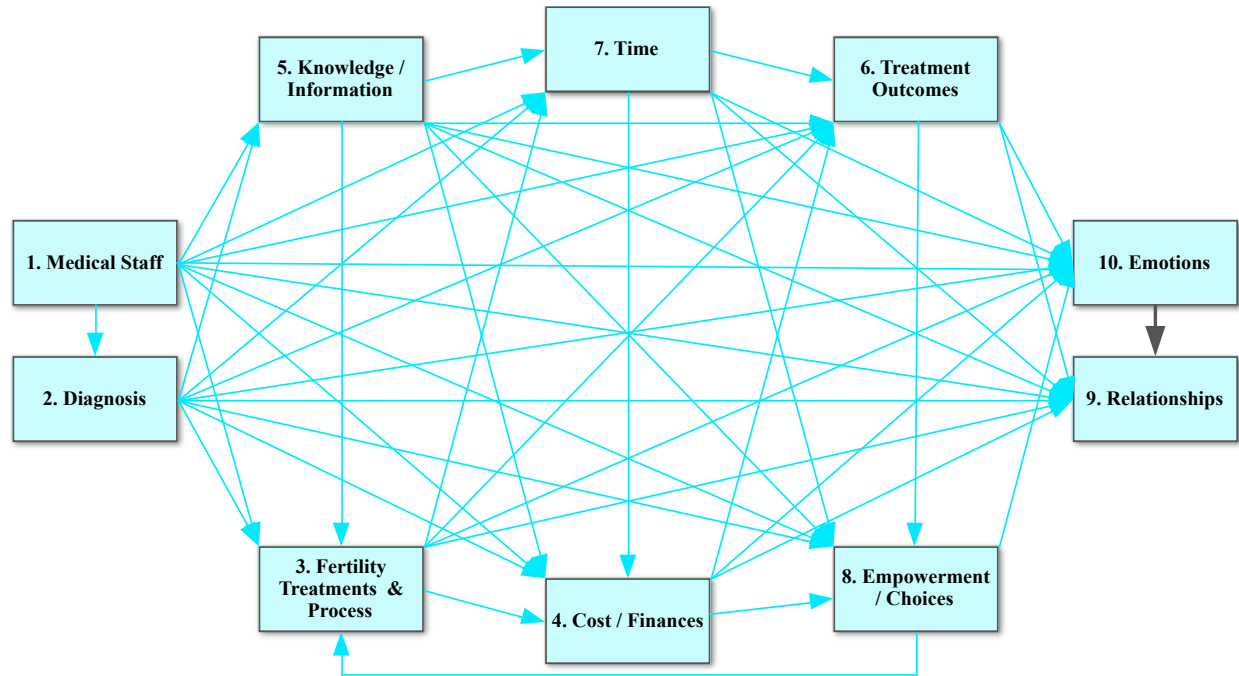
“The more in control and positive you feel, the better emotional state I was in. The less power we feel we have over it increases our frustrations. Making the choices on what treatment to do, when to do, it is really stressful. Is it the wrong time? Are you doing the wrong thing? I am going to the wrong doctor? Always doubting yourself. Not being in control of everything makes you feel helpless.”

“The empowerment came first on every bit specifically the self-esteem. The more empowered you feel the higher your self-esteem is. You feel like it is not as much your fault. If you have some choices, you feel like there is hope. The more I felt in control for the situation, the better the emotion were. When I did not feel empowered, the emotions took a dive.”

“When we make the choice to do IUI, we are setting ourselves up for a set of emotions. If we make a choice to do IVF we are setting ourselves up for more emotions; be a positive or a negative. With the lining, there was nothing that I could do, I feel powerless. It does leave you with bad emotions.”

“When you make a good decision and you feel you are going in the right way, it will all give you more positive attitude about things. The choices I made positively affected my emotions. At the time all these things were really hard but now have grown through it. It was stressful but I learned a lot more about myself and that is important.”

Emotions Influences



Relationships

“I was just so upset and angry all the time that it took away from my ability to enjoy the people around me. My emotions drive my relationships a lot of time. Or maybe lack thereof, you know, not wanting to be isolation and stuff, not so much anymore, but for a long time.”

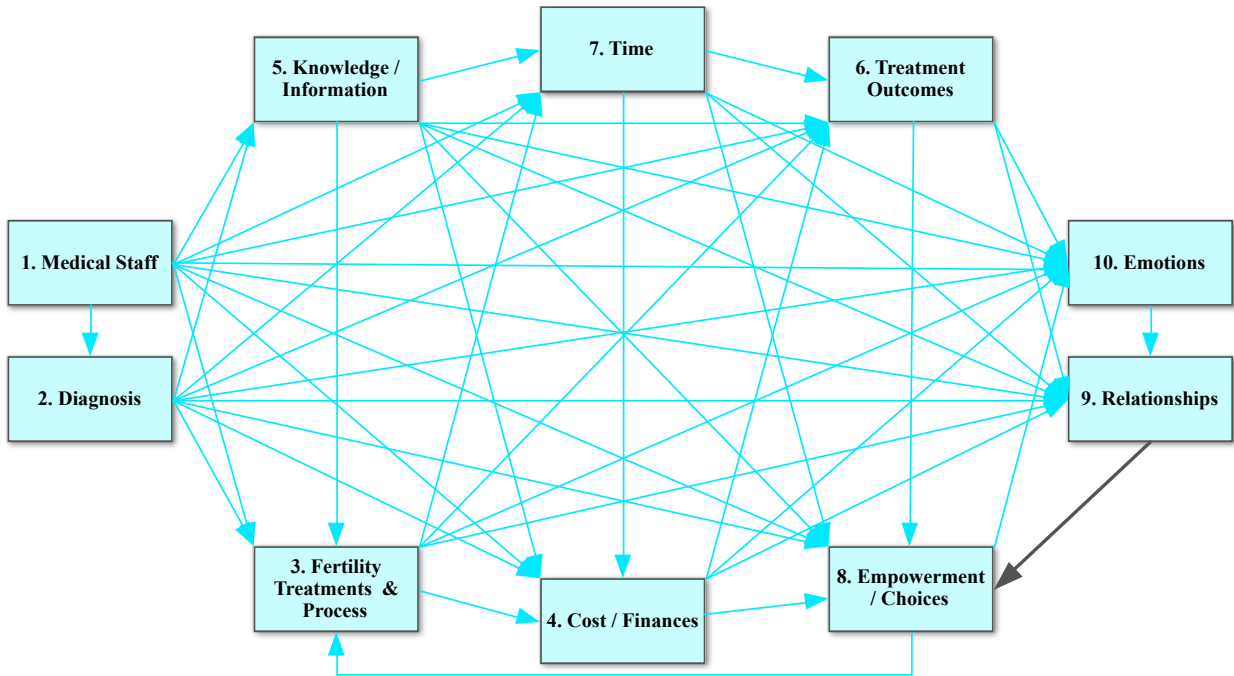
“My emotions impact my relationship on a daily basis. Just how you were depending on what was going on at that time. If you did not want to talk, you did not want to hug, have sex or anything it affects and in all relationships.”

“I am influenced by what friends and my husband have to say. In life in general, even in work relationships, to create a relationship you have to have an emotion about something.”

“Sometimes when I was on medications, I would be a little short or snippy and he would be like, “You are pumping yourself full of drugs every day and you are not yourself.” It is kind of remembering what I am putting myself through. I am not going to be the normal person I am. I am under a lot of drugs. Just going back and forth through that.”

“Emotion makes a wreck in your relationship and you have to be on the same page emotionally and make sure your relationship is stronger. Sometimes being irritable with each other, sometimes you need a hug but you just want to be alone and so push someone away. Heavy emotions may cause one to withdraw, impacting relationships.”

Relationships Influences



Empowerment / Choices

“Your relationships, your significant other in particular can make you feel empowered and encourage you to feel different way. If you have a bad relationship you do not feel like you have any power. Our relationships help us feel more empowered and drive our choices in whatever we do. I felt that we were on the same page and that really helped to make the choices and feel like, “There is something that we can do about this.”

“Relationships help you make good choices you feel good about. They help you feel empowered or not. When talking about it with my husband sometimes I feel like paralyzed. Throughout this he has been very accommodating to my choices. Before it was always his way or the highway, he did not want to have kids at the time. Since we have started trying every single decision is my decision because I am the one who wants to have kids. That has been frustrating to me because

he was super onboard with our plan when we were not having kids, but now that we are trying to have kids and it has not working, then you are just like “Nothing I can do about it. You have to make the decisions by yourself.”

“My relationship with my husband and with my doctor allowed me empowerment. I do not think that with the previous doctor my husband and I would have had a really a good relationship. I do not know that we would have felt empowered to make choices. So I think it is important to be comfortable with the doctors because that affects the choices and empowerment of a patient.”

“Usually in infertility you go through it with a loved one and that relationship can help you pick what your next step is going to be. We would work together to make those choices, so the relationship would help making the choices. We would work as a team and look at things then make a decision. My relationship definitely led to a sense of empowerment, getting my hand held through the process as well as holding hers.”

“The stronger your relationships then more empowered you feel to make those choices. Because the stronger your relationship is the more empowerment you would have to go through it together. My relationship affects how empowered I feel about things. Like if that is not solid, why the hell I am I doing this?”

The Infertility Treatment Experience Uncluttered SID

The cluttered SID contains all of the relationships described by the group. It is saturated with relationships. The problem with saturation is that a cluttered SID, while being comprehensive and rich, can be very difficult to interpret, even for a modest number of affinities that are highly interlocked or embedded within the system. In other words, many systems have so many links that the explanatory power of the system becomes bogged down in the details of the relationships. Comprehensiveness and richness are certainly objectives of the SID; on the other hand, so is parsimony. A way to reconcile the richness-parsimony dialectic is to produce a supplementary or secondary SID called the *Uncluttered* SID, one that has redundant links removed. Below is the Uncluttered SID.

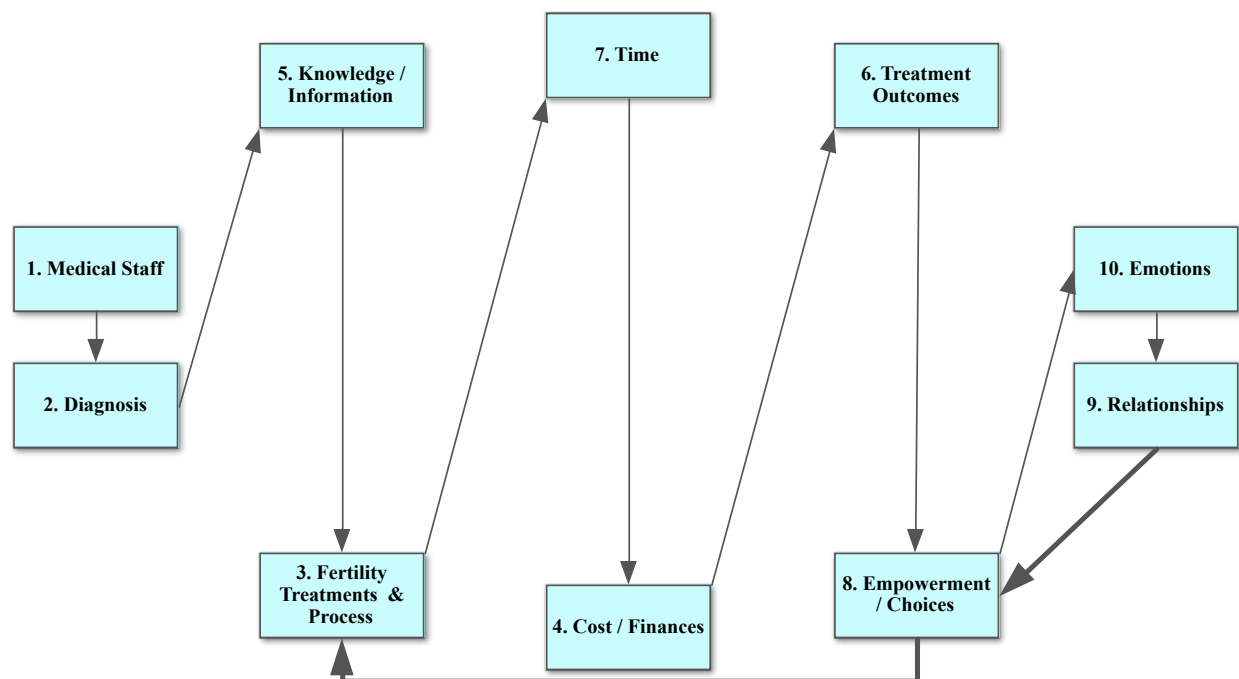


Figure 5.1: The Infertility Treatment Experience Uncluttered SID

The Infertility Treatment Experience Pareto Reconciled SID

Once the researcher had removed all redundant links, the Pareto Protocol, as referenced in Appendix A in the IQA process, was examined for conflicting relationships. Conflicts occur when the same affinity pair has relationships in both directions and a significant enough frequency to include both in the system. The lesser frequency is temporarily ignored in the IRD but is reconciled in the uncluttered SID. To account for the relationships, the system was examined to see if the conflicting relationship was indicated in the system, possibly as part of a feedback loop. If such was the case, nothing needed to be done. If the conflicting relationship was not accounted for in the system, it was added into the uncluttered system. For this system three conflicting relationships were added back to the system.

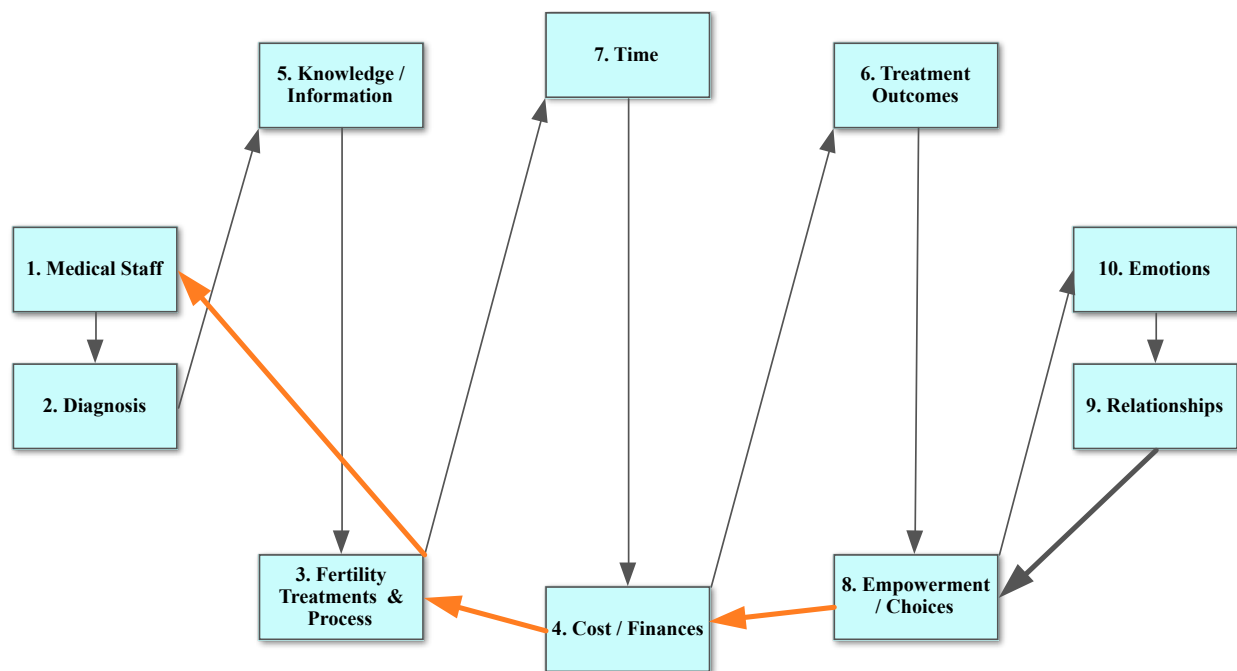


Figure 5.2: The Infertility Treatment Experience Pareto Reconciled Uncluttered SID

Fertility Treatments & Process Influences... Medical Staff

“You will have professionals specific towards the process.”

“He does the same treatment on everybody, it works so much percent of the time and he will just want to do that same treatment for everybody.”

“Obviously every woman is different, for me I had to do more; they had to do more sonograms on me. So I had more medical staff involved on a daily basis. They had to check on me in terms of my medication to make sure I was not over stimulated with the injections.”

“The medical staff did the fertility treatment within the IUI, and prescribed the medication. I did not get pregnant and so that told them that we would try again and move on to other treatments.”

Cost / Finances Influences... Fertility Treatments & Process

“If you cannot afford it you cannot do it, and so it affects what decisions you are making. Even though we knew we had to do IVF, because insurance covered IUIs and you knew that was much cheaper choice and even though that we had already done it three times and it did not work and they say it is not going to work, it is like well should we try it again. The fact that the only reason I entered into the conversation was because of cost.”

“For me finances influence fertility because the cost would help determine how far I go. If you have all the money in the world you can do whatever you want. Cost definitely played a factor of what we were going to do.”

“Depending on what you are able to afford you will move forward in different ways. In my case because the cost determined how many Fertility treatments we were willing to go through.”

“Money is a powerful driver of treatment decisions and next step determinations. I signed up to receive free IUI through the local clinic for a study on a type of progesterone. I think if it weren't free, we would have waited a little bit longer.”

Empowerment / Choices Influences... Cost / Finances

“You looked at it and you said “Ok, at the beginning let us just go with IUIs because we can afford ten of them.” Then as the money goes down I feel I had to say, “Ok. We have to stop until we can go” and then when we could go, I could say “Ok. Let us go.” How much we could do, we were able to afford it. I guess we have control over the cost.”

“Me choosing based on cost affected which one I am going to go with. You are not incurring this cost without making a choice to go through it. We were given choices and that affects cost. An example would be how many embryos we want to try to implant or do we want to do ICSI on more than ten.”

“Just to figure out if you are going to take the money out of savings, if you are going to charge it. We are going to come up with the money and the choices that are going to be best for paying it off.”

The Infertility Treatment Experience System

Below is the SID that will be used throughout the study.

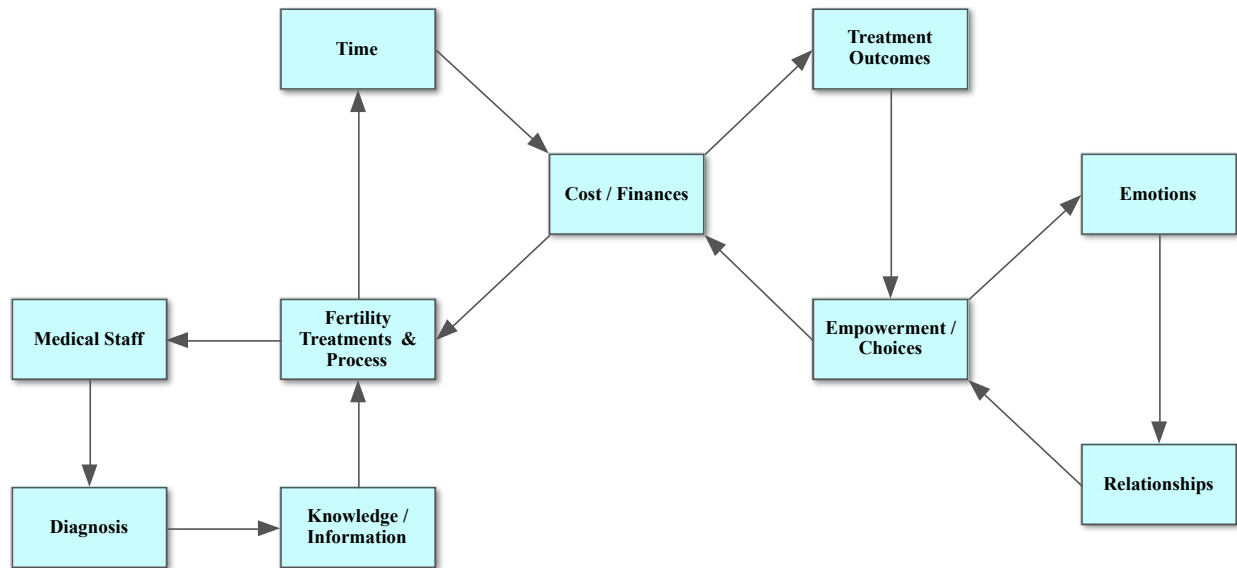


Figure 5.3: The Infertility Treatment Experience

CHAPTER 6: ANALYSIS OF THE INFERTILITY TREATMENT EXPERIENCE SYSTEM STATISTICS

Participant Demographics

Forty-three participants completed the affinities surveys; 33 females (76.2%) and 10 males (23.8%). Participants ranged in age from late twenties (26-30 years old) to late forties (46-50 years old). The greatest represented age group was the 31-35 year old group (37.2%); followed by the 41-45 year old group (23.3%). Most participants self-identified as White (76.7%); with 9.3% identifying as Biracial, 7% identifying as Hispanic or Latino, 4.7% Asian/Pacific Islander, and 2.3% as Black or African American. A majority of respondents were currently married (93%) with 4.7% single, never married, and 2.3% separated. All respondents had received a high school diploma and 51.2% of respondents had earned a Bachelor's degree or higher. Most participants were currently employed full-time (67.4%) or part time (14.0%). The annual personal income of respondents ranged from no income to \$100,000+ with most participants earning \$50,000 a year or more (23.3%). Additionally, 58.1% of respondents indicated their annual combined family income was \$100,000 or more. Over half (60.5%) of respondents self-identified as Christian; 9.3% identified as another religion, including Jewish, Buddhist, and Hindu; 14.0% identified as agnostic and 14.0% identified as atheist (see Table 6.1).

Table 6.1: Participant Demographics

<i>Variable</i>	<i>N</i>	<i>%</i>
Gender		
Male	10	23.3
Female	33	76.7
Age Range		
26-30	7	16.3
31-35	16	37.2
36-40	7	16.3
41-45	10	23.3
46-50	3	7
Race		
White	33	76.7
Hispanic	3	7
Black or African American	1	2.3
Asian/Pacific Islander	2	4.7
Other	4	9.3
Marital Status		
Single, never married	2	4.7
Married	40	93
Separated	1	2.3
Education		
High School Diploma	1	2.3
Completed Some College	5	11.6
Undergraduate Degree	22	51.2
Master's Degree	12	27.9
Doctorate Degree	3	7
Level of Income		
Under \$15,000	6	13.9
\$15,000 - \$24,999	3	7
\$25,000 - \$34,999	4	9.3
\$35,000 - \$49,000	8	18.6
\$50,000 - \$74,999	10	23.3
\$75,000 - \$99,999	5	11.6
\$100,000 and Above	7	16.3
Family Level of Income		
Under \$15,000	0	0
\$15,000 - \$24,999	0	0
\$25,000 - \$34,999	0	0
\$35,000 - \$49,000	1	2.3
\$50,000 - \$74,999	2	4.7
\$75,000 - \$99,999	10	23.3
\$100,000 and Above	25	58.1

Survey Valence Responses

As part of the IQA interview protocol, descriptive statistical analyses were conducted to explore the quantitative data collected on the affinities derived. Each affinity was closely examined to identify the perceptions of the respondents with regards to valence. Valence, in IQA terms, means the range of feeling between two poles of a continuum from negative to positive. During interviews, participants were asked to respond to items regarding their experiences within each affinity and sub-affinity on a scale from 1 (Very Negative Experience) to 5 (Very Positive Experience) with a midpoint of 3 (Neutral Experience). The only exception was within the Emotions Affinity – where participants responded on a scale from 1 (Very Low Level of Emotional Experience) to 5 (Very High Level of Emotional Experience). Some participants indicated certain areas or affinities were not applicable to them, in which case their data were considered missing data and not used in that particular analysis. Total frequencies were obtained for each response within each Sub-Affinity and for the responses of each Main Affinity category (Tables 6.2 - 6.11) as well as for the responses of the Overall Infertility Treatment Experience (Table 6.12).

Table 6.2: Medical (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Doctors (<i>N</i> = 40)	2	7	12	17	2	130
Fertility Specialists (<i>N</i> = 39)	1	5	11	15	7	139
Surgeons (<i>N</i> = 31)	0	2	5	15	9	124
Physician Assistants (<i>N</i> = 23)	2	2	6	10	3	79
Nurses (<i>N</i> = 40)	0	2	9	21	8	155
Lab Techs (<i>N</i> = 38)	1	2	9	22	4	140
Office Staff (<i>N</i> = 41)	1	4	12	17	7	148
<i>Sub-Affinity Total Responses</i>	7	24	64	117	40	915
Overall Medical Staff Experience (<i>N</i> = 43)	1	2	12	25	3	156

Table 6.3: Diagnosis (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Diagnostic Labs & Tests (<i>N</i> = 42)	2	10	18	12	0	124
Ovulation (<i>N</i> = 35)	0	12	13	9	1	104
Sperm (<i>N</i> = 40)	6	15	7	10	2	107
Genetic / Physiological (<i>N</i> = 21)	1	3	8	9	0	67
Medical History (<i>N</i> = 30)	0	4	18	7	1	95
Unexplained Infertility (<i>N</i> = 27)	9	13	5	0	0	50
Doctors' Opinions (<i>N</i> = 42)	2	18	8	13	1	119
<i>Sub-Affinity Total Responses</i>	20	75	77	60	5	666
Overall Diagnosis Experience (<i>N</i> = 43)	2	19	12	10	0	116

Table 6.4: Fertility Treatment & Process (Survey Valence Responses)

	Response Options					Sum
	1	2	3	4	5	
Treatment Labs & Tests (<i>N</i> = 40)	2	10	21	6	1	114
Treatment Preparation & Scheduling (<i>N</i> = 40)	0	13	15	10	2	121
Medication (<i>N</i> = 38)	6	16	10	6	0	92
Diet (<i>N</i> = 31)	2	8	10	9	2	94
Rest (<i>N</i> = 26)	1	5	16	2	2	77
Surgery (<i>N</i> = 29)	6	3	10	8	2	84
Assisted Reproductive Technology (ART) (<i>N</i> = 32)	1	12	8	9	2	95
Alternative Medicine (<i>N</i> = 31)	1	1	8	11	10	121
<i>Sub-Affinity Total Responses</i>	19	68	98	61	21	798
Overall Fertility Treatment & Process Experience (<i>N</i> = 42)	0	22	11	7	2	115

Table 6.5: Cost/Finances (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Insurance ($N = 42$)	19	10	3	7	3	91
Medical Bills ($N = 42$)	12	15	11	4	0	91
Medication Cost ($N = 41$)	9	17	5	7	3	101
Out of Pocket Expenses ($N = 36$)	8	18	6	3	1	79
Loans ($N = 6$)	1	2	2	1	0	15
Sacrifice ($N = 42$)	13	14	9	4	2	94
Missed Work ($N = 37$)	1	13	14	5	4	109
<i>Sub-Affinity Total Responses</i>	63	89	50	31	13	580
Overall Cost/Finances Experience ($N=43$)	12	18	7	5	1	94

Table 6.6: Knowledge/Information (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
From Medical Staff (<i>N</i> = 42)	0	14	8	17	3	135
From the Web (<i>N</i> = 39)	2	9	9	17	2	125
From Family & Friends (<i>N</i> = 38)	5	9	6	16	2	115
From Support Groups (<i>N</i> = 26)	1	1	2	10	12	109
From Books, journals, etc. (<i>N</i> = 24)	1	1	9	12	1	83
Asking Questions (<i>N</i> = 42)	0	5	7	26	4	155
Understanding Information (<i>N</i> = 42)	0	8	8	22	4	148
<i>Sub-Affinity Total Responses</i>	9	47	49	120	28	870
Overall Knowledge/Information Experience (N = 43)	0	7	11	25	0	147

Table 6.7: Treatment Outcomes (Survey Valence Responses)

	Response Options					Sum
	1	2	3	4	5	
Medical Conditions Treated ($N = 38$)	4	18	9	6	1	96
A Baby ($N = 24$)	3	2	1	6	12	94
Miscarriage / Loss ($N = 34$)	17	10	3	4	0	62
Continuing Fertility Treatments ($N = 34$)	5	15	8	5	1	84
Donors ($N = 19$)	3	4	6	4	2	55
Surrogacy ($N = 7$)	1	1	1	4	0	22
Adoption ($N = 26$)	3	9	8	2	4	73
Living Childfree ($N = 33$)	8	7	10	5	3	87
<i>Sub-Affinity Total Responses</i>	44	66	46	36	23	573
Overall Fertility Treatment Outcomes Experience ($N = 43$)	3	12	11	12	5	133

Table 6.8: Time (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Years Trying (<i>N</i> = 41)	19	13	6	3	0	75
Schedules / Cycles (<i>N</i> = 40)	6	24	5	5	0	89
Waiting (<i>N</i> = 41)	18	17	4	2	0	72
Biological Clock (<i>N</i> = 41)	13	17	9	2	0	82
<i>Sub-Affinity Total Responses</i>	56	71	24	12	0	318
Overall Time Experience (<i>N</i> = 43)	10	26	5	2	0	85

Table 6.9: Empowerment/Choices (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Seeking Information (<i>N</i> = 41)	0	9	6	22	4	144
Choosing Doctors (<i>N</i> = 42)	1	7	7	24	3	147
Choosing Treatments (<i>N</i> = 42)	0	15	12	12	3	129
Controlling Cost (<i>N</i> = 41)	17	13	8	3	0	79
Controlling Diet (<i>N</i> = 36)	2	6	10	12	6	122
Control Over Body (<i>N</i> = 41)	9	20	6	6	0	91
Support / Sharing (<i>N</i> = 40)	1	7	9	17	6	140
Choosing How Far to Go (<i>N</i> = 39)	1	13	6	14	5	126
<i>Sub-Affinity Total Responses</i>	31	90	64	110	27	978
Overall Empowerment/Choices Experience (<i>N</i> = 43)	1	12	10	20	0	135

Table 6.10: Relationships (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Spouse / Partner ($N = 42$)	1	8	5	14	14	158
Family ($N = 40$)	1	8	11	14	6	136
Friends ($N = 41$)	2	11	11	9	8	133
Co-workers ($N = 36$)	0	9	10	12	5	121
Support Groups ($N = 22$)	0	1	2	6	13	97
Medical Staff ($N = 40$)	0	4	13	18	5	144
<i>Sub-Affinity Total Responses</i>	4	41	52	73	51	789
Overall Relationship Experience ($N = 43$)	0	9	14	16	4	144

Table 6.11: Emotions (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Anger (<i>N</i> = 41)	1	5	5	18	12	158
Frustration (<i>N</i> = 42)	0	2	3	15	22	183
Anxiety / Fear (<i>N</i> = 41)	4	9	7	8	13	140
Stress (<i>N</i> = 42)	2	1	7	15	17	170
Isolation / Lonely (<i>N</i> = 39)	5	8	6	15	5	124
Insecurity / Self –esteem (<i>N</i> = 39)	8	9	11	9	2	105
Jealousy / Unfair (<i>N</i> = 40)	2	7	6	14	11	145
Depression (<i>N</i> = 41)	3	9	10	13	6	133
Sorrow / Grief (<i>N</i> = 40)	3	5	6	16	10	145
Coping (<i>N</i> = 41)	2	5	16	16	2	134
Hope (<i>N</i> = 42)	3	12	8	16	3	130
Love (<i>N</i> = 42)	0	0	8	18	16	176
Excitement (<i>N</i> = 41)	7	11	8	10	5	118
Happiness/Joy (<i>N</i> = 41)	5	15	14	4	3	108
Acceptance (<i>N</i> = 42)	4	9	11	14	4	131
<i>Sub-Affinity Total Responses</i>	49	107	126	201	131	2100
Overall Emotions Experience (<i>N</i> = 43)	5	20	8	9	1	110

Table 6.12: Overall Infertility Treatment Experience (Survey Valence Responses)						
	Response Options					Sum
	1	2	3	4	5	
Overall Infertility Treatment Experience ($N = 43$)	6	23	7	6	1	102

Means Percentages

Overall experience scores from each affinity category were averaged across participants to determine which Overall experiences were most positive. Although many individuals have a generally negative or neutral experience Overall with infertility, there are some aspects of the infertility process that are more positive than others. Respondents reported the most positive experience within the Medical Staff affinity, with 65.1%. Other positive experiences were reported within the Knowledge/Information affinity (58.1% positive), Empowerment affinity (46.5% positive) and Relationship affinity (46.5% positive). The lowest positive experiences were reported within the Time affinity (4.7% positive), and the Cost affinity (14.0% positive). For a complete list of average scores and percentages of respondents indicating a positive experience see Table 6.13.

Additionally, experiences scores from each sub-affinity within each affinity category were averaged across participants to determine which specific experiences were most positive. Within the Medical Staff affinity the most positive experiences were reported with Surgeons at 77.4% while the least positive were with Doctors at 47.5% (Table 6.14). Within the Diagnosis affinity the most positive experiences were reported with Genetic/Physiological at 42.9% while the least positive were with Unexplained Infertility at 0% (Table 6.15). Within the Fertility Treatment and Process affinity the most positive experiences were reported with Alternative Medicine at 67.7% while the least positive were with Rest at 15.4% (Table 6.16). Cost/Finances affinity the most positive experiences were reported with Medication at 24.4% while the least positive were with Medical Bills at 9.5% (Table 6.17). Within the Knowledge/Information affinity the most positive experiences were reported with Knowledge/Information acquired from Support Groups at 84.6% while the least positive were with Information from Family and Friends at 47.4% (Table 6.18). Within the Treatment Outcomes affinity the most positive experiences were reported with A Baby as an outcome at 75% while the least positive were with Miscarriage/Loss at 11.8% (Table 6.19). Within the Time affinity the most positive experiences were reported with

Schedules/Cycles at 12.5% while the least positive were associated with Waiting and Biological Clock both at 4.9% (Table 6.20). Within the Empowerment/Choices affinity the most positive experiences were reported with Seeking Information at 63.4% while the least positive were associated with Controlling Cost at 7.3% (Table 6.21). Within the Relationships affinity the most positive experiences were reported with Support Groups at 86.4% while the least positive were with Friends at 41.5% (Table 6.22). Within the Emotions affinity, high levels of Frustration was experienced by 88.1% of people, while Happiness was experience by 17.1% of responders (Table 6.23). Only 16.3% of participants reported the Overall Infertility Experience as Positive (Table 6.13).

Table 6.13: Overall Experiences (Means Percentages)

	Mean	SD	% Positive
Medical Staff (N = 42)	3.63	.787	65.1%
Diagnosis (N = 42)	2.70	.887	23.3%
Fertility Treatment and Process (N = 41)	2.74	.912	21.4%
Cost/Finances (N = 42)	2.19	1.052	14.0%
Knowledge/Information (N = 41)	3.42	.763	58.1%
Treatment Outcomes (N = 41)	3.09	1.151	39.5%
Time (N = 40)	1.98	.740	4.7%
Empowerment/Choices (N = 40)	3.14	.915	46.5%
Relationships (N = 40)	3.35	.923	46.5%
Emotions (N = 40)	2.56	1.031	23.3%
Overall Infertility Treatment Experience Survey Responses	2.37	0.98	16.3%

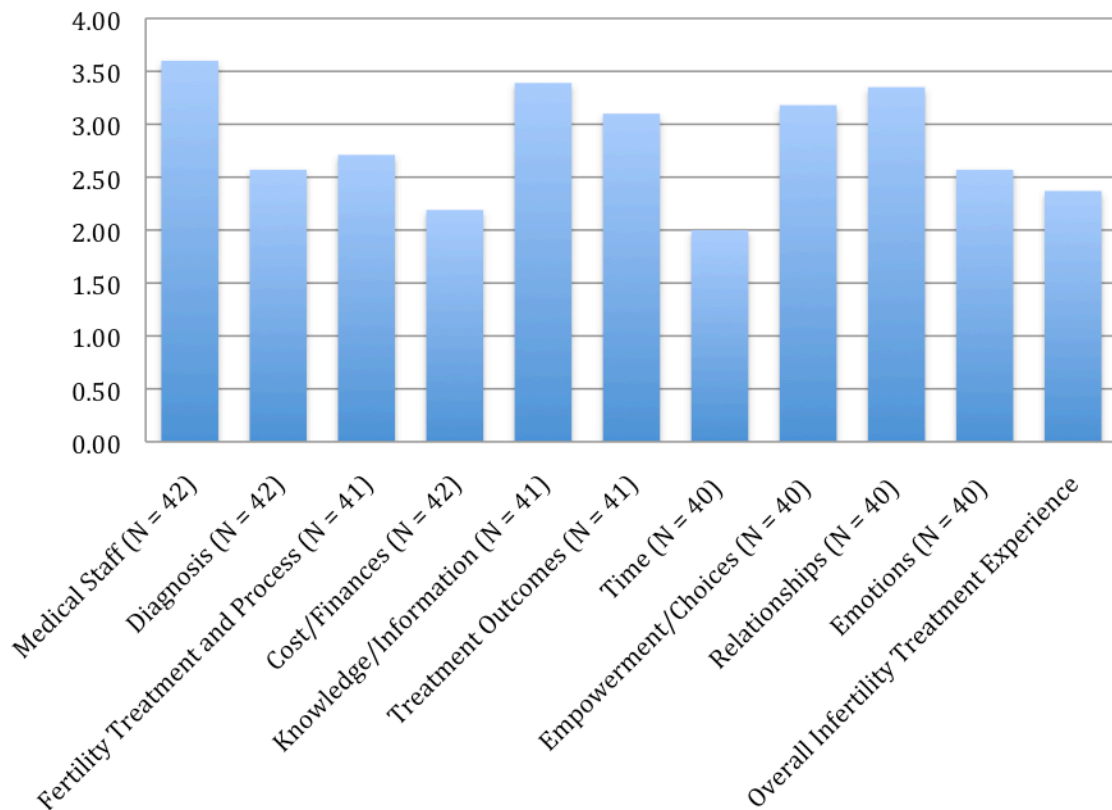


Table 6.14: Medical Staff (Means Percentages)			
	Mean	SD	% Positive
Doctors (<i>N</i> = 40)	3.25	0.98	47.5%
Fertility Specialists (<i>N</i> = 39)	3.56	1.02	56.4%
Surgeons (<i>N</i> = 31)	4.00	0.86	77.4%
Physician Assistants (<i>N</i> = 23)	3.43	1.12	56.5%
Nurses (<i>N</i> = 40)	3.88	0.79	72.5%
Lab Techs (<i>N</i> = 38)	3.68	0.84	68.4%
Office Staff (<i>N</i> = 41)	3.61	0.97	55.8%
<i>Overall Sub-Affinity Average</i>	3.63		
Overall Medical Staff Experience (<i>N</i> = 43)	3.63	0.79	65.1%

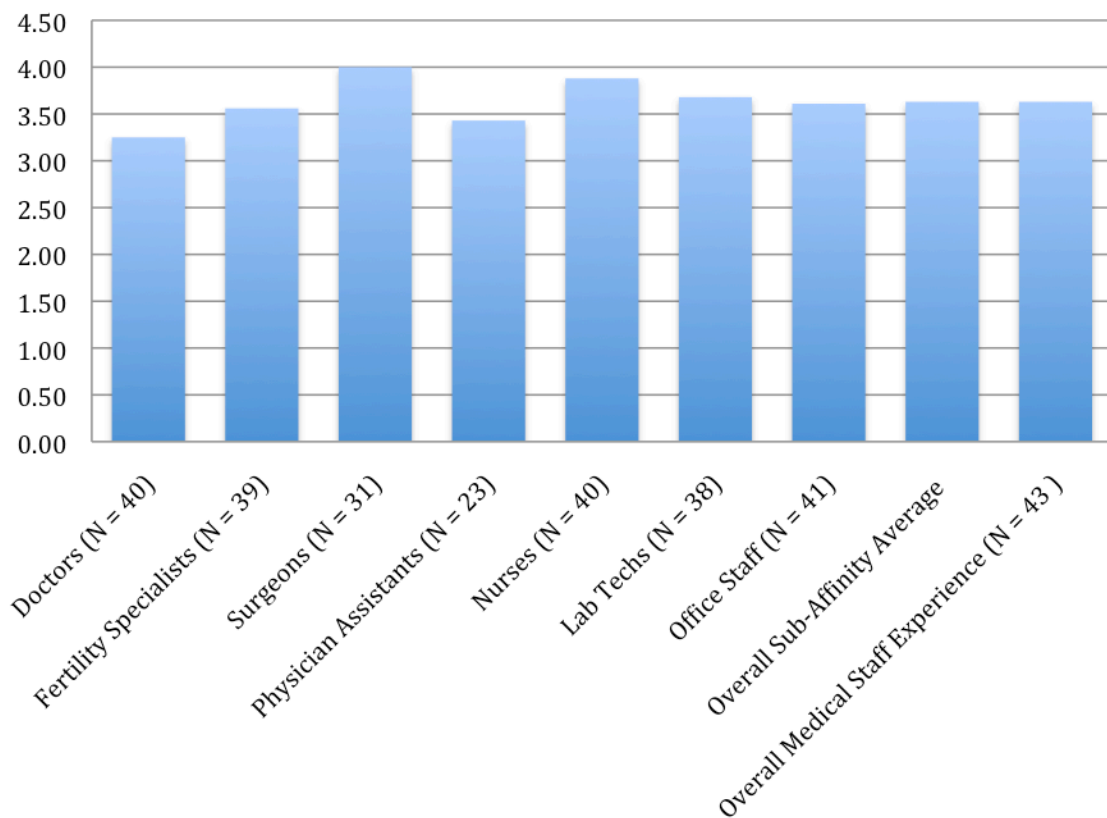


Table 6.15: Diagnosis (Means Percentages)			
	Mean	SD	% Positive
Diagnostic Labs & Tests (<i>N</i> = 42)	2.95	0.85	28.6%
Ovulation (<i>N</i> = 35)	2.97	0.86	28.6%
Sperm (<i>N</i> = 40)	2.68	1.16	30.0%
Genetic / Physiological (<i>N</i> = 21)	3.19	0.87	42.9%
Medical History (<i>N</i> = 30)	3.17	0.70	26.7%
Unexplained Infertility (<i>N</i> = 27)	1.85	0.72	0.0%
Doctors' Opinions (<i>N</i> = 42)	2.83	1.01	33.3%
<i>Overall Sub-Affinity Average</i>	<i>2.81</i>		
Overall Diagnosis Experience (<i>N</i> = 43)	2.70	0.89	23.3%

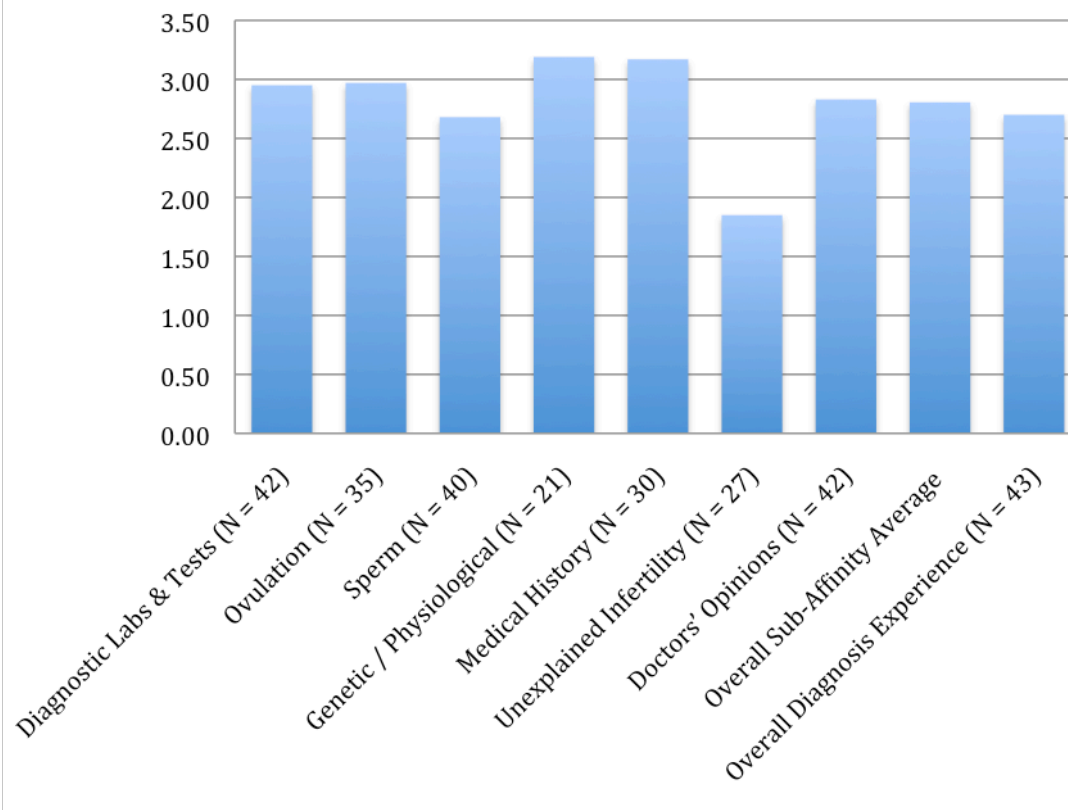


Table 6.16: Fertility Treatment & Process (Means Percentages)

	Mean	SD	% Positive
Treatment Labs & Tests (<i>N</i> = 40)	2.85	0.83	17.5%
Treatment Preparation & Scheduling (<i>N</i> = 40)	3.02	0.89	30.0%
Medication (<i>N</i> = 38)	2.42	0.95	15.8%
Diet (<i>N</i> = 31)	3.03	1.05	35.5%
Rest (<i>N</i> = 26)	2.96	0.87	15.4%
Surgery (<i>N</i> = 29)	2.90	1.24	34.5%
Assisted Reproductive Technology (ART) (<i>N</i> = 32)	2.97	1.03	34.4%
Alternative Medicine (<i>N</i> = 31)	3.90	1.01	67.7%
<i>Overall Sub-Affinity Average</i>	<i>3.01</i>		
Overall Fertility Treatment & Process Experience (<i>N</i> = 42)	2.74	0.91	21.4%

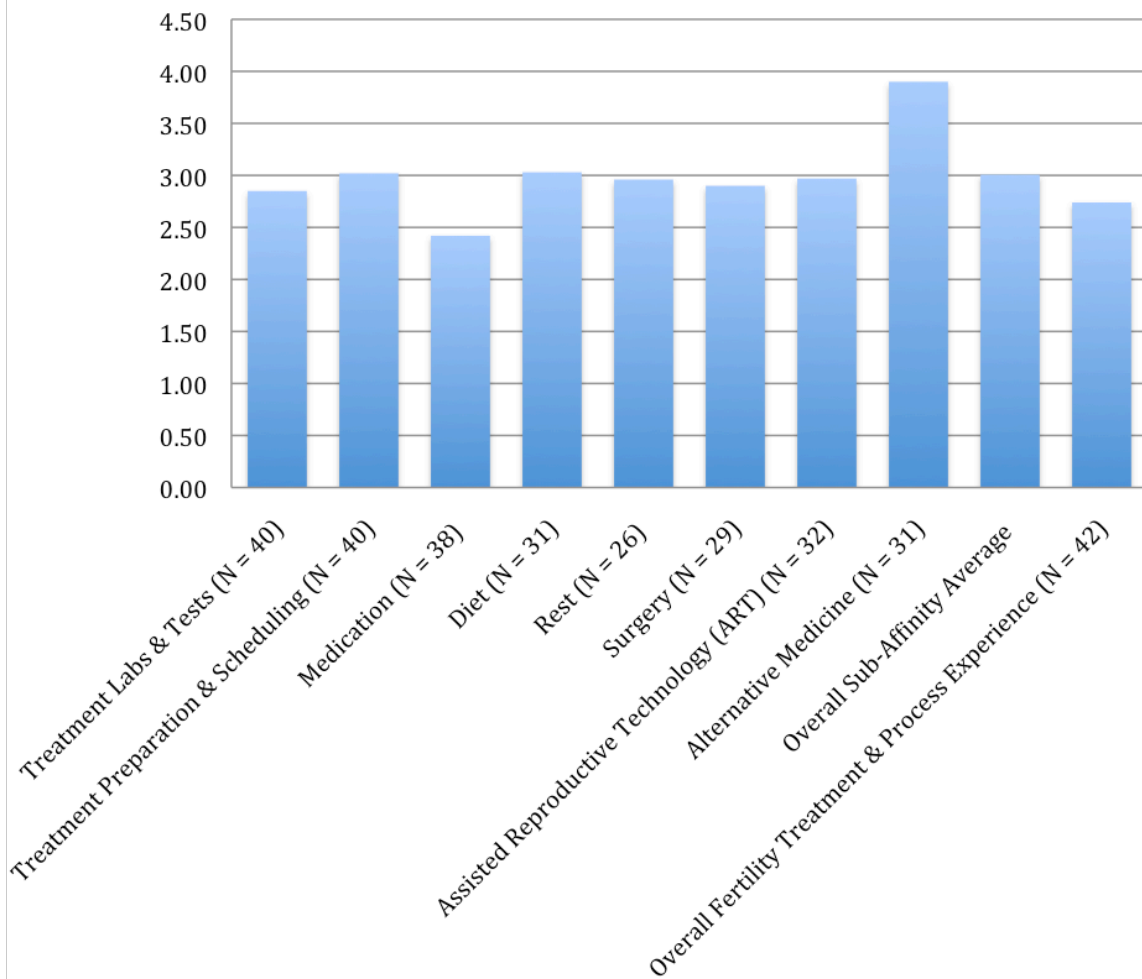


Table 6.17: Cost/Finances (Means Percentages)			
	Mean	SD	% Positive
Insurance (<i>N</i> = 42)	2.17	1.36	23.8%
Medical Bills (<i>N</i> = 42)	2.17	0.96	9.5%
Medication Cost (<i>N</i> = 41)	2.46	1.23	24.4%
Out of Pocket Expenses (<i>N</i> = 36)	2.19	0.98	11.1%
Loans (<i>N</i> = 6)	2.50	1.05	16.7%
Sacrifice (<i>N</i> = 42)	2.24	1.14	14.3%
Missed Work (<i>N</i> = 37)	2.95	1.03	24.3%
<i>Overall Sub-Affinity Average</i>	2.38		
Overall Cost/Finances Experience (<i>N</i> = 43)	2.19	1.05	14.0%

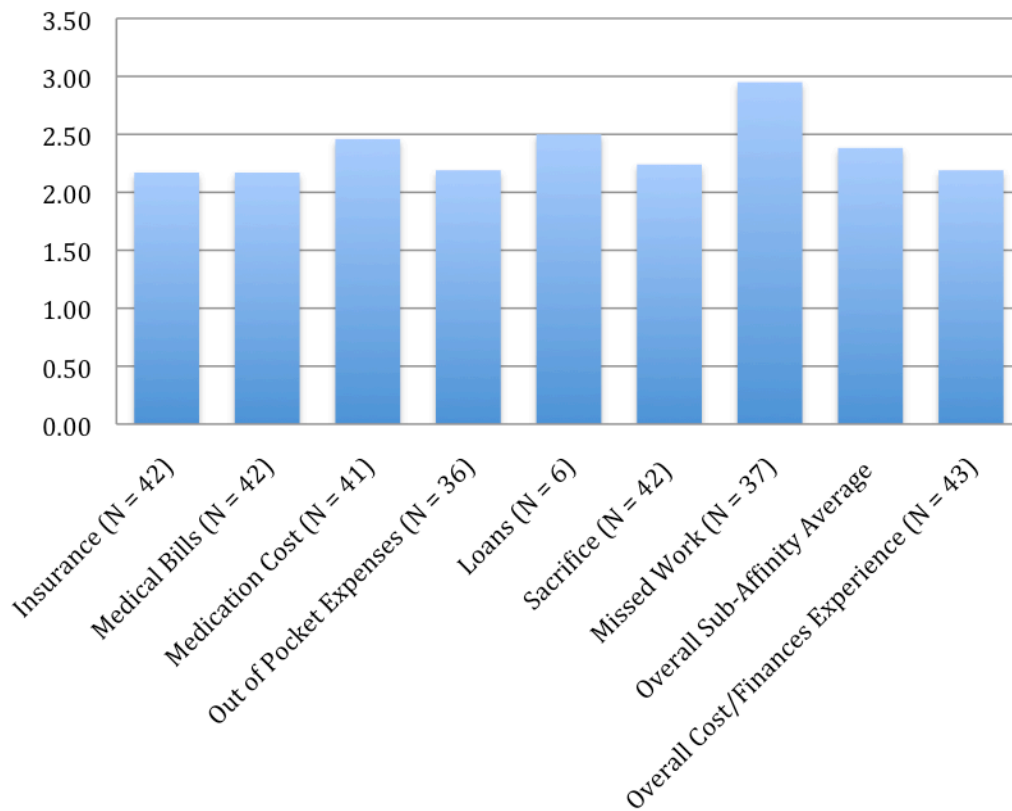


Table 6.18: Knowledge/Information (Means Percentages)

	Mean	SD	% Positive
From Medical Staff (<i>N</i> = 42)	3.21	1.00	47.6%
From the Web (<i>N</i> = 39)	3.21	1.03	48.7%
From Family & Friends (<i>N</i> = 38)	3.03	1.20	47.4%
From Support Groups (<i>N</i> = 26)	4.19	1.02	84.6%
From Books, journals, etc. (<i>N</i> = 24)	3.46	0.83	54.2%
Asking Questions (<i>N</i> = 42)	3.69	0.81	71.4%
Understanding Information (<i>N</i> = 42)	3.52	0.92	61.9%
<i>Overall Sub-Affinity Average</i>	3.47		
Overall Knowledge/Information Experience (<i>N</i> = 43)	3.42	0.76	58.1%

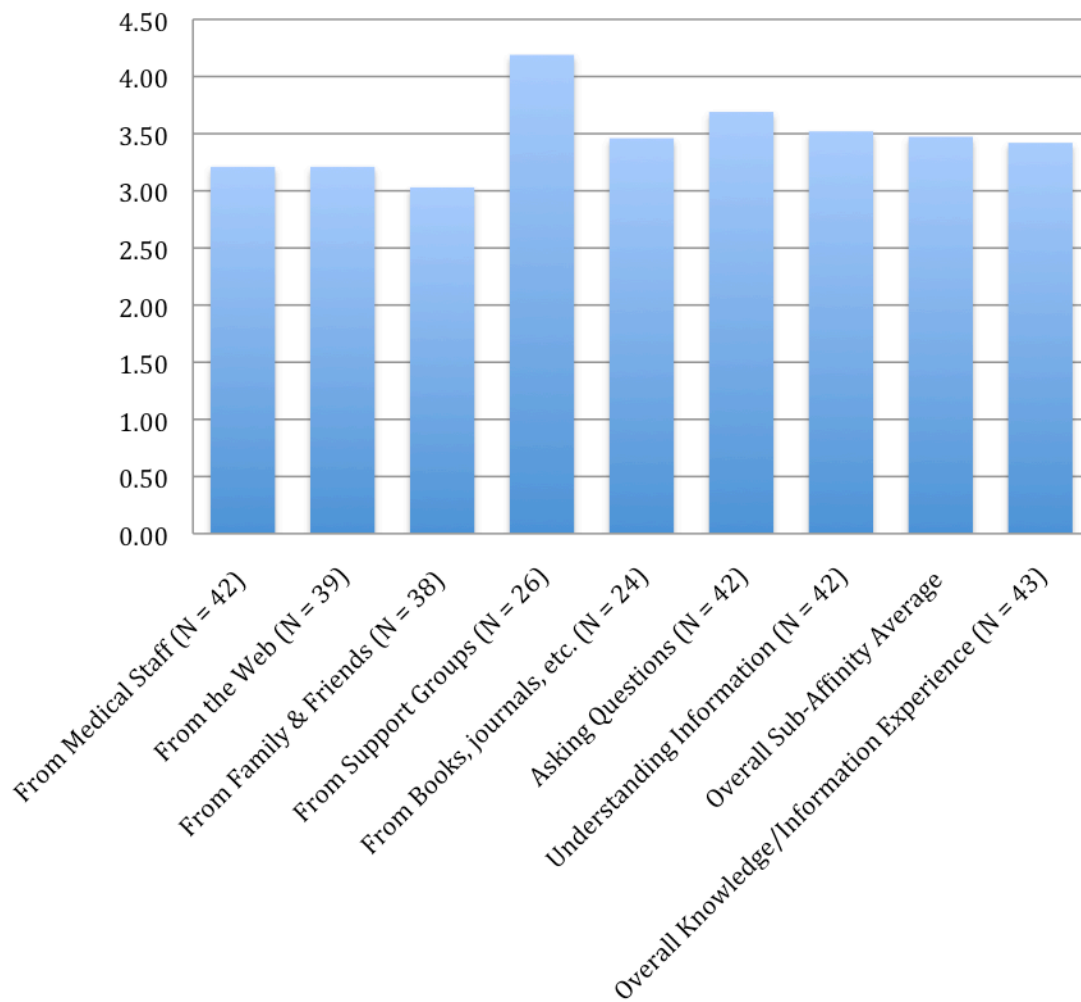


Table 6.19: Treatment Outcomes (Means Percentages)

	Mean	SD	% Positive
Medical Conditions Treated (<i>N</i> = 38)	2.53	0.98	18.4%
A Baby (<i>N</i> = 24)	3.92	1.44	75.0%
Miscarriage / Loss (<i>N</i> = 34)	1.82	1.03	11.8%
Continuing Fertility Treatments (<i>N</i> = 34)	2.47	1.02	17.6%
Donors (<i>N</i> = 19)	2.89	1.24	31.6%
Surrogacy (<i>N</i> = 7)	3.14	1.22	57.1%
Adoption (<i>N</i> = 26)	2.81	1.23	23.1%
Living Childfree (<i>N</i> = 33)	2.64	1.27	24.2%
<i>Overall Sub-Affinity Average</i>	2.78		
Overall Fertility Treatment Outcomes Experience (<i>N</i> = 43)	3.09	1.15	39.5%

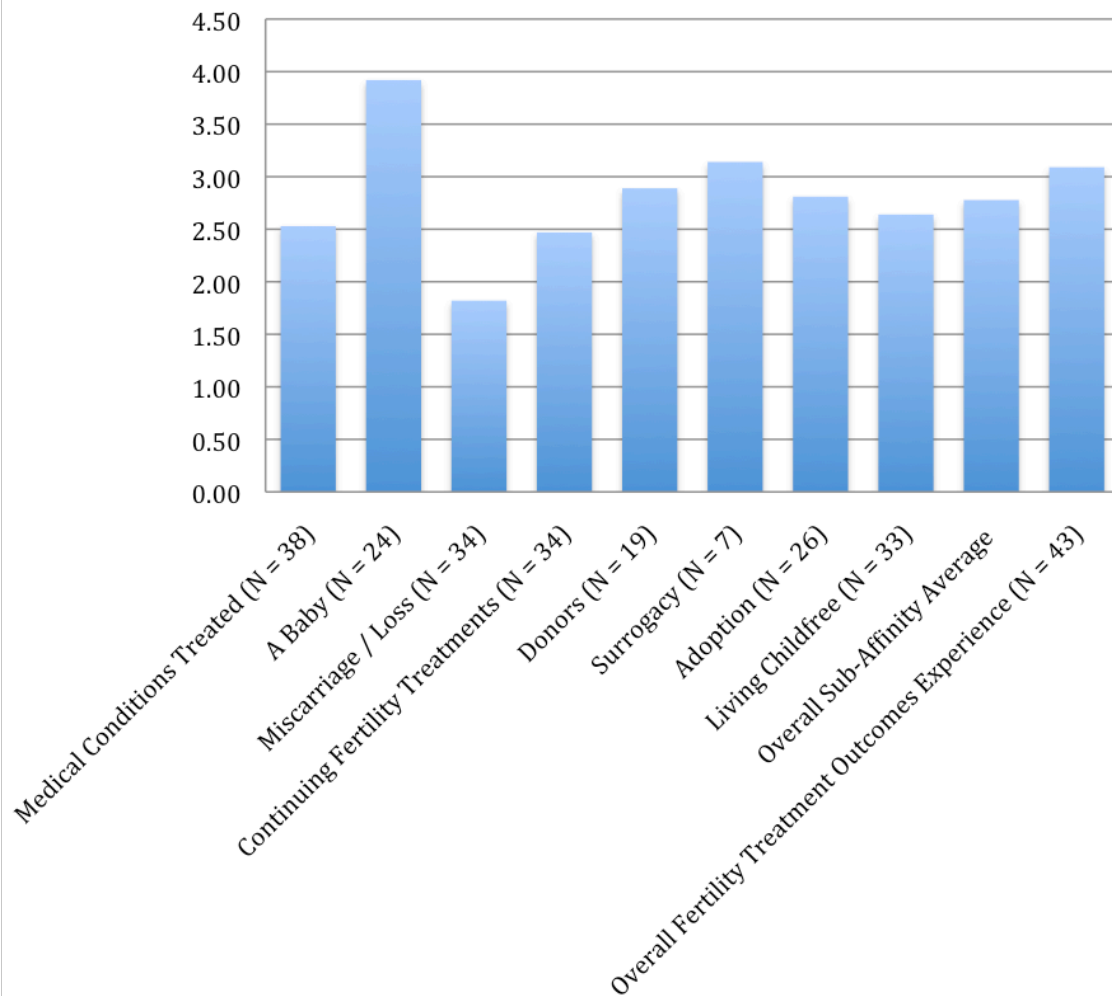


Table 6.20: Time (Means Percentages)			
	Mean	SD	% Positive
Years Trying (<i>N</i> = 41)	1.83	0.95	7.3%
Schedules / Cycles (<i>N</i> = 40)	2.22	0.86	12.5%
Waiting (<i>N</i> = 41)	1.76	0.83	4.9%
Biological Clock (<i>N</i> = 41)	2.00	0.87	4.9%
<i>Overall Sub-Affinity Average</i>	<i>1.95</i>		
Overall Time Experience (<i>N</i> = 43)	1.98	0.74	4.7%

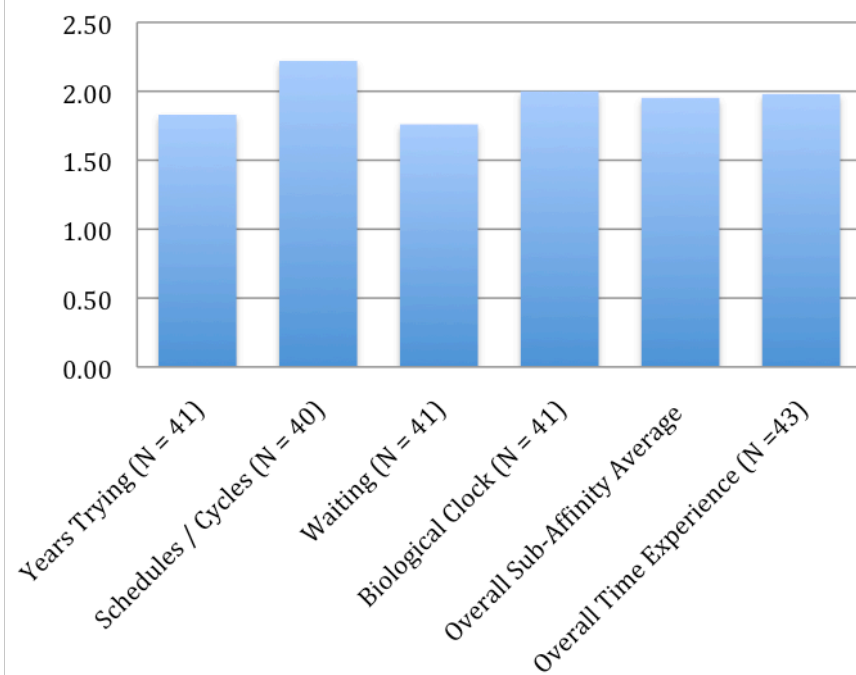


Table 6.21: Empowerment/Choices (Means Percentages)

	Mean	SD	% Positive
Seeking Information (<i>N</i> = 41)	3.51	0.95	63.4%
Choosing Doctors (<i>N</i> = 42)	3.50	0.94	64.3%
Choosing Treatments (<i>N</i> = 42)	3.07	0.97	35.7%
Controlling Cost (<i>N</i> = 41)	1.93	0.96	7.3%
Controlling Diet (<i>N</i> = 36)	3.39	1.13	50.0%
Control Over Body (<i>N</i> = 41)	2.22	0.96	14.6%
Support / Sharing (<i>N</i> = 40)	3.50	1.04	57.5%
Choosing How Far to Go (<i>N</i> = 39)	3.23	1.14	48.7%
<i>Overall Sub-Affinity Average</i>	<i>3.04</i>		
Overall Empowerment/Choices Experience (<i>N</i> = 43)	3.35	0.92	46.5%

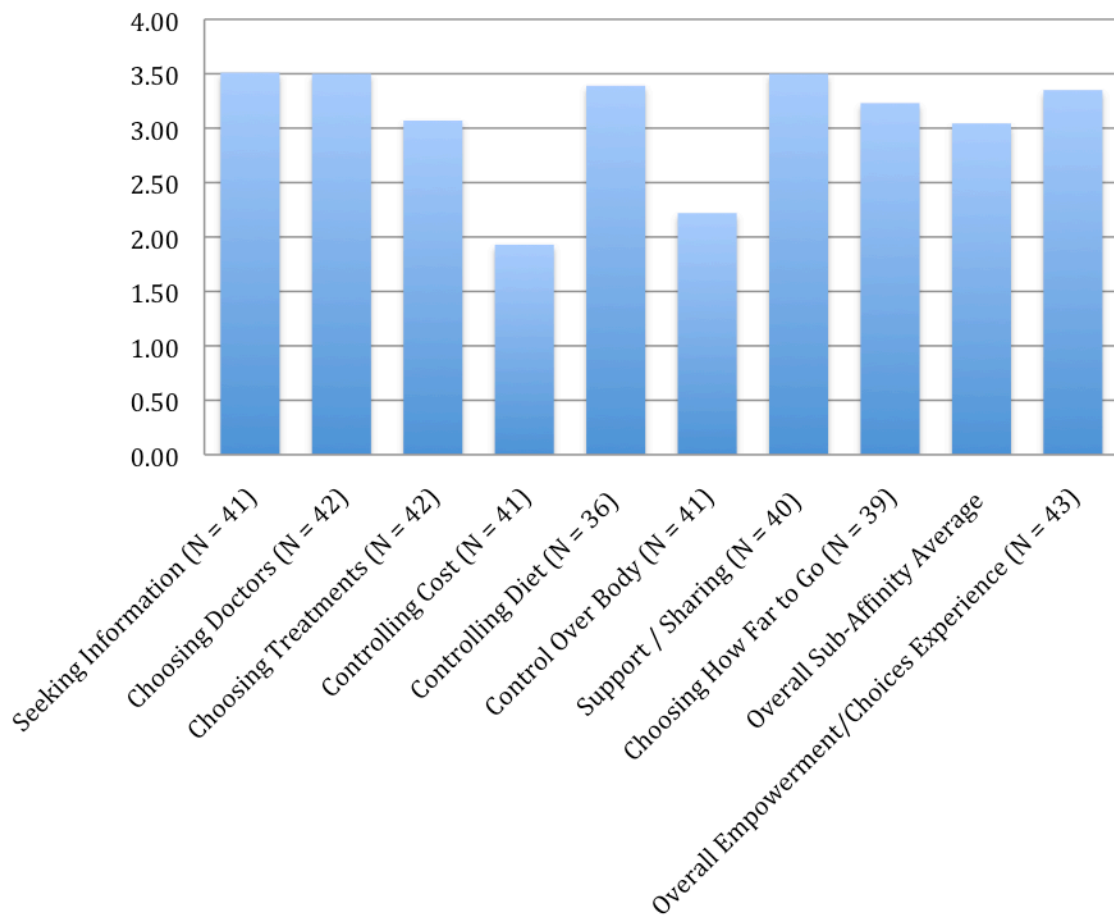


Table 6.22: Relationships (Means Percentages)			
	Mean	SD	% Positive
Spouse / Partner (<i>N</i> = 42)	3.76	1.19	66.7%
Family (<i>N</i> = 40)	3.40	1.06	50.0%
Friends (<i>N</i> = 41)	3.24	1.20	41.5%
Co-workers (<i>N</i> = 36)	3.36	1.02	47.2%
Support Groups (<i>N</i> = 22)	4.41	0.85	86.4%
Medical Staff (<i>N</i> = 40)	3.60	0.84	57.5%
<i>Overall Sub-Affinity Average</i>	3.63		
Overall Relationship Experience (<i>N</i> = 43)	3.35	0.92	46.5%

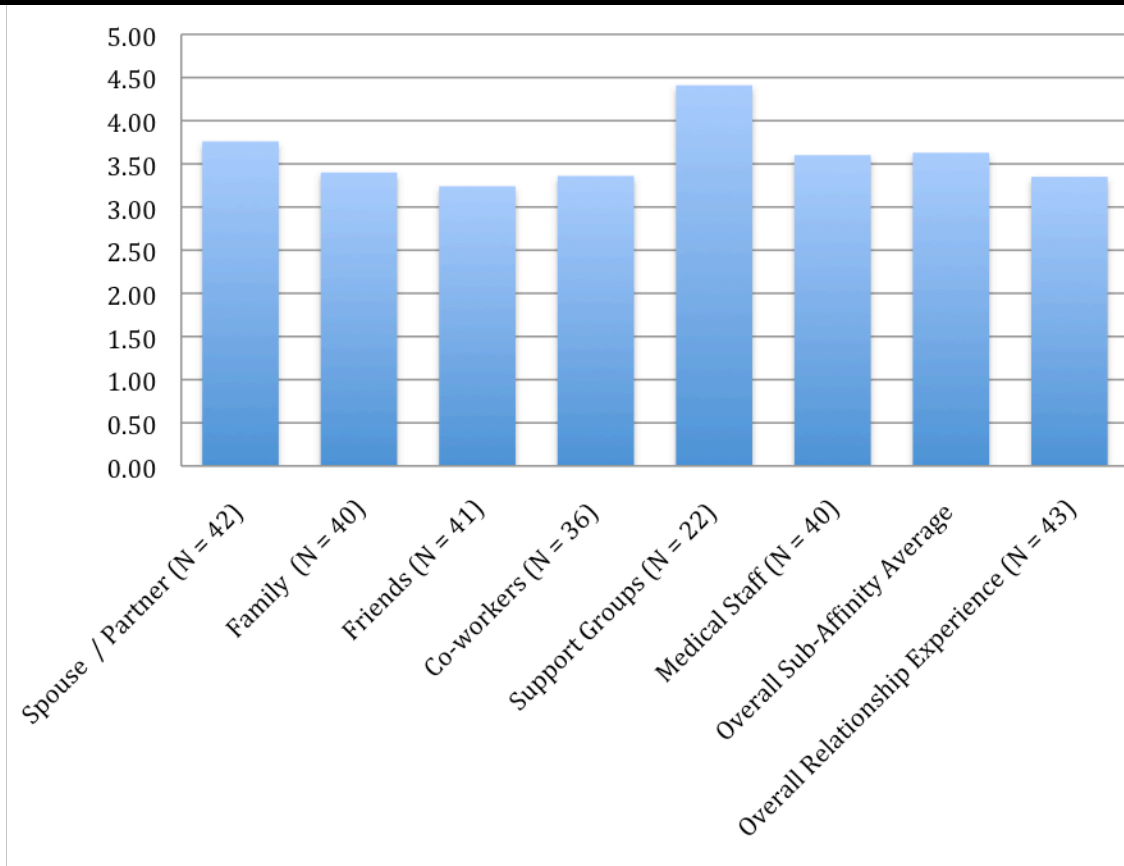
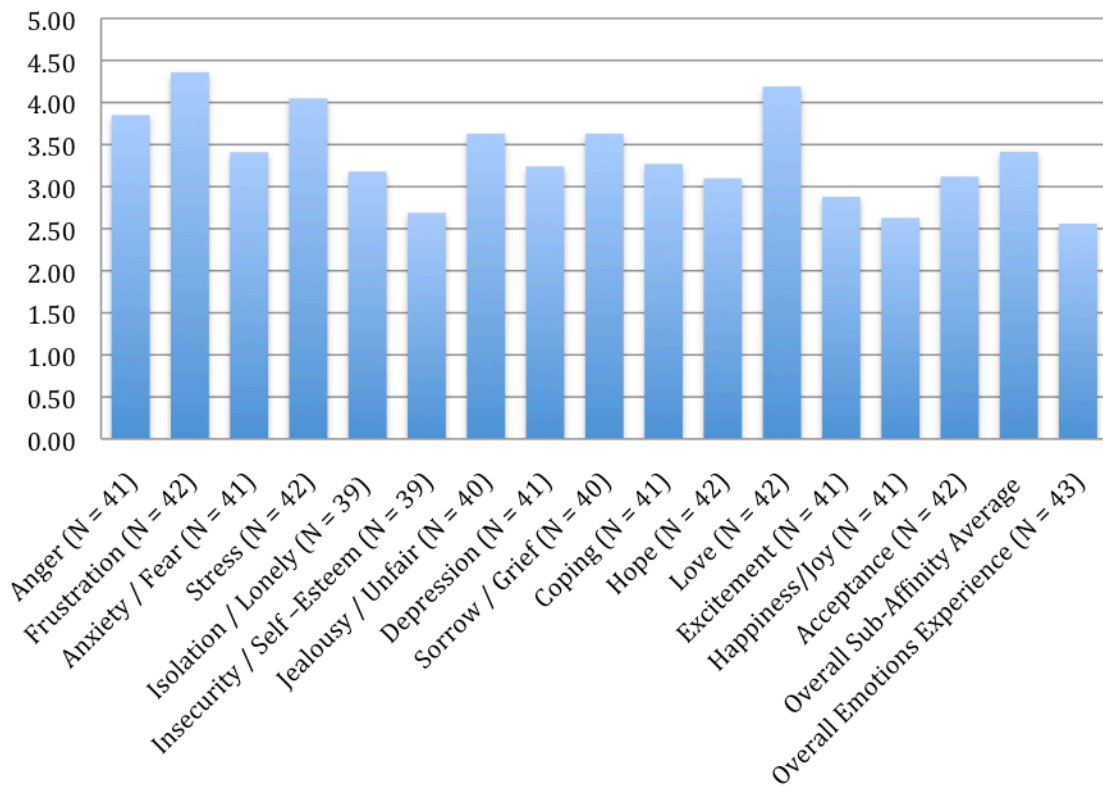


Table 6.23: Emotions (Means Percentages)

	Mean	SD	% Occurrence
Anger (<i>N</i> = 41)	3.85	1.06	73.2%
Frustration (<i>N</i> = 42)	4.36	0.82	88.1%
Anxiety / Fear (<i>N</i> = 41)	3.41	1.40	51.2%
Stress (<i>N</i> = 42)	4.05	1.06	76.2%
Isolation / Lonely (<i>N</i> = 39)	3.18	1.28	51.3%
Insecurity / Self –Esteem (<i>N</i> = 39)	2.69	1.20	28.2%
Jealousy / Unfair (<i>N</i> = 40)	3.63	1.21	62.5%
Depression (<i>N</i> = 41)	3.24	1.18	46.3%
Sorrow / Grief (<i>N</i> = 40)	3.63	1.21	65.0%
Coping (<i>N</i> = 41)	3.27	0.92	43.9%
Hope (<i>N</i> = 42)	3.10	1.12	45.2%
Love (<i>N</i> = 42)	4.19	0.74	81.0%
Excitement (<i>N</i> = 41)	2.88	1.31	36.6%
Happiness/Joy (<i>N</i> = 41)	2.63	1.07	17.1%
Acceptance (<i>N</i> = 42)	3.12	1.15	42.9%
<i>Overall Sub-Affinity Average</i>	3.42		
Overall Emotions Experience (<i>N</i> = 43)	2.56	1.03	23.3%



Reliability Analyses

Additional analyses were conducted to evaluate the psychometric properties of the subscales, determine the extent to which the affinities related to each other, as well as to the rating of the overall experience with fertility treatments. The Emotions affinity was broken up into a positive emotions category and negative emotions category. Positive emotions included Coping, Hope, Love, Excitement, Happiness / Joy, Acceptance. Negative emotions included Anger, Frustration, Anxiety / Fear, Stress, Isolation / Lonely, Insecurity / Self –esteem, Jealousy / Unfair, Depression, Sorrow / Grief.

First, a reliability analysis was conducted on each affinity in order to determine the extent to which the items in each affinity measure the same variable. The items included in the reliability analysis did not include the “overall experience” question. Overall, Chronbach’s α for each affinity was moderate to low (Table 6.24). As shown in the table, an α below .7 indicates low reliability, meaning the sub-scales are not measuring the same constructs or there might be few number of items in the scale. For Medical Staff, Fertility Treatment & Process, Cost/Finance, and Negative Emotions, Chronbach’s α above .7 indicates that the sub-items measured closely among them therefore they are closely related to each other.

In this case low reliability is not necessarily a disadvantaged. It could be an indication that more information on satisfaction with that specific aspect is captured. In other words, the loss of reliability could indicate a gain in content validity, or capturing more aspects of the same variable. This is confirmed by examining the inter-item correlations, which indicated that none of the items were highly correlated with other items in the same subscale. The inter-item correlations indicate that the questions are potentially capturing unique pieces of information rather than being redundant. In this case, the unshared variance is not necessarily all error variance, but unique information about the specific affinity.

Table 6.24: Scale Reliability		
Affinities	<i>Cronbach's Alpha</i>	N of Items
Medical Staff	.775	7
Diagnosis	.692	7
Fertility Treatment and Process	.723	8
Cost/Finances	.817	7
Knowledge/Information	.212	7
Treatment Outcomes	.655	4
Time	.380	8
Empowerment/Choices	.562	6
Relationships	.757	9
Negative Emotions	.684	6
Positive Emotions	.775	7

In order to determine whether the “overall experience” in each subcategory is highly correlated with each of the items in that affinity, the item was added to the analyses and inter-item correlations were reexamined. The goal was to determine which items are strongly related to the overall experience satisfaction with that affinity. In this analysis, items are analyzed two at a time, and effect size is examined. Values of .1 to .2 indicate low effect size, .3 to .5 indicate medium effect size, and .5 to 1 indicate high effect size. As shown in the following tables, most of the inter-item correlations with the overall experience question were weak positive relationships. This indicates that, although each of the items of each subcategory has something to do with the overall experience, it is not just one item or aspect that determined individuals overall satisfaction with each affinity. For example, having a positive experience with doctors will not necessarily mean a positive overall medical experience, because other factors contribute to that overall satisfaction with the medical affinity. However, having high positive experience with doctors increases that chance that one will have an overall highly positive medical experience (Tables 6.25 – 6.34).

Table 6.25: Medical Staff (Inter-Item Correlation Matrix)

	Overall Medical Staff Experience
Doctors	.539
Fertility Specialists	.680
Surgeons	.697
Physician Assistants	.576
Nurses	.315
Lab Techs	.680
Office Staff	.119
Overall Medical Staff Experience	1.000

Table 6.26: Diagnosis (Inter-Item Correlation Matrix)

	Overall Diagnosis Experience
Diagnostic Labs & Tests	.254
Ovulation	.611
Sperm	.236
Genetic / Physiological	.487
Medical History	.484
Unexplained Infertility	.777
Doctors' Opinions	.226
Overall Diagnosis Experience	1.000

Table 6.27: Fertility Treatment & Process (Inter-Item Correlation Matrix)

	Overall Fertility Treatment & Process Experience
Treatment Labs & Tests	.399
Treatment Preparation & Scheduling	.369
Medication	.223
Diet	.420
Rest	.494
Surgery	.426
Assisted Reproductive Technology (ART)	.802
Alternative Medicine	.355
Overall Fertility Treatment & Process Experience	1.000

Table 6.28: Cost/Finances (Inter-Item Correlation Matrix)	
	Overall Cost/Finances Experience
Insurance	.643
Medical Bills	.327
Medication Cost	-.535
Out of Pocket Expenses	.869
Loans	.367
Sacrifice	.873
Missed Work	.488
Overall Cost/Finances Experience	1.000

Table 6.29: Knowledge/Information (Inter-Item Correlation Matrix)	
	Overall Knowledge/Information Experience
From Medical Staff	-.062
From the Web	-.014
From Family & Friends	.063
From Support Groups	-.231
From Books, journals, etc.	.109
Asking Questions	.270
Understanding Information	.565
Overall Knowledge/Information Experience	1.000

Table 6.30: Time (Inter-Item Correlation Matrix)	
	Overall Time Experience
Years Trying	.521
Schedules / Cycles	.538
Waiting	.667
Biological Clock	.288
Overall Time Experience	1.000

Table 6.31: Empowerment/Choices (Inter-Item Correlation Matrix)

	Overall Empowerment Choices Experience
Seeking Information	.280
Choosing Doctors	.344
Choosing Treatments	.628
Controlling Cost	.302
Controlling Diet	.018
Control Over Body	.360
Support / Sharing	-.074
Choosing How Far to Go	.670
Overall Empowerment Choices Experience	1.000

Table 6.32: Relationships (Inter-Item Correlation Matrix)

	Overall Relationships Experience
Spouse / Partner	.431
Family	.510
Friends	.704
Co-workers	.482
Support Groups	-.042
Medical Staff	.655
Overall Relationships Experience	1.000

Table 6.33: Emotions (Inter-Item Correlation Matrix)	
	Overall Emotions Experience
Anger	-.361
Frustration	-.337
Anxiety / Fear	-.156
Stress	.070
Isolation / Lonely	-.180
Insecurity / Self –Esteem	.205
Jealousy / Unfair	-.244
Depression	-.154
Sorrow / Grief	-.374
Coping	.358
Hope	.408
Love	.112
Excitement	.468
Happiness/Joy	.379
Acceptance	.384
Overall Emotions Experience	1.000

Factor and Correlation Analysis

As for whether the “overall experience” item is sufficient to capture all the information captured by the other items in that subscale, a factor analysis was conducted. For each of the subscales, 2-4 factors emerged. Factor loadings indicated that the “overall” question was not cross-loading across all factors. The results of the factor analysis show that reducing the subscales to one item would not capture as much information. In other words, each item in each subscale captures a significant amount of unique information that would be lost if the scale was to be reduced to one item. An additional factor analysis was carried out to determine whether it is reasonable to treat all the items as one scale. Based on the factor analysis, the emerging factors are not highly correlated enough to be considered one scale. For this reason, the sum of each affinity was calculated separately.

After the sum of each subscale was calculated, the relationships between each of the subscales were examined. Positive emotions was significantly (positively and moderately) correlated with all other subscales, except negative emotions, which could indicate that all the other components play a factor in positive emotions. However, since positive and negative emotions were not significantly correlated, it points out that in regards to the fertility treatment experience, having positive emotions does not necessarily mean the absence of negative emotions. The experience of infertility treatments is filled with mixed positive and negative emotions.

In order to answer the question which components are most important for individual’s rating of the overall infertility treatment, a correlation analysis was conducted with the sum of each subcategory as predictors and the rating of overall experience as the dependent variable. The results indicated that overall experience is positively predicted by positive emotions, choice/empowerment experience, time, medical experience, and fertility treatment experience. All these relationships were positive, so as one increases, the other increases as well.

Table 6.34: Correlation Matrix												
	Positive Emotion	Negative Emotions	Relationships	Empowerment/ Choices	Time	Diagnosis	Medical Staff	Fertility Treatment and Process	Cost	Knowledge/Information	Treatment Outcome	OVERALL EXPERIENCE
Positive Emotion	1	-	-	-	-	-	-	-	-	-	-	-
Negative Emotions	.091	1	-	-	-	-	-	-	-	-	-	-
Relationships	.511**	.381*	1	-	-	-	-	-	-	-	-	-
Empowerment / Choices	.571**	.218	.449**	1	-	-	-	-	-	-	-	-
Time	.650**	.019	.521**	.594**	1	-	-	-	-	-	-	-
Diagnosis	.337*	.267	.168	.541	.383*	1	-	-	-	-	-	-
Medical Staff	.448**	.313*	.475**	.479**	.445**	.433**	1	-	-	-	-	-
Fertility Treatment and Process	.424**	.050	.379*	.428**	.449**	.325*	.535**	1	-	-	-	-
Cost	.441**	.051	.451**	.681**	.573**	.313*	.326*	.169	1	-	-	-
Knowledge / Information	.423**	.427**	.521**	.566**	.314*	.386*	.437**	.485**	.300	1	-	-
Treatment Outcomes	.459**	.093	.420**	.460**	.218	.316*	.371*	.466**	.357*	.439**	1	-
OVERALL EXPERIENCE	.403**	-.278	.234	.349*	.555**	.124	.345*	.282	.535**	.045	.150	1

N = 43. ** $p < .01$; * $p < .05$

Demographics Correlations Analysis

As for demographics differences, it was found that females have significantly higher positive emotion ($r = .314, p < .05$) and significantly better diagnosis experience ($N=43, r = .475, p < .05$) compared to males. Those who are married have significantly higher positive emotions ($N=43, r = -.490, p < .05$), significantly more positive diagnosis experience ($N=43, r = -.465, p < .05$) and medical experience ($N=43, r = -.324, p < .05$) compared to those who were not married. Furthermore, higher education is correlated with higher relationship satisfaction ($N=43, r = .327, p < .05$) and better medical experience ($N=43, r = .309, p < .05$) and better fertility experience ($N=43, r = .352, p < .05$). Lastly, Individual income: lower individual income is correlated with higher negative emotions.

Table 6.35: Demographics Correlations Analysis

		Positive Emotion	Negative Emotions	Relationships	Diagnosis	Medical Staff	Fertility Treatment and Process	Gender	Marital Status	Education	Individual Income		
Positive Emotion	r	1	-	-	-	-	-	-	-	-	-		
Negative Emotions	r	.091	1				-	-	-	-	-		
Relationships	r	.511**	.381*	1	-	-	-	-	-	-	-		
Diagnosis	r	.337*	.267	.168	1	-	-	-	-	-	-		
Medical Staff	r	.448**	.313*	.475**	.433**	1	-	-	-	-	-		
Fertility Treatment and Process	r	.424**	.050	.379*	.325*	.535**	1	-	-	-	-		
Gender	r	.085	.314*	.152	.475**	.293	-.140-	1	-	-	-		
Marital Status	r	-.490**	-.298	-.400**	-.465**	-.324*	-.246	-.140	1	-	-		
Education	r	.028	.257	.327*	-.171	.309*	.352*	.097	.109	1	-		
Individual Income	r	.039	-.357*	-.042	-.146	-.113	.205	-.481**	.081	.149	-.1		
**. Correlation is significant at the 0.01 level (2-tailed).													
*. Correlation is significant at the 0.05 level (2-tailed).													

Emotional Reactions Correlations Analysis

To explore the emotional reaction to the satisfaction (or lack thereof) with each aspect of the fertility treatment experience, a correlation analysis was conducted with each positive and negative emotion state as a dependent variable, and the sum of each subsection as predictors. Results indicated that a negative experience with fertility treatment was associated with higher anxiety/fear ($r = -.325, p < .05$). The lower one's satisfaction with relationships is, the more lonely he/she is ($r = -.422, p < .05$). Overall lower treatment satisfaction was associated with more intense ratings of depression ($r = -.400, p < .05$). Individuals' coping was positively related with satisfaction with their choices and sense of empowerment ($r = .363, p < .05$). Finally, higher excitement and acceptance are both related to higher satisfaction with the pace at which the treatment is going (time; $r = .590$ and $r = .384, p < .05$).

CHAPTER 7: INTERPRETATION OF THE INFERTILITY TREATMENT EXPERIENCE SYSTEM

Introduction

The goal of this exploratory study was to better understand how people process and cope with their difficulty conceiving children. This study focuses on infertility and In Vitro Fertilization (IVF) experiences of individuals affected by this condition and/or undergoing IVF treatments. Therefore, the main aim was to increase our understanding of the experience of infertility and what tools can be developed to help these individuals cope psychologically with this condition.

The analysis of language and discourse specific to the participants of this study revealed the psychological toll this condition took on them. Furthermore, this study uncovered aspects, feelings, and struggles these individuals encounter when undergoing medical treatments to bear their biological child, as well as of those who found themselves unable to pursue treatments. The analysis of the research findings enabled this researcher to pinpoint the more difficult aspects of both the condition and the process, and therefore contributed to the understanding of the quality of treatments as well as the quality of experiences. Three focus groups of twenty-six people, followed by thirty-four individual interviews and forty-three surveys were conducted utilizing the research design from Interactive Qualitative Analysis (Northcutt & McCoy (2002), which contributed to a robust collection of data, as well as a rigorous means of data analysis. During the focus group, main themes about the topic were unearthed and named. These themes allowed for a description of the process and answered the '*what*' question - what factors comprise the phenomenon of the infertility experience. The systems influence diagram (SID) component facilitated the interaction of the factors within a system of attributed relationships or influences. The SID answered the *how* and *why* questions.

Results of interviews and surveys were reported in chapters 4, 5, and 6. Using the IQA methodology, an analysis narrative from the participants' perspective was provided. This narrative told the participants' story in their own words, thus the description of each affinity was free of commentary and interpretation by the researcher. Chapters 4 and 5 addressed research questions from the point of view of the individuals who have lived the infertility treatment

experience. Chapter 4 detailed a composite analysis to tell the story of the group as a whole to answer research question #1: *What are the elements that make up The Infertility Treatment?* Chapter 5 used a detailed composite analysis to tell the story of the group to answer research question #2: *How do these elements relate in a system of influence?* The participants' combined stories provided the reader with an idea of the range of meaning for each affinity and sub-affinity. Chapters 4 and 5 allow the reader to draw meaning from the participants. Additionally, during the axial interview following the description of each affinity, respondents were also asked to rate that particular theme as it applied to their personal experience, as well as to rate the overall experience with each main category (affinity) and with the overall infertility experience. Results of the statistical analyses of the surveys were reported in Chapter 6.

Chapter 7 provides the researcher's interpretation of the findings. The researcher examines the meaning of each affinity and their relationships, and how they all come together in a system. By examining the system in several ways, the researcher offers insight and solutions into common problems with the final goal of identifying how to have a positive outcome in the system. First, the chapter presents a brief general description of the Infertility Treatment Experience System and its components. Then, detailed descriptions of each affinity, and how all the affinities interact to form the system, are provided. Next, the reader is taken on a tour of the system, explaining where the elements of the system lay, and how the relationships among them work. During this tour, feedback loops are identified, named, and examined individually. In the Exercising the System section, the researcher describes hypothetical scenarios that predict outcomes that may result from certain conditions, as well as describes what must occur to achieve a desired outcome. Next, Predictions, Interventions, and Practical Implications are examined to provide solutions to identified problems. Following the statistical analyses are discussed as they might confirm or dispute points brought up in the narratives. Limitation and Future directions will conclude this chapter.

The Infertility Treatment Experience System

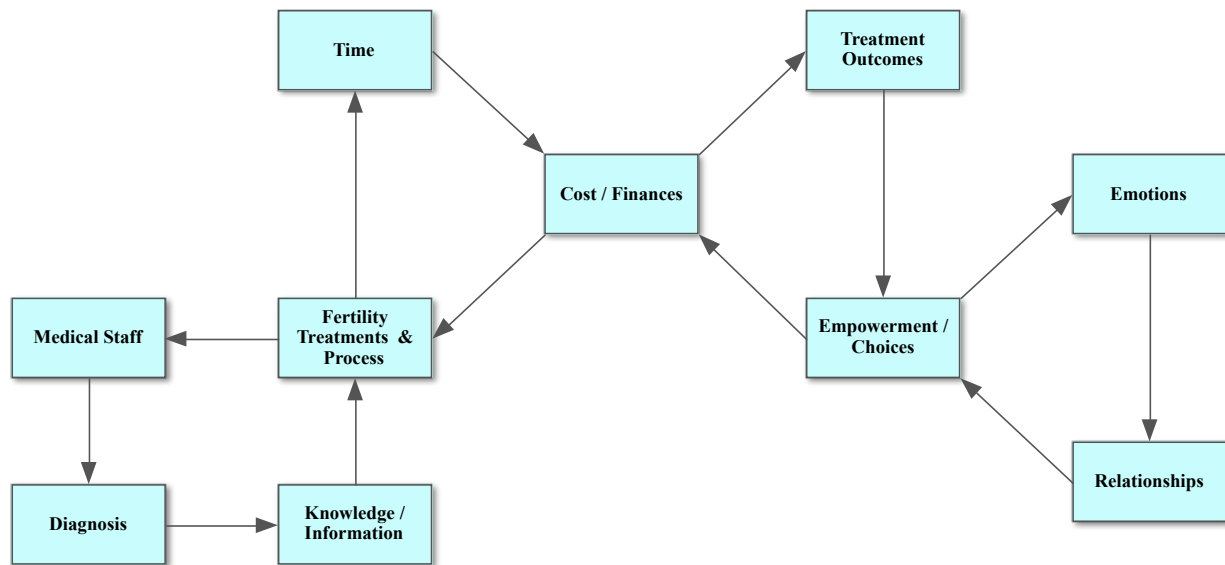


Figure 7.1: The Infertility Treatment Experience System

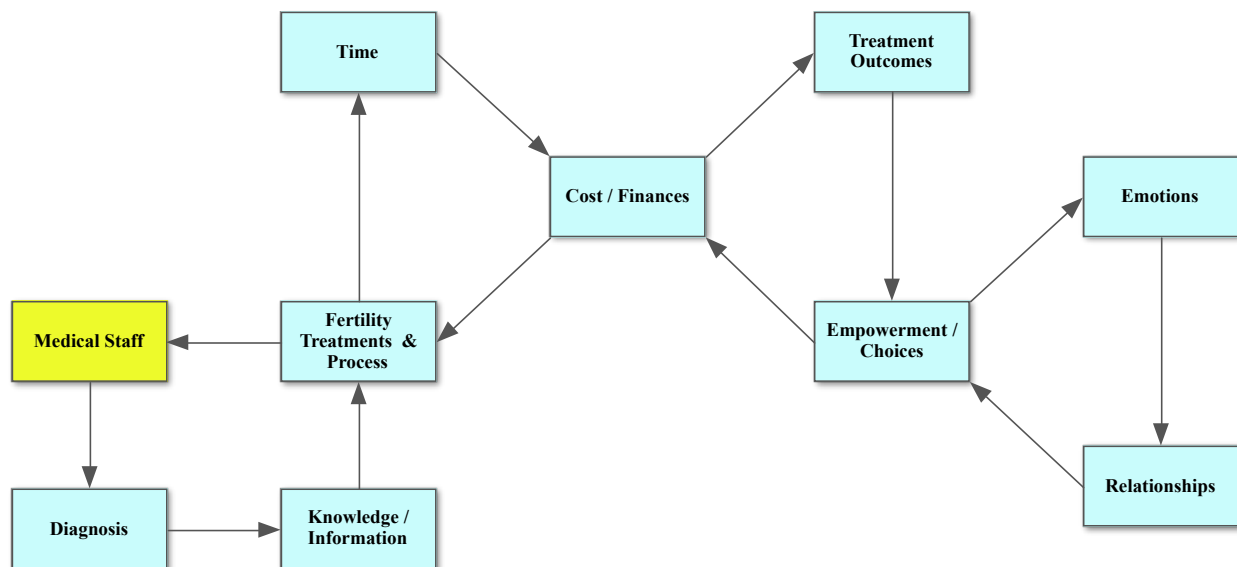
Table 7.1: The Infertility Treatment Experience Affinities

Affinity	Sub-Affinities	
Medical Staff	<ul style="list-style-type: none"> ◆ Doctors ◆ Fertility Specialists ◆ Surgeons ◆ Physician Assistants 	<ul style="list-style-type: none"> ◆ Nurses ◆ Lab Techs ◆ Office Staff
Diagnosis	<ul style="list-style-type: none"> ◆ Diagnostic Labs & Tests ◆ Ovulation ◆ Sperm ◆ Genetic / Physiological 	<ul style="list-style-type: none"> ◆ Medical History (Medications, Trauma, Disease, etc.) ◆ Unexplained Infertility ◆ Doctors' Opinions
Fertility Treatments & Process	<ul style="list-style-type: none"> ◆ Treatment Labs & Tests ◆ Treatment Preparation & Scheduling ◆ Medication ◆ Diet 	<ul style="list-style-type: none"> ◆ Rest ◆ Surgery ◆ Assisted Reproductive Technology (ART) ◆ Alternative Medicine
Cost/Finances	<ul style="list-style-type: none"> ◆ Insurance ◆ Medical Bills ◆ Medication Cost ◆ Out of Pocket Expenses 	<ul style="list-style-type: none"> ◆ Loans ◆ Sacrifice ◆ Missed Work
Knowledge/Information	<ul style="list-style-type: none"> ◆ From Medical Staff ◆ From the Web ◆ From Family & Friends ◆ From Support Groups 	<ul style="list-style-type: none"> ◆ From Books ◆ Asking Questions ◆ Understanding Information
Treatment Outcome	<ul style="list-style-type: none"> ◆ Medical Conditions Treated ◆ A Baby ◆ Miscarriage / Loss ◆ Continuing Fertility Treatments 	<ul style="list-style-type: none"> ◆ Donors ◆ Surrogacy ◆ Adoption ◆ Living Childfree
Time	<ul style="list-style-type: none"> ◆ Years Trying ◆ Schedules / Cycles 	<ul style="list-style-type: none"> ◆ Waiting ◆ Biological Clock
Empowerment / Choices	<ul style="list-style-type: none"> ◆ Seeking Information ◆ Choosing Doctors ◆ Choosing Treatments ◆ Controlling Cost 	<ul style="list-style-type: none"> ◆ Controlling Diet ◆ Control Over Body ◆ Support / Sharing ◆ Choosing How Far to Go
Relationships	<ul style="list-style-type: none"> ◆ Spouse / Partner ◆ Family ◆ Friends 	<ul style="list-style-type: none"> ◆ Co-workers ◆ Support Groups ◆ Medical Staff
Emotions	<ul style="list-style-type: none"> ◆ Anger ◆ Frustration ◆ Anxiety / Fear ◆ Stress ◆ Isolation / Lonely ◆ Insecurity / Self-esteem ◆ Jealousy / Unfair ◆ Depression 	<ul style="list-style-type: none"> ◆ Sorrow / Grief ◆ Coping ◆ Hope ◆ Love ◆ Excitement ◆ Happiness / Joy ◆ Acceptance

The Infertility Treatment Experience Affinity Descriptions

The following section describes each affinity of The Infertility Treatment Experience system. The table below orders the affinities according to their level of system influence from highest (starting with the primary driver) and lowest (ending with the primary outcome).

Medical Staff



Medical staff comprises a number of specialists and health care workers. They are responsible for the quality of medical care provided to patients. Based on the position they held, they have different roles varying from taking direct care of a patient, to administering drugs and procedures, to running tests, to taking care of the medical bills and the administrative paper work. This category includes Doctors, Fertility Specialists, Surgeons, Physician Assistants, Nurses, Lab Techs, and Office Staff.

Doctors include general practitioners, OB/GYNs, and specialists. For this particular experience, people will usually start by inquiring with their family doctor or their OB/GYN, with whom they might start some minimal intervention ranging from medications to IUIs. Fertility Specialists are

gynecologist with specialization in areas of interest such as Reproductive Endocrinology or male infertility.

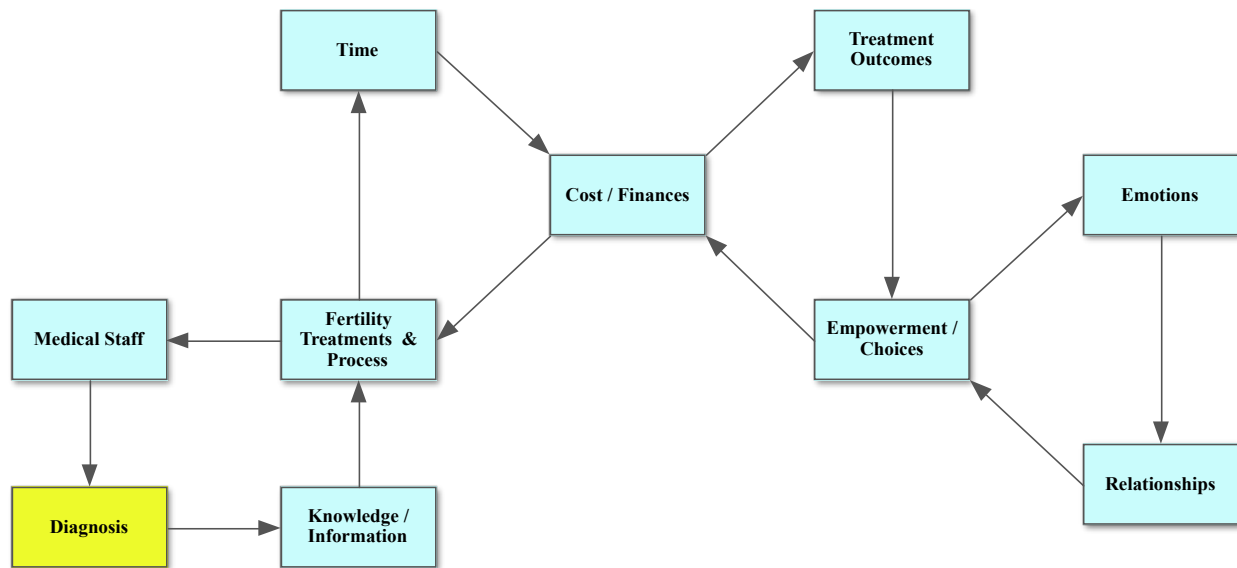
Surgeons, in the case of women, usually are the same as the gynecologists and fertility specialists. They perform surgeries that might impact fertility such as removal of fibroids, endometriosis, cysts, and polyps. In the case of men, surgeons are often urologists who perform operations to fix issues related to low sperm count, such as Varicocele.

Physicians Assistants (PAs) and Nurses are often thought to be the same people, but while most of the duties are similar, including doing preliminary examinations and taking medical history, using equipment, recommending, administering and interpreting tests, administering medications and providing medical advice and education, PAs perform some of the same tasks that doctors do and can prescribe medication.

Lab Technicians vary from people doing blood draws, collecting samples and performing tests to analyzing body fluids, tissue, and other substances, to those doing sonograms and scans, to embryologists who assist with fertilization, incubation, and embryo implantations.

Finally, Office Staff include Front Desk/Check-In, Medical Records, Billing/financial, and Coder personnel.

Diagnosis



Diagnosis describes the actual experience of undergoing medical testing, consulting with doctors, and exploring personal and families' medical history in order to identify the nature of any issue and the causes of infertility. In this category, participants have included Diagnostic Labs & Tests, Ovulation, Sperm, Genetic/Physiological, Medical History (Medications, Trauma, Disease, etc.), Unexplained Infertility, and Doctors' Opinions.

Diagnostics Labs and Tests are part of the initial steps in the experience, and they are the first, and least expensive tools used to get an answer whether a medical condition is present or not. They guide doctors in reaching an opinion on the condition and ultimately help the patients too in making decisions on further steps to take. Although they are usually non-invasive, or minimally invasive, and require samples taken from the body, blood, urine, or body tissues, oftentimes they can be more involving and might require elaborate equipment and techniques, like in the case of Transvaginal Ultrasounds and Hysterosalpinograms, or even exploratory surgeries like Hysteroscopies and Laparoscopies. A transvaginal ultrasound allows for an inspection of the uterus and ovaries for any abnormalities with a wand introduced into the

vagina. A Hysterosalpinogram or HSG allows for detection of blockages in the fallopian tubes and defects of the uterus, and requires either a saline solution or a liquid dye to be injected through the vagina into the uterus and forced into the tubes. Hysteroscopies and Laparoscopies are more invasive and require sedation or anesthesia. While hysteroscopies use a flexible tube with a camera inserted through the vagina, laparoscopies involve a small incision. Both are used to inspect, detect and correct problems such as polyps, fibroids, endometriosis, and scar tissue.

Labs and tests include also exploring Ovulation, Sperm, and Genetic/Physiological issues. Ovulation initially can be self-checked by using ovulation predictor kits at home. These tests detect the surge in the luteinizing hormone (LH) just before ovulation. The best practice to detect ovulation dysfunction is to run a series of blood work looking at levels of luteinizing hormone, follicle stimulating hormone (FSH), and progesterone hormones. Thyroid function and prolactin levels are also often checked.

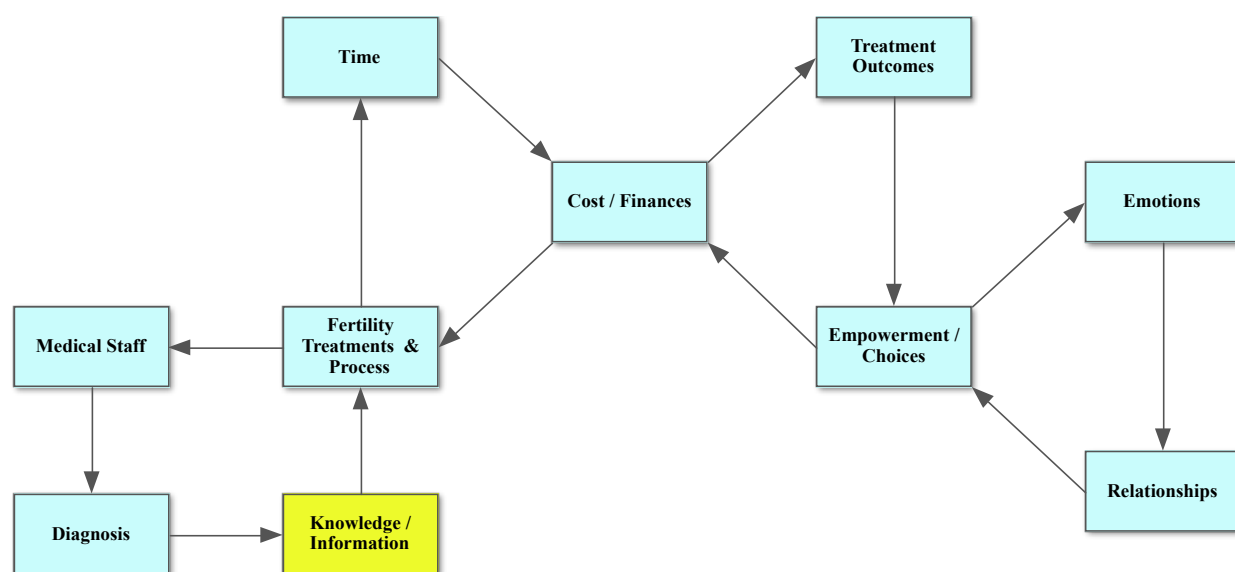
Sperm is tested by doing a sample semen analysis. This test looks into sperm count (number of sperm present in the sample), morphology (the percentage of sperm with normal shape), volume present in one sample, and motility (percentage of sperm that moves forward normally). Genetic/physiological issues can be detected during the initial blood work and/or semen analysis. Additional and more advanced testing is pursued when results are inconclusive or indicate the need to explore further for other conditions.

For medical history, the doctor collects both personal and family health information by asking questions about illnesses and medical conditions affecting the patient and its family members to detect patterns or issues that might be relevant to fertility and might not otherwise be considered.

When all the testing and information-gathering is complete, but the results are inconclusive, doctors might be unable to detect any specific issues and determine the cause of the problem. In that instance, a diagnosis of Unexplained Infertility is given. This diagnosis is more likely to be given to women 35 and over with the assumption that as women age, their egg quality and quantity decreases.

Frequently, people feel the need to pursue more than one medical opinion. However, more than one consultation may bring about more than one opinion. Oftentimes opinions might slightly differ or differ altogether. In a field new and rapidly progressing such as infertility, multiple doctors' opinions could help shed light onto various issues, but they may also produce the opposite results and leave patients confused and frustrated and with the necessity to pursue more opinions, adding further complexity and cost.

Knowledge/Information



Knowledge/Information describes how one gets information, and from what sources information is acquired during the Fertility Treatment Experience. This category includes information acquired From Medical Staff, From the Web, From Family & Friends, From Support Groups, From Books, Asking Questions, and Understanding Information.

Gaining knowledge often starts before consulting doctors. The actual experience of having difficulties getting pregnant is the first catalyst in starting to look for information that might provide suggestions. Asking questions is vital for any type of knowledge-seeking. While questions are asked to people and doctors, the most readily-available source is the Internet. The Internet has become a vital tool and a primary source for all types of information, from medical to anecdotal. Easy access to the web provides the opportunity to look at medical information through reputable websites like PubMed, WebMd, the Mayo Clinic or medical journals, and also allows connections to others through Forums and Blogs. Forums or discussion boards are often created and maintained by healthcare professionals with the objective of providing specific information and for facilitating discussion on specific health topics. Blogs are often created and

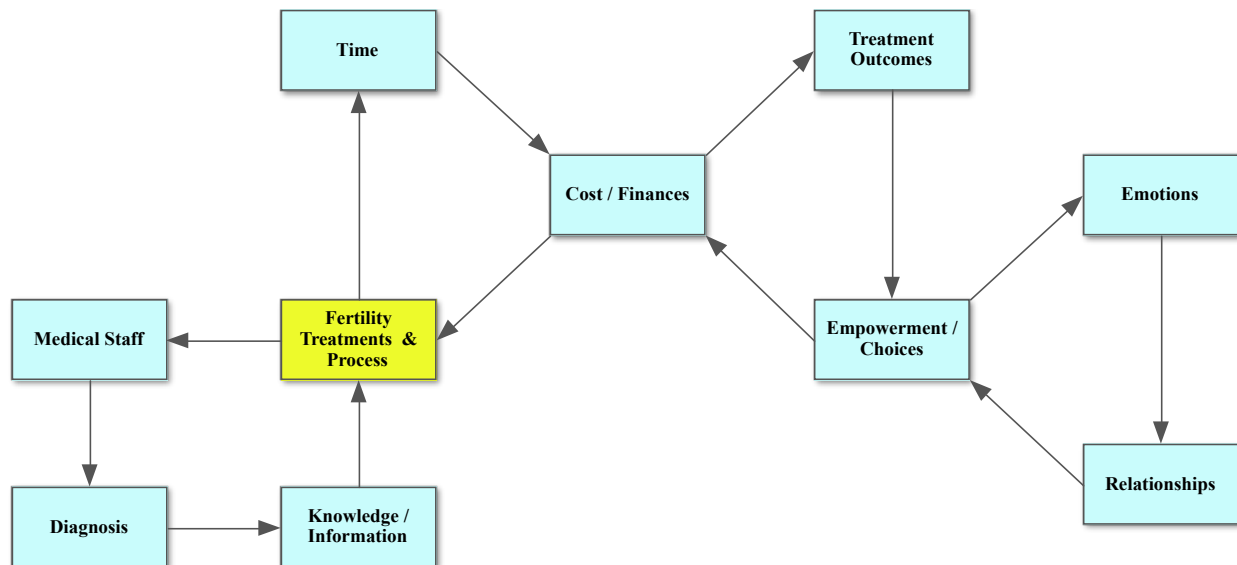
maintained by the general public and allow people to share ideas, information and real experiences on particular issues. However, because the Internet is not governed or controlled, it also contains significant amounts of less-reputable or false information.

Books are also used to gain knowledge. While the Internet provides a vast array of information, a book is more self-contained and provides a single perspective. For people who might feel overwhelmed by the internet, books are a more comfortable and preferred vehicle to gather material and insights.

In general, doctors and medical staff are among the first source of information. Usually, doctors provide quick and specific answers to patients' questions and might supplement their communication with brochures or print outs of literature of interest.

Very often, people having fertility issues find a strong source of both support and information in support groups, family, and friends. While, at times, talking or brainstorming with family and friends might become very complex and challenging due to the sensitive nature of the topic, opening up and getting information from other individuals in support groups might be easier. Individuals who have experience with the topic might be able to provide, not only information but also insights, advice, tips, and suggestions based on actual experience, all important to facilitate decision making.

Fertility Treatments & Process



Fertility Treatments & Process describes the various types of treatments and their components. This category includes Treatment Labs & Tests, Treatment Preparation & Scheduling, Medication, Diet, Rest, Surgery, Assisted Reproductive Technology (ART), and Alternative Medicine.

While in the initial stage, Tests and Labs are used to determine the likelihood that a medical condition is present, later on in the process they become a vehicle to monitor the course of treatment, and the patient's response to treatments, so that decisions can be made, on any adjustments that might need to be made on medications or procedures, and on whether further steps are necessary.

Keys to IUI and IVF treatments and processes are Preparation and Scheduling. These procedures involve a careful and very rigorous schedule to coordinate medications, check-ups, and testing before the actual procedure. For the IUI, blood testing and sonograms are used to monitor for ovulation and determine optimal timing for insemination. For the IVF, a series of injectable

medications are used at precise days of the cycle and at appropriate times of the day to stimulate ovulation, as well as to aid oocyte maturation, to precisely coordinate the time of egg release, and to prepare uterine lining to receive and sustain the pregnancy. All of these medications are used in concomitance with blood tests to monitor hormones levels and responses to medication and with vaginal ultrasounds to check on ovaries' responses and production of oocytes.

Infertility can be addressed with increasing aggression depending on the diagnosis. Often times, treatments begin with only medications, which are used to stimulate ovulation and multiple egg production. In some cases, the use of medication alone can be the solution. In many cases, if medication is not resulting in the target outcome, more aggressive procedures such as artificial insemination are explored and potentially pursued.

Traditionally, associated dieting involved only few restrictions, mostly on the use of alcohol and caffeine. No specific diet was advised by doctors. Lately more attention has been paid on the Importance of nutrition and how nutrition has a big role in having a healthy body and a healthy reproductive system.

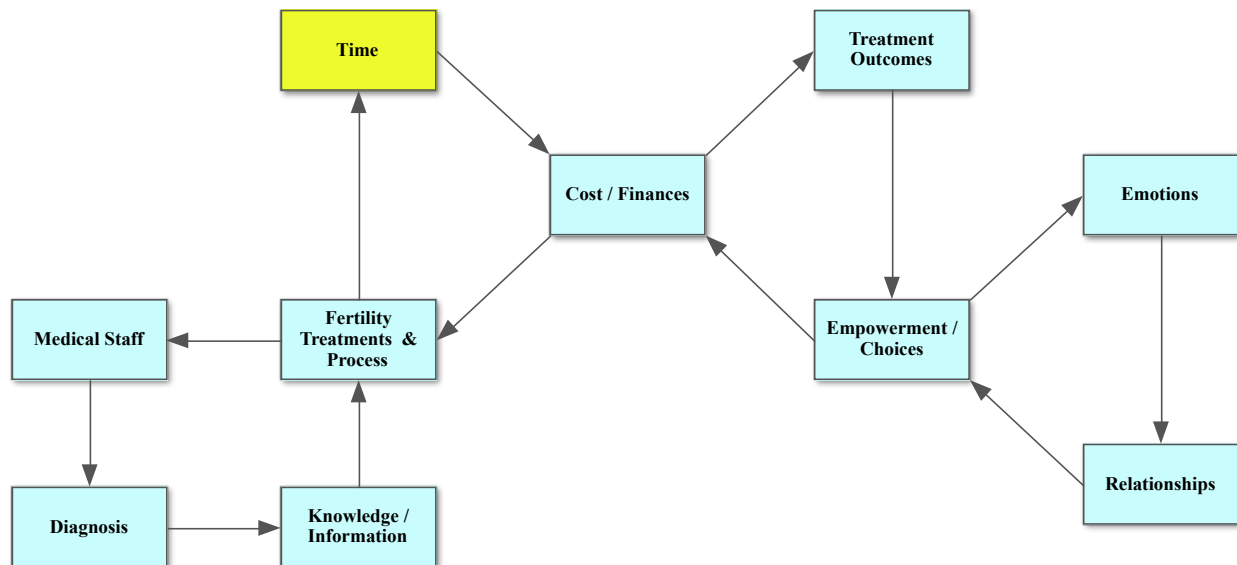
Surgery is often performed when physiological issues are present. Hysteroscopies and Laparoscopies and DNCs are usually more common during treatments. The former are used to correct problems such as polyps, fibroids, endometriosis, tubal blockage, and scar tissue. The latter are often necessary to remove tissue in the uterus during, or after a miscarriage. Rest is usually advised after major surgeries, or insemination or after implantation.

Assisted Reproductive Technology (ART) refers to treatments in which both eggs and sperm are handled. In general, ART procedures involve surgically removing eggs from a woman's ovaries, combining them with sperm in the laboratory, and implanting the fertilized embryos in the woman's uterus. Thus, it includes IVF procedures, intracytoplasmic sperm injection (ICSI) - when a single sperm is injected into the center of an egg using a micro needle and cryopreservation - a process that enables freezing eggs, sperm and fertilized embryos for later

IVFs. It does not include treatments in which only stimulating medications are taken, or when only sperm is handled (i.e., intrauterine—or artificial—insemination).

Alternative Medicine refers to a Holistic or Complementary Medicine that incorporates traditional medical practices like chiropractic, homeopathy and naturopathy with traditional Chinese medicine. This type of approach combines acupuncture, Chinese herbs, and Stress Reduction/Relaxation Therapies such as yoga and meditation.

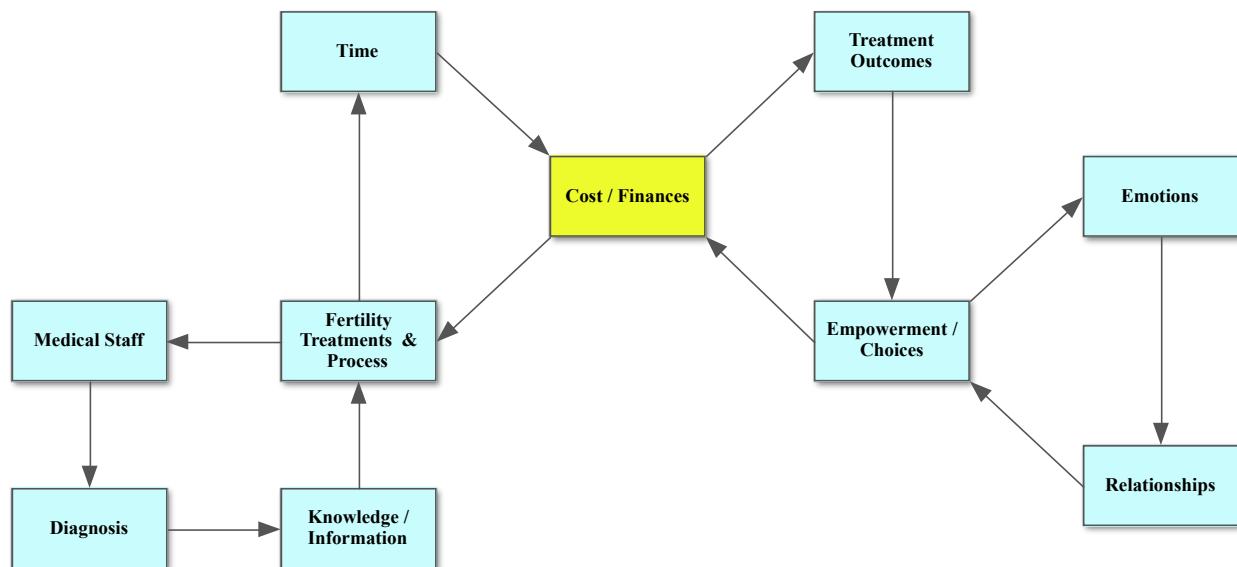
Time



This affinity describes the urgency of various aspects of time during the Fertility Treatment Experience. The sub-affinities comprising time are Years Trying, Schedules/Cycles, Waiting, and Biological Clock.

When defining Years Trying, many participants clearly expressed that they encountered a very long, frustrating, and arduous journey. It is a long process that, in numerous cases, took years. The infertility treatment process includes long bouts of scheduling, trial and error, decision-making and waiting for results and next steps. Scheduling of treatments is entirely based on the woman's cycle and abilities to start the treatments in the midst of regular personal and work duties. Even if everything goes without complications, one treatment process can take months to complete. Given that many couples went through several treatments, the measurements of time, and the frustration that was prevalent in these couples was measured in years. As time goes by, women's fertility begins to decline due to decreasing egg quality and quantity. This Biological Clock in women is in direct competition with the time taken to treat them through infertility treatments, creating urgency, stress and further time taken to make difficult decisions.

Cost / Finances



Cost / Finances describes the different types of expense incurred during the Fertility Treatment Experience. The sub-affinity components are Insurance, Medical Bills, Medication Cost, Out of Pocket Expenses, Loans, Sacrifice, and Missed Work.

Insurance coverage for infertility and its treatments varies greatly. In general, most insurance plans cover only diagnostic labs and tests because they are the least expensive part of the process. As soon as a diagnosis is given, these insurance plans stop covering. On average, a basic IVF cycle in the U.S ranges from about \$12,000 to \$15,000. The cost varies depending on specific cases, on individual clinics, on the number of IVFs done, on medications, and on additional ART treatments that might need to be done, such as ICSI, Cryopreservation, and PGD testing of embryo. Certain states have some type of mandate for coverage. In Texas, group insurers are required only to offer coverage, but not to provide it as part of a regular plan, and employers can choose whether or not to include it in their employee health benefit package. Many do not, due to the increased cost to carry the option. Even when offered, there are many conditions, limitations, and requirements to be met. In the best-case scenarios, plans would cover between \$10,000 and \$25,000 total. In general, insurance will cover diagnostics testing and

treatment up to intrauterine inseminations. If fertility dysfunctions, i.e. ovulatory dysfunctions, are coded as medical conditions, blood and ultrasound tests are covered, but IVFs are not.

Since insurance coverage is very limited, the majority of the medical costs are out of individuals' pockets. Cost also involves trips to the doctors, gas, lunches, second opinion consultations, or unforeseen extra testing and sonograms. Medication cost is also often part of the out-of-pocket expenses. While some medications might be covered by insurance, the majority of them, including hormone injections, are not. The cost of these injections varies, and it is mostly based on the specific case, the unit price, the dosage and duration of the stimulation, and the number of cycles. The average cost is \$3000 and can go up to \$7000. This expense is usually not included in the IVF pricing.

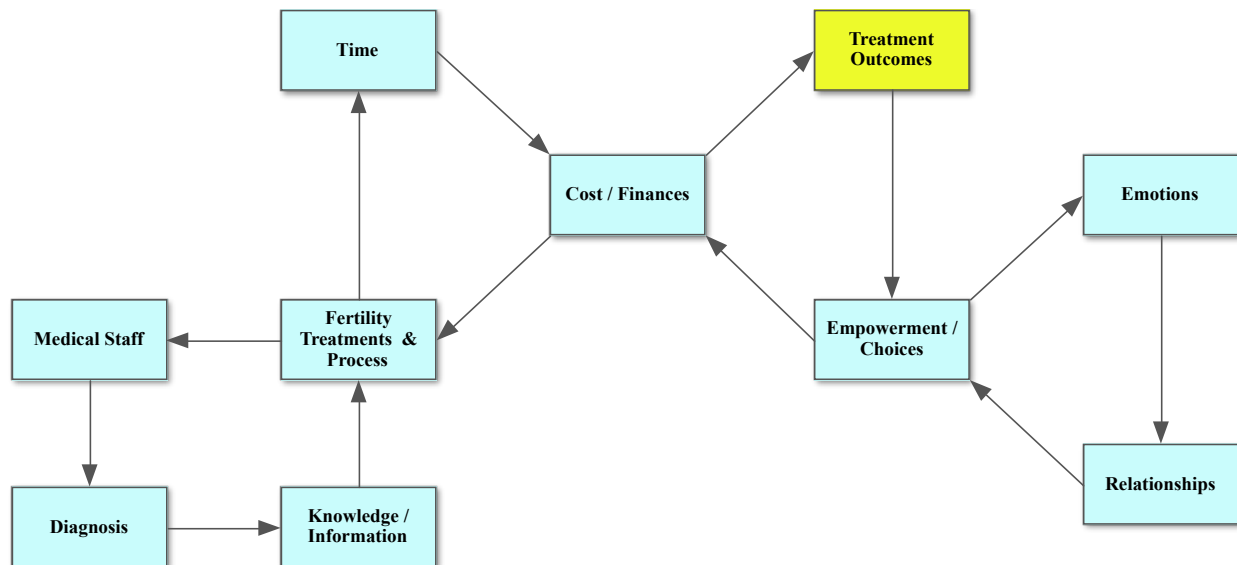
Loans to pay for IVF are often considered by individuals seeking infertility treatments. While it is common for people in this sample to have accepted help and loans from parents, some have preferred to either not pursue treatments, or to apply for loans through financial institutions. Also, many clinics are starting to offer financing or guarantee programs. In at least one case in this study, one of the leading clinics in the area offered grants to requesting couples.

Sacrifice as part of cost goes above and beyond monetary sacrifice; it mostly refers to a loss of the sense of normalcy. Because the infertility treatment process includes long bouts of complicated scheduling, trial and error, decision-making and waiting for results and next steps, it is an encompassing process that dictates every decision and step taken during that time. During such a long and complicated process, lives are put on hold and every decision rotates around scheduling and cycles. In that sense, not only the day-to-day life is dependent on the process, but also plans and opportunities are on hold - not going on vacations, getting a house, moving, changing careers, etc. Many pointed out that they sacrificed years of their lives, their emotional well-being, and their relationships with other people.

As discussed already, the process of infertility treatments takes time and money from couples' lives. Treatments, and their related decisions, come with numerous medical and personal

appointments. These appointments are often during regular business hours, requiring couples to miss work. While vacation and sick time sometimes apply, people noted that missing work takes a financial toll on their lives as well. Additionally, as treatments are not always successful, often couples miss work to recuperate medically and psychologically from failed treatments. While sometimes intangible, the direct and indirect cost of infertility is manifested through missing work.

Treatment Outcomes



Treatment Outcomes describes the various outcomes and results of the Fertility Treatment Experience. This category includes Medical Conditions Treated, A Baby, Miscarriage/Loss, Continuing Fertility Treatments, Donors, Surrogacy, Adoption, and Living Childfree.

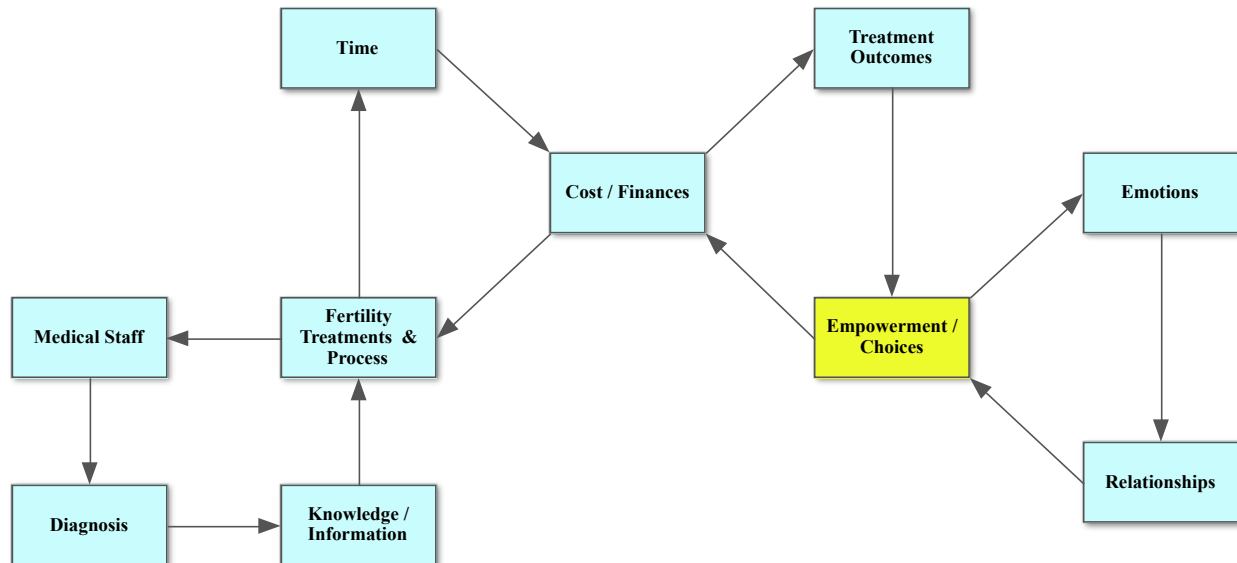
When a diagnosis is provided, the next step is to treat the condition so that a positive outcome can be reached with minimum, to no intervention. Treating a condition might require just taking medicines and following changes in lifestyle habits, but it might also require invasive procedures, such as surgeries, in order to correct problems women and men might have. Most common problems encountered in men are low sperm count or quality due to Varicocele or low testosterone. The former is corrected with a simple surgical procedure, while the latter can be addressed with medication. In women, most conditions are related to hormonal dysfunction including thyroid, or physiological issues such as tubal blockage, fibroids, polyps, Endometriosis. These problems can be corrected with surgery. In the case of advanced maternal age, severe male factor, or unexplained infertility, conditions cannot be treated with traditional

approaches, and infertility treatments requiring reproductive technologies can be pursued to overcome the obstacles and reach the ultimate goal of getting a baby.

Miscarriages and losses are sad parts of the infertility treatment experience. In general, about 15%-20% of all pregnancies end in miscarriage, with the majority ending in the first 12 weeks of pregnancy. The rate of miscarriage is often higher for people undergoing treatments because the average age of the mothers is often higher, and because of the infertility problems, which are already creating complications. Recurrent miscarriage can be difficult emotionally and physically and may require further diagnostic testing and treatment. With recurrent miscarriages or failing cycles, people are forced to decide if and for how long they want to keep trying. Continuing Fertility Treatments involves either continuing with reproductive techniques that include the use of the parents' genetic material, or resorting to Donors and Surrogacy. These last two are referred as third party reproduction because they involve donation of sperm or eggs, or both, or when another woman is used as a gestational surrogate. Continuing Fertility Treatments is extremely costly monetarily, physically, and emotionally.

Coping with numerous failures takes a deep toll on people, and many decide to pursue a child through Adoption, or to stop pursuing a child altogether. The decision to stop pursuing children and to live childfree involves a long process of coping with treatment failures, mourning the loss of many pregnancies and the loss of genetics and the ability to bear a child, as well as reaching acceptance of the condition. Only after one moves through the grief process can they fully move forward and live a fulfilling life.

Empowerment / Choices

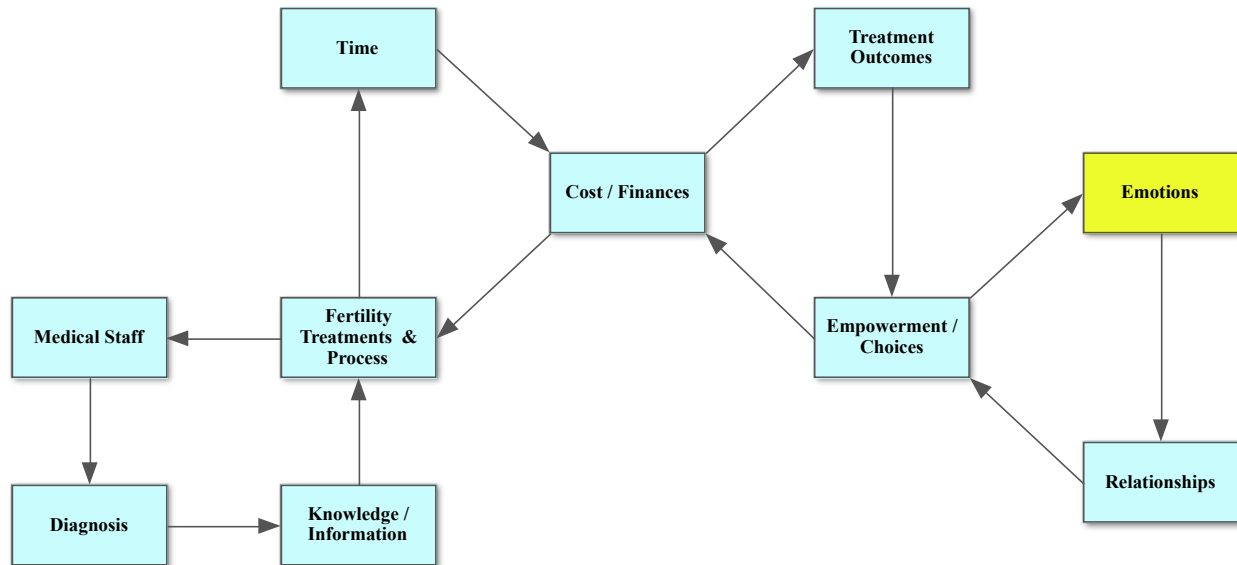


Empowerment / Choices describes the degree of control or power over the situation one might have, or might feel not having during the Fertility Treatment Experience. The components of Empowerment/Choices are Seeking Information, Choosing Doctors, Choosing Treatments, Controlling Cost, Controlling Diet, Control Over the Body, Control Over Support/Sharing, and Choosing How Far to Go.

When defining the components of this affinity, participants felt they had lots of power and control over Seeking Information, Diet, Support/Sharing and How Far to Go because those are areas that can be influenced by the person. On the other hand, choosing doctors can be more challenging due to location, expertise, limited pool, availability, or insurance listing. The least control people feel is over the cost and over their body. Controlling cost is very hard because patients are the recipients of a service with a set cost. People felt empowered only in the choice to pursue, or not to pursue treatments, when to refuse to continue treatments, or by providing some suggestions on alternative routes to explore. Also, researching the market on medication cost, and places from which to order them, was often a way to feel in control. Finally, the least

control participants felt was over their body. Although working very hard toward the end goal of having a baby, no one could control their ovulation, or stop a miscarriage, or positively alter functions to enhance their chances of success.

Emotions

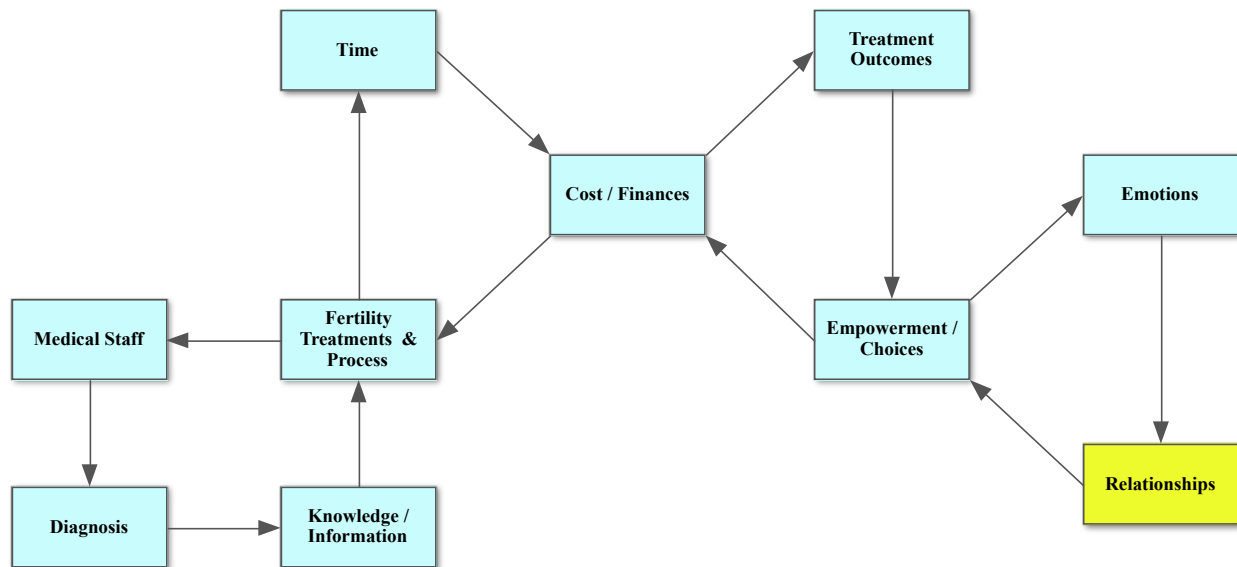


The Affinity “Emotions” is a Primary Outcome, and it describes the possible feelings and range of emotions felt during the Fertility Treatment Experience. Emotions can range from negative to positive, and can vary greatly in impact. Negative emotions include Anger, Frustration, Anxiety/Fear, Stress, Isolation/Lonely, Insecurity/Self-Esteem, Jealousy/Unfair, Depression, Sorrow/Grief. Positive emotions or states of mind that contribute to create more balanced and positive emotions are Coping, Hope, Love, Excitement, Happiness/Joy, and Acceptance.

Anger, frustration, and stress are part of the experience, but as time goes by, and in combination with negative outcomes and losses, they contribute to increased levels of depression, anxiety and isolation and loneliness and decreased hope and happiness. When negative feelings are acute, and last for long periods of time, in some instances for years, they impact relationships with partners, friends and family. Additionally, continuous losses impact people’s sense of empowerment, and eventually over time, drive people to feeling overwhelmed and wanting to discontinue treatments or pursuing a child altogether. Over time, especially in the case of

prolonged treatments, strong negative feelings become chronic and can be very difficult to overcome without help.

Relationships



The affinity Relationships is also a Primary Outcome and it includes all the various interactions people have during the Fertility Treatment Experience. Related Sub-Affinities are all the numerous types of relationships people engage in and they comprise relationships with Spouse/Partner, Family, Friends, Co-workers, Support Groups, and Medical Staff. Although many of these interactions are with familiar people, such as family members, friends and partners, during this time, many new extended relationships are created through interactions with acquaintances. New connections are made with medical staff and other individuals and couples met during this journey. These people often prove to be easier to communicate with and to share because they have encountered many of the same issues and challenges. New connections made with people who have similar issues usually are very strong and tend to become life-long friendships because of the nature of the experience that seals these new relationships. On the other hand, due to the sensitivity of these experiences and conditions, many relationships with family members and friends become challenged and complex and can become very trying depending on communication and the difficulty of sharing efforts. These relationships often are affected by the fact that infertile people feel misunderstood and pressured by family and friends who often lack sensitivity or empathy toward them.

A Walk Through the Infertility Treatment System

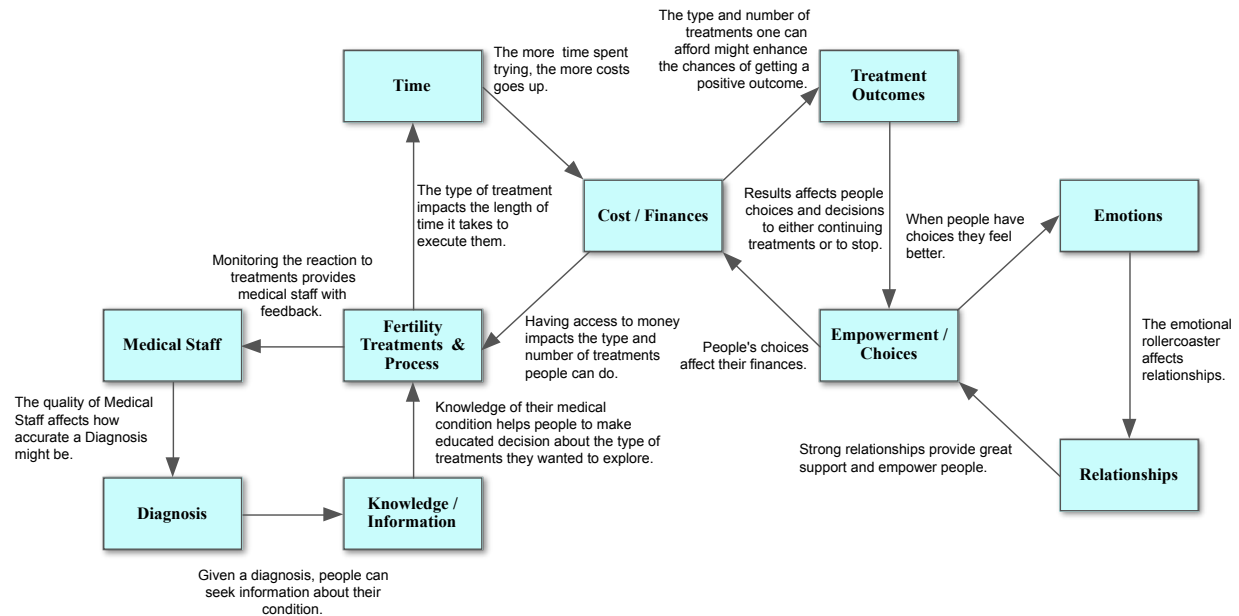


Figure 7.2: The Infertility Treatment Experience System Relationships

Systems have two components: *elements (affinities)* and *relationships among the elements*. The affinities govern the entire system and affect one another. The system is read from top to bottom, left to right.

The affinity named Medical Staff, lying at the top left, is the primary driver because this is the first step in the experience, and it is the constant element that will drive the entire experience. This includes impacts to providing the initial diagnosis, to offering treatments to pursue, to the information people get, to the cost involved in the treatments pursued. Secondary Drivers, placed on the left middle part of the system, are Fertility Treatment & Process, Time, and Cost/Finance Affinities. On the right side of the system, Secondary Outcomes are Cost/Finances, Treatment Outcomes, and Empowerment/Choices. All these elements, as domino-effect, ultimately influence the outcomes, Emotions and Relationships, which are at the furthest right point of the system.

In a system, feedback loops can be identified when following the relationships' links from a particular element and a path returning back to that element is traced. Feedback loops are key features of a system, and they are important to interpretation. These loops, also known as Recursions, are characterized by the presence of a relationship from an element later in the system, in the outcome Zone, back to one earlier in the system, in the Driver Zone, (Northcutt & McCoy, 2004) meaning that a relative outcome feeds back or influences a relative driver. These loops require a minimum of three affinities, each influencing the other directly or indirectly. Feedback Loops can be virtuous or vicious. A virtuous loop has favorable results, while a vicious loop has negative results.

The sections below walk the reader through the Infertility Experience system, describing how the relationships work and identifying feedback loops.

In the Infertility Experience System there are three feedback loops. From left to right, they are the Clinical Loop, the Struggle Loop, and the Roller Coaster Loop.

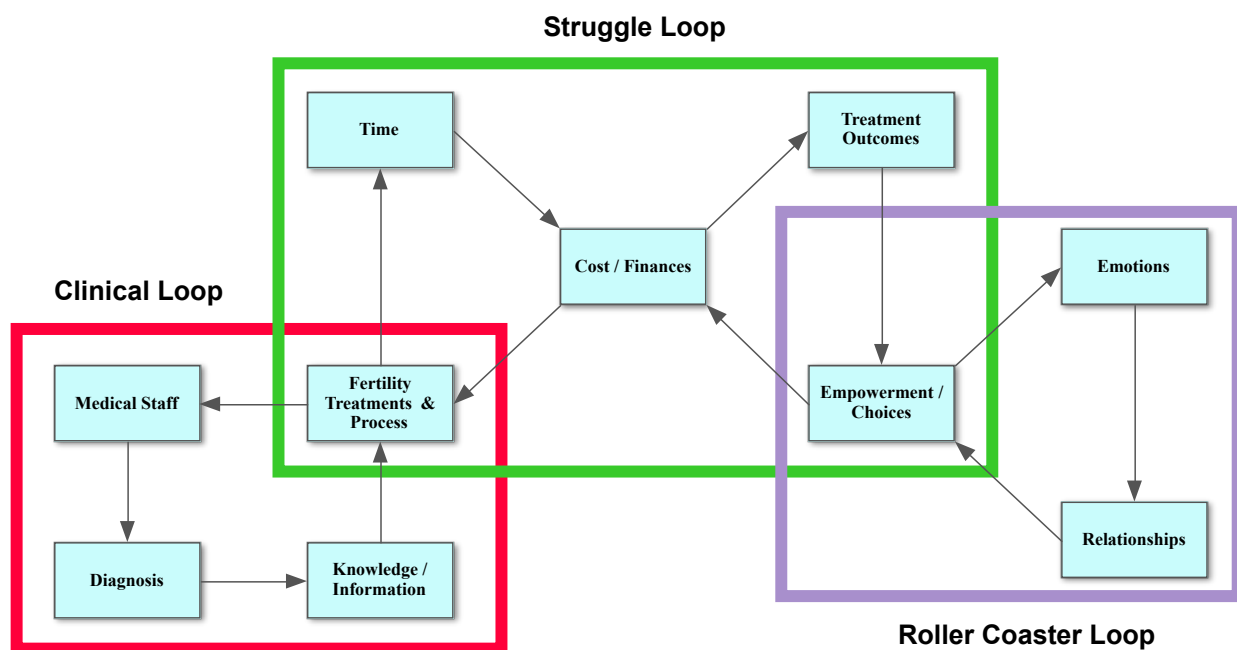


Figure 7.3: The Infertility Treatment Experience System Feedback Loops

The Clinical Loop

The Clinical Loop is focused on the initial medical part of the journey. Doctors and medical staff with their expertise, specializations and personalities, diagnosis and information provided, treatments suggested and offered, as well as other factors associated with the initial medical experience, are all variables in this loop.

In the Clinical Loop, medical staff drives Diagnosis, which influences Knowledge/Information, which influences Fertility Treatment & Process, which comes back to Medical Staff.

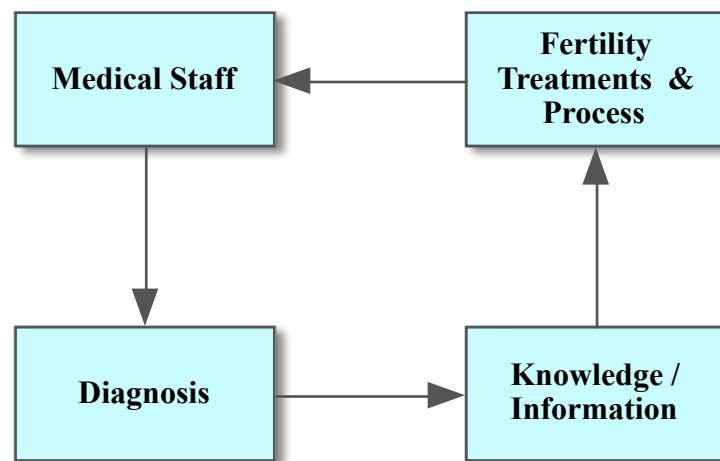


Figure 7.4: The Clinical Loop

As previously mentioned, Medical Staff is the primary outcome because it represents the initial step people take when starting to inquire, and it is the constant element that drives the entire experience. While this category includes many different staff, the sub-affinities that seem to weigh more in people's experiences are doctors, fertility specialists, and nurses. These professionals are viewed as highly influential on one's experience because they either make the strongest impact on the outcome or because they are the ones with whom patients spend more time. As mentioned earlier, upon the decision to have a child and when, after a period of time of unsuccessful trying in becoming pregnant or keeping a pregnancy, people will inquire with doctors. Thus, the first step in the fertility experience is to consult with doctors to find out if any

issues are present. Usually people start meeting with their family doctors and/or their OB/GYNs, and eventually, as time goes by or under referral, they move on to fertility specialists. Doctors, and medical staff in general, play a major role from the beginning, first with determining the source of the issue, and then with coordinating and executing treatments to reach a desired outcome. Although many variables, including time, cost, biology and personal strengths and beliefs, might affect decision-making and whether the journey of starting treatments might occur, doctors' ability and expertise strongly influence decision-making, strategies and paths pursued. Since medical staff is the first step of the experience, and together they work in producing the first answer to the patients, this affinity directly impacts diagnosis. For example, during the exploratory period, with the assistance of other staff such as nurses, PA, lab tech etc., doctors investigate to discover possible reasons and sources of issues so that they can provide a diagnosis that might shed some light into the causes of why people encounter difficulties.

Diagnosis describes the actual experience of undergoing medical testing, consulting with doctors, and exploring personal and families' medical history in order to identify the nature of any issue and the causes of infertility. In this category participants have included Diagnostic Labs & Tests, Ovulation, Sperm, Genetic / Physiological, Medical History (Medications, Trauma, Disease, etc.), Unexplained Infertility, Doctors' Opinions.

Diagnosis directly influences Knowledge/Information and indirectly influences Fertility Treatment & Process. It directly influences Knowledge because it puts people in a position of needing as much information possible about their condition so that they can understand it, understand doctors' rationale and opinions, and make the most educated decisions on treatments to pursue. While doctors provide the diagnosis, they are also influenced by it. It is the diagnosis that will drive what type of treatment to pursue.

During the interviews, people pointed out how a knowledgeable and competent staff would be able to reach an accurate diagnosis. Their knowledge and expertise would allow them to run the appropriate tests to find out the source of the issue. Poor medical staff not only leads to poor and inaccurate diagnoses, but it might also impact the length of time it takes to get answers.

Additionally, some people mentioned the need and importance of getting multiple opinions. However, when consulting different doctors, one might get slightly different answers and diagnoses due to a mixture of several components, including personal opinions, time spent getting to know their patients, knowledge of cutting-edge technologies, and years of experience, all of which, along with the tests results, has the potential of adding complexity and variation of diagnoses.

Based on the type of diagnosis, or the lack thereof, doctors provide information on the condition and make suggestions on the most appropriate treatments to pursue, and patients can seek information about their condition and about choices to explore.

Knowledge/Information describes the type of information and from what sources information is acquired during the Fertility Treatment Experience. This affinity directly influences Fertility Treatment & Process and indirectly influences Diagnosis. Participants described how they felt the need to seek information above, and beyond what they acquired in the doctors' office. Many expressed the frustration that it was hard to get the doctor to sit down with them long enough to explain and answer questions, and to be very thorough and comprehensive. Coming from outsiders to the field, many patients did not know what questions to ask, and when they did, they felt they faced hurried experiences, piecemealed type of information, very sterile and not well-articulated answers. *"They just piecemealed us the information as we went rather than giving up to us as a front"* and *"The doctors' offices are great in giving you pamphlets, and there is jargon and that is great knowledge, but a lot of times you do not know how to educate yourself, how to proceed. It would be nice if they were the ones taking on the role of education."*

Forced to take on the role of self-educators, patients resorted to alternative sources. The most common alternative sources were searching the Internet, talking to people experiencing the same issues, and attending support groups. Due to the need to be very informed, many people felt they became experts and learned to advocate for themselves so that they could seek the best help and treatments they could afford. Through this knowledge-seeking and acquisition, they were often able to influence not only the type of investigation the doctors would pursue, and consequently

the diagnosis, but also the types of treatment or the treatment aggression level they wanted to explore.

Fertility Treatments & Process directly influences Medical Staff and it also branches into the next loop, “The Struggle Loop,” by directly influencing Time. After decisions to pursue a specific treatment are made, and the treatment is implemented, doctors and other medical staff monitor patients’ reactions to the treatment. Based on these reactions, adjustment might be necessary to increase chances of a successful outcome. Some people described how their bodies would not react to hormonal stimulation, or that they would overreact and become hyper-stimulated. In those instances, medication dosages needed to be adjusted or stopped. Also, failures due to inaccurate choices of treatment, or due to miscarriages and loss would provide doctors and medical staff with valuable information to adjust the course of future treatments. It might take a series of trial and error, and more or less invasive procedures before positive outcomes are reached.

The Struggle Loop

As previously mentioned, Fertility Treatment & Process branches into an infinity loop labeled “The Struggle Loop.” An infinity loop is characterized by a repetitive cycle that has one element around which the other elements of the loop pivot, as shown in the diagram below. This loop starts with Fertility Treatment & Process by directly influencing Time and Cost.

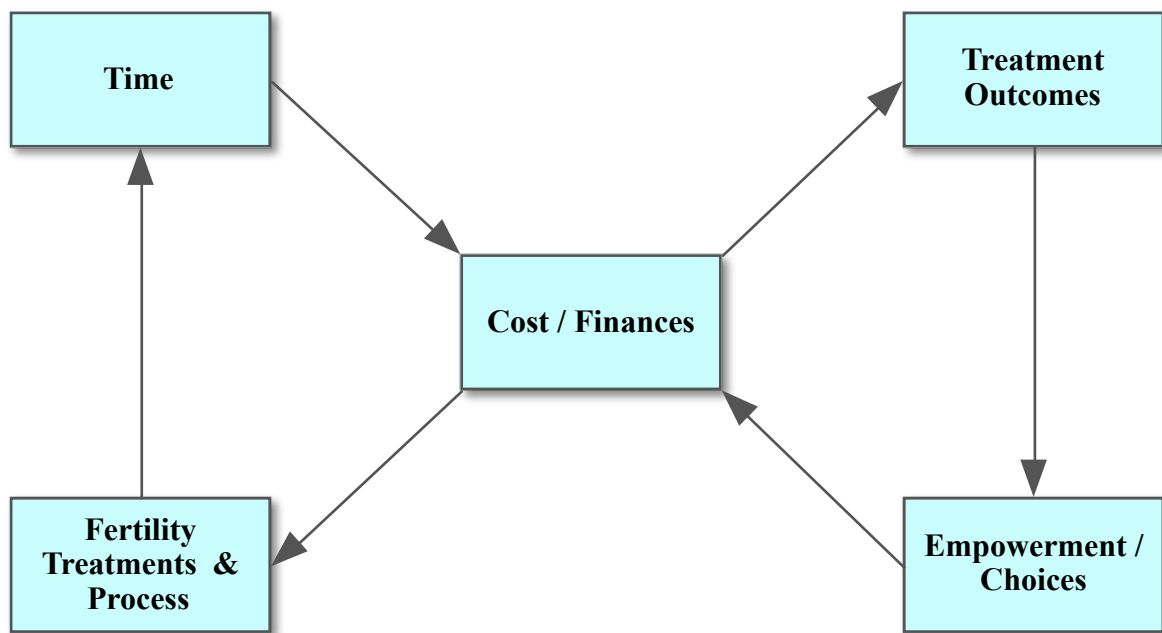


Figure 7.5: The Struggle Loop

Continuing fertility issues are often addressed with increasing aggression. Doctors might begin with simply regulating ovulation or testosterone levels with the aid of medication, then might advise to step up to assisted insemination techniques such as IUI, the least aggressive, and then may progress to IVF, which is the most aggressive treatment. Fertility Treatment & Process takes two possible directions in this loop. The type and the number of treatments pursued have a major impact on the amount of time it takes to execute them, as well as on the cost involved with the procedures. When talking about how treatments affected time, during the interviews people said, *“It is not something that happens overnight. The length of time it took was dependent on the*

treatments. IVF takes way more time because of the different schedules and cycles. Each of those treatments on their own, took three or five months a piece to set up and execute. As you went through treatments you are turning around your life, your travels, money. So it affected how you used your time long before you could do something else. The more treatment you do it definitely impacts all the time that it is taking.”

Time has a direct impact on cost in this study. People pointed out how time affected their experiences in different ways, including time as seen in terms of clock ticking away due to aging. For example, since fertility is biologically tied to age, as time goes by, and patients become older, they might need to pursue more aggressive treatments, which involve more costly protocols, more medications, and more check ups. *“The older you get they may cost more and the more you have to do... the more cost,”* as well as length of time involved in executing complicated procedures *“If you have to do ten treatments it is going to take a long time and it is going to cost a lot of money. The more time that we are spending trying, the more the cost goes up. The more time I was required to be there, the more it cost because of the treatments but also because of loss of work.”*

Cost is the central element, not only of this loop, but also of the entire system, and it either directly or indirectly drives the other Affinities. It directly influences Treatment Outcomes and Fertility Treatments & Process, and indirectly influences Time and Empowered/Choices. In a system made of elements and their relationships, relationships are interconnected parts of a whole, so change in one part leads to changes among all parts, and in the system itself. Thus, a change in cost leads to changes to all other elements, and vice versa, a change in any element might impact cost. Indeed, not only the treatments. and the time involved, impacted the expenses, but also the cost impacted the possible outcome. The type and the degree of treatments pursued are tied to cost as well. As infertility is addressed with increasing aggression, treatments that start with only medications might proceed to IUI, and ultimately to IVF procedures. Increasing aggression is directly proportionate to cost, which is tied to increasing changes of desiderate outcomes.

When describing Cost/Finances people said, *“The fertility treatment [is] pretty pricy. Longer the process greater the cost. Which treatments you are doing definitely affect the cost. Depending on the treatment, the cost is different. IUIs are less expensive then IVF. Knowing that we needed to do IVF affects whether or not we are willing to invest the money to do it. We have not gone that far, but the further we go we will have to start making more decisions based on cost.”*

According to the participants, Cost drives the quality and the success of your treatment in many ways. First, clinic location seemed to play a major role. Renowned clinics in urban centers and major cities, or out of state, can be more costly and involve more out-of-pocket expenses, but might provide higher success rates. *“If I were in some small town I would not expect to get the same good treatment. I would want to be where there is more knowledge. If I could afford to go to the best clinic in the country, I might be more likely to have the best outcome. The more you spend the greater likelihood you might have of having a baby. I truly think if we had spent more the options would increase.”* Therefore, some are willing to spend more to enhance their likelihood of getting a better outcome. Secondly, the type of procedure is viewed as a major player, *“If you have unlimited funds and you are able to pay for IVF versus IUI, then your outcomes there is a greater chance that it is going to be positive. The reason why IVF is more expensive, and your chance for an outcome is better, is because there is so much more involved and a cost to that. We did have results and we had to pay for it. In the sense that we had to pay for the babies.”*

This infinity loop continues with Treatment Outcomes impacting Empowerment/Choices - both the control and empowerment one feels having over a situation and the choices one might, or might not have. For example, people described how empowered they felt by the outcome of continuing treatments and pursuing more aggressive or new routes to achieve their goal of having a baby. Often, the continuous failures would debilitate individuals and couples and spawn an overwhelming feeling of lack of control over their body, or over the situation, which ultimately would bring them to a decision of giving up on medical interventions altogether, and to either pursue a child via different routes, or stop pursuing it altogether. The way people felt about control, and choices they might have had, depended not only on the results, but also on

coping and accepting strategies people employed. While negative results and failures left some defeated and with diminishing control, others were able to gain knowledge and embrace negative results as an opportunity to explore new procedures. The following quotes express people feeling, *“The treatment outcomes eliminated choices for us, in the sense that diminished the amount of choices or made the choice for us. The outcome had control on what we did next, it affected my feelings of empowerment. Not getting anywhere makes us feel like we have less control.”*

“Treatment results influence what choices I am able to make next time depending on whether a cycle works or whether it shows that I ovulated. When I got a negative outcome, I would just move on to the next thing and I felt I could control that. Like for my miscarriages I was, “Ok. Let us get through surgery and then what do we do next?” so, I was ready to move on.””

Feeling more or less empowered in many areas, including feeling in control of seeking knowledge, to controlling external factors such as diet or the amount of information shared with others, to feeling in control of choosing doctors and how far to go, ultimately impacts decisions to continue or to discontinue the pursuit of treatments. In turn, this then impacts Cost/Finances, and restarts the cycle of influences in this infinity loop. This affinity branches out into “The Roller Coaster Loop.”

Roller Coaster Loop

In “The Roller Coaster Loop,” three affinities interconnect: Empowerment/Choices, Emotions, and Relationships. Empowerment/Choices encompasses the feeling of having control over situations or various aspects of life, thus having an array of choices available. The sense of control one might have over things or situations directly impacts how they feel, and it originates a cascade of emotions that ends up running all aspect of life during this experience, as well as the relationships in ones’ life.

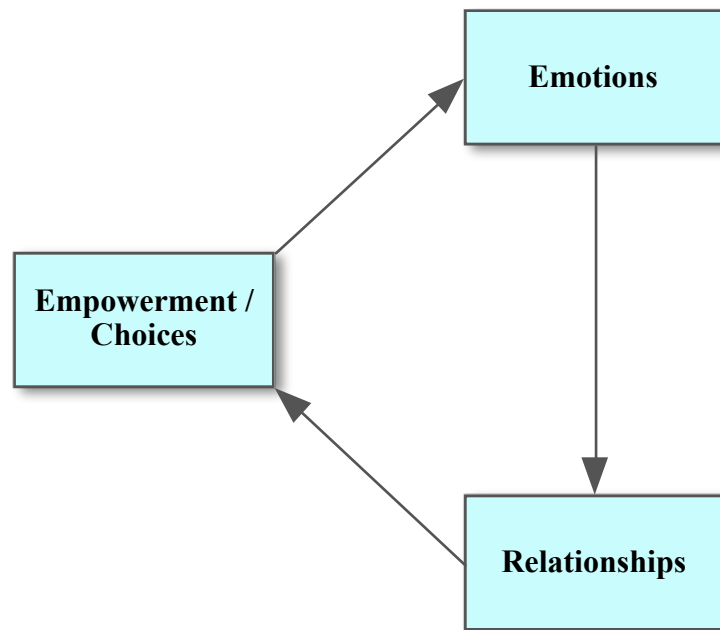


Figure 7.6: The Roller Coaster Loop

Throughout the fertility journey, many circumstances affect people’s empowerment and the choices available to them. As previously mentioned, a cascade of effects from early affinities in the system impacts affinities further down. Thus, many experiences in earlier affinities ultimately weigh on the sense of control one might have over situations, and ultimately on the outcome, which might leave individuals with more or less choices. Many individuals described that, in the beginning, empowerment was felt very strongly and was an important component in building up

their self-esteem, hence in assisting with decision-making and with leading their own path. They felt very secure and confident in their ability and strength to encounter such a challenging and mysterious journey. “The more empowered you feel the higher your self-esteem is.” When people felt in control and positive about their situation they felt they were in a more positive and stable emotional state. However, the opposite happens with failures and negative outcomes. Over time, repetitive failures hinder people’s sense of control, which directly affects emotions.

“When I did not feel empowered, the emotions took a dive. The less power we feel we have over it increases our frustrations.” Not being in control of everything makes you feel helpless.”

Emotion and Relationships are the outcomes of the Infertility Experience System. Emotions influence Relationships, which in turn affects Empowerment/Choices. Emotions encompass a large number of feelings, ranging from positive to negative, and participants experienced the full spectrum, from happiness to anger. Among the many emotions outlined, the most significantly impacts were from negative emotions such as frustration, stress, anger, sorrow/grief, loneliness and anxiety/fear. People described the treatment experience as draining, frustrating and overwhelming. They may have fond feelings in one minute and frustration the next. Feeling upset and angry at the situation often drove individuals into isolation, making it difficult to manage relationships. People would describe that they felt upset and angry on a daily basis, which affected or took away their ability to interact and enjoy others. Although literature points out that many people embarking the treatment experience might start with strong and well-established relationships, the harshness of treatments might take a toll on the couple so that feelings of closeness and intimacy could be compromised during the process, but also often last into the future. A recurrent theme was withdrawal from family and friends due to fear of being misunderstood, judged, or pressured. On the other hand, strong and long-lasting friendships often are built during this journey with others who experience the same issues and challenges. Relationship lasting through this process offered strong support, and empowered the individuals.

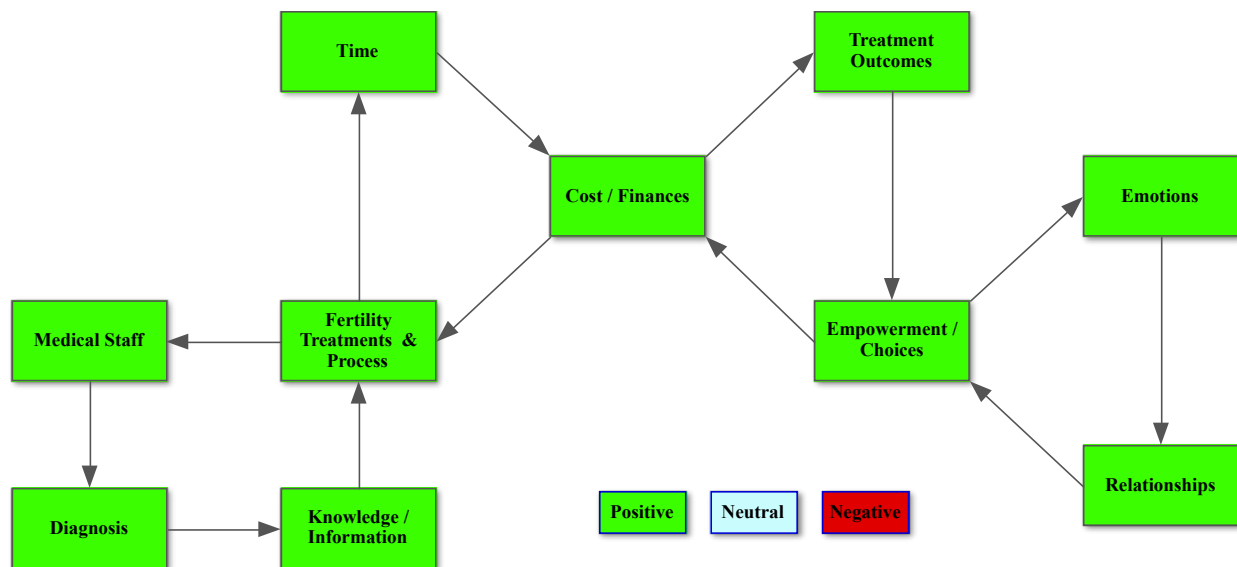
“The stronger your relationships then more empowered you feel to make those choices. Because the stronger your relationship is the more empowerment you would have to go through it together.”

“Your relationships, your significant other in particular can make you feel empowered and encourage you. I felt that we were on the same page and that really helped to make the choices. If you have a bad relationship you do not feel like you have any power. When talking about it with my husband sometimes I feel paralyzed. Since we have started trying every single decision is my decision because I am the one who wants to have kids.

Exercising the Model

Systems can be exercised to predict how certain conditions and scenarios in one element may affect other elements. Not only does it help to identify desired states in one element and predict what must occur to reach an optimum outcome, but the opposite exercise can be done as well. A desired condition might be analyzed in an outcome so that retrospectively the researcher can find out and describe what led to that state. The following scenarios illustrate several uses of the system.

Scenario 1: When Medical Staff is Good



Since Medical Staff is the driver of the system, having good Medical Staff can positively impact the entire infertility experience. The system illustrates how an ideal affinity's state should be to achieve this positive outcome. Ideally, people who encounter difficulties getting pregnant will consult with a highly recommended doctor in a well-established clinic. In these clinics several elements come together to provide the best care: use of technology to reach patients and

operate at high standards, constructive use of consultations and follow-up times, cutting-edge technology and state of the art medical equipment, information provided, highly qualified financial personnel, and psychological support offered.

In this venue, offices are set up with online portals, which allow patients to fill out initial paper work and monitor their medical records from home and help doctors to access this important information ahead of time so that they can prepare for the actual appointment. For the first consultation, this early start would cut down on the time spent for the preliminary medical data collection and would allow patients to use the visit time to ask further and more precise questions necessary to build a medical opinion as well as allowing doctors to get to know the people and their story. Establishing the initial rapport is fundamental for continuation of services and initiation of treatments in an environment of support that aims at minimizing external and additional unnecessary stress. In this perfect scenario, doctors, lab techs, and nurses are highly sensitive and aware that time and cost are major stressors for people who encounter infertility issues.

In these highly organized clinics, knowledge and information have an important role. In addition to having an attractive and user-friendly website, along with the customary pamphlets, brochures, and various magazines' articles found in waiting rooms, the element that makes a successful clinic stand apart is having their doctor and nurses involved in providing on-going education via workshops and seminars. During these periodic workshops, patients have the opportunity to interact directly with their medical staff and learn about infertility, the technology used to address issues, the latest discoveries and procedures, and they have access to other resources they might need. They also have the invaluable opportunity to meet other couples who have the same issues and possibly form friendships or support systems.

When knowledge is transferred to patients, they are empowered. They learn facts about their condition, they understand chances and rates of success, they can engage in more constructive and productive discussions with their doctors. They ultimately can also play a major role in

choosing the most appropriate treatments to pursue. Well-informed individuals recognize the challenges of fixed and very structured treatment schedules. Understanding the sensitivity of timed medication, labs, and sonogram check-ups can make the difference on how one undergoes treatments. A decreased level of stress associated with such strict schedules and processes might also contribute, along with a variety of factors, to enhancing chances of patients' success.

A good Medical Staff will work tirelessly to provide their services in the most timely and cost-effective manner. These clinics employ highly trained and specialized personnel, who would assist with filing insurance claims, finding pharmacies that offer discounted infertility drugs, locating the best financial opportunities to find the funds necessary to cover the cost of treatments. They would offer their own credit care programs and options, or work closely with financial institutions that serve healthcare providers and patients, or might also have grant programs and opportunities for eligible families.

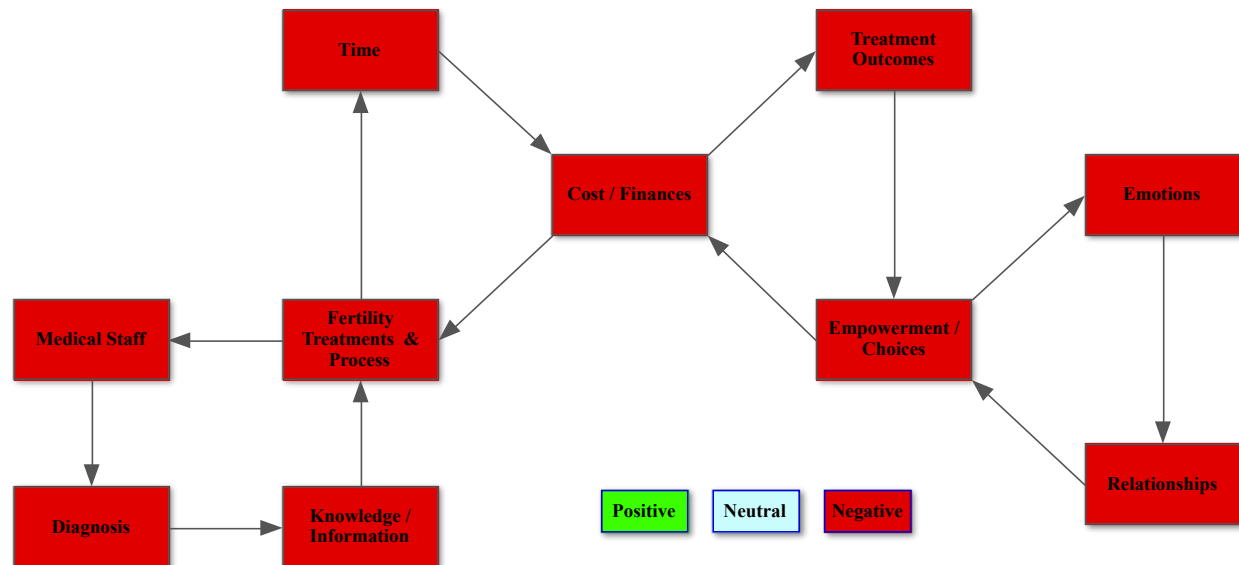
As seen in the system, the Clinical Loop will drive, and in this case, positively impact the Struggle Loop in several ways, contributing to an overall positive experience. Good medical staff and good patient knowledge and interaction will likely reduce the time stressors involved in the treatment experience. This major mental impact affinity is able to be managed positively with guidance and expedience from the positive experience with the medical staff. The knowledge-transfer may also allow the patient to better choose when to move to a more aggressive treatment, such as IVF, thus reducing the time significantly, as well as avoiding potentially unwarranted expenses of a treatment that has little chance of success.

As patients understand, and choose the appropriate treatment, through open discussions with positive medical staff, their opportunities for a desired treatment outcome will increase significantly.

Driven by a positive experience with the associated medical staff, the Clinical Loop and the Struggle Loop will both influence, and drive the Roller Coaster Loop, the ultimate outcome of

the System. Patients' understanding and positive experience throughout the treatments allows them the full array of choices available throughout the experience, including decisions to pick more aggressive treatment protocols, or even choosing when to stop the treatments altogether. While choosing to stop may ultimately lead to the absence of the outcome sought, a baby, the mental toll and stresses involved in the treatments are ultimately the direct impacts felt by the patients, and their families. Conversely, a positive experience may also lead couples to continue another round of treatment, or a more aggressive treatment protocol even if the process did not yield their desired result, a baby. The emotional toll of a stressful experience, or the positive impact of a good experience will directly impact the relationships of the patient. As a good relationship and experience through a positive working environment with the medical staff drives the knowledge, time, cost and outcomes, patients are better able to build and maintain strong relationships with their partner, families, friends and new acquaintances. This System completion scenario is ideal for everyone involved, and shows the importance of Medical Staff of the entire Infertility Treatment Experience System.

Scenario 2: A Tale of Two Bank Accounts



The cost associated with treatments can become a financial burden and a source of high stress on the experience. The System illustrates how a challenging affinity's state, in this scenario Cost, could impact other elements and contribute to a negative outcome, while someone with unlimited funds may be able to weather negative outcomes better.

As we saw in the first scenario, positive Medical Staff can drive the entire experience through positive outcomes, emotions and relationships. However, equally as important in the System is access to financial resources. A patient whose available financial resources are not a limiting factor may have access to better clinics and doctors, allowing them to start off with a tendency toward a more positive interaction with Medical Staff. Even if the finances are not immediately available, a patient who is successful in pursuing loans, grants or even similar/equal treatments at lower costs through other means, such as treatments in a different country, may be apt to experience an ultimately successful treatment experience.

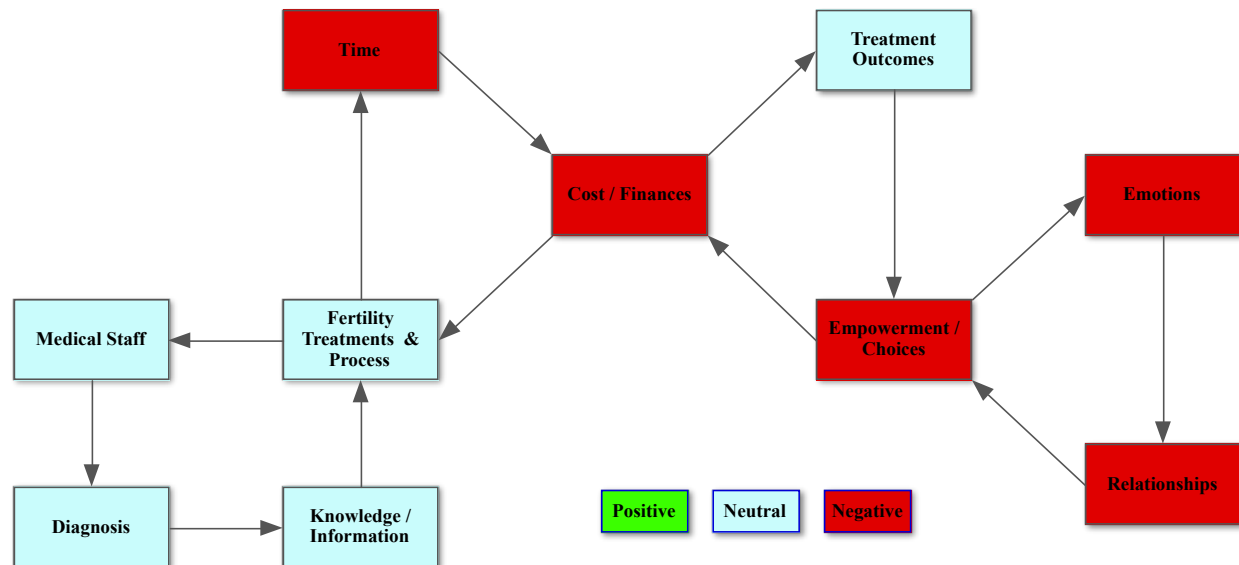
To the contrary, financial resources are rarely unlimited, and oftentimes, they can be extremely unavailable, stressing the Infertility Treatment Experience System to a point of negativity. While little access to financial resources is a limiting factor on the choices of the best clinics and doctors, an acute challenge of severely strained finances is in the choices and time associated with the experience. As discussed prior, the progression of fertility treatments can start with medication, progress through the IUI process, and culminate with various levels of IVF. Finally, donors and surrogacy are options explored by some, however, considerable financial access is necessary for these options.

As financial stresses occur with corresponding negative effects throughout the System, couples tend to become frustrated and may lose their will to continue treatments, or decide to pursue costlier treatments, and these couples are more likely to drop out of the System altogether, choosing instead to no longer pursue Assisted Reproductive Technologies.

Fertility treatments are often explored by women, or couples later in their biological clock. As this clock continues to tick, propensity to infertility becomes even greater. Therefore, time is something that many couples cannot afford. However, when money is a limiting factor, patients may be lured to try lower cost and less aggressive options simply due to price and expectations. These treatments may not be appropriate for the particular patient, and as the treatments take their course, ending in unsuccessful outcomes, patients will be driven to more negative emotions, placing strains on their relationships with family, friends and Medical Staff.

As noted through the System, access to financial means is, perhaps, the key Affinity to fulfilling the fertility dream of achieving a live birth through infertility treatments. This primary element of the Struggle Loop impacts negatively, or positively the entire System from Medical Staff available to Empowerment/Choices and ultimately through the Roller Coaster Loop of the Emotions and Relationships. When finances are unavailable in the process, the entire System tends to break down and results in a negative overall experience.

Scenario 3: Relationships as Key Outcome



As we have focused in the previous scenarios on elements that drive the System, this scenario starts with the focus on the end of the System, Relationships, to understand how to work backwards through the system to understand how a particular scenario led to a positive or negative conclusion.

Relationships was described earlier to include Medical Staff, Family, Friends, Spouse/Partner, Co-workers, and Support Groups. If we take the most direct relationship in the Infertility Experience, we must look at a patient's Spouse/Partner. Some couples pursue infertility treatments after failing multiple years in having a baby. Motives of wanting children vary in most all couples as individual emotions, desires and needs drive their decisions. If a couple's relationship breaks down following infertility treatments, we may be able to trace the System backwards and identify an Affinity that created strain on the relationship. Again, while this scenario focuses on a couple's Relationship, similar exploration can be pursued to trace any Relationship outcome.

You will recall from the previous scenario that access to finances can help drive a successful conclusion to the treatment process. Assume, if you will, that a couple has access to financial means and begins the process of infertility treatments. However, a result of the treatment is that the couple's Relationship is severely strained. The System shows us that, while finances are important, they are not the only Element that can lead to emotional and relational breakdown.

As we look at the Roller Coaster Loop, we see a direct impact from Empowerment/Choices. These Choices are impacted directly by Treatment Outcomes, successful or not. In an unsuccessful outcome experience, the decision to continue the process or not can cause strains on the couple as one may want to stop, and the other is not content until a successful Treatment Outcome is obtained. With finances not a limiting factor in this scenario, we must look back at the Clinical Loop to find key clues to what went wrong.

Perhaps the Medical Staff drove the couple through the treatments with access to little information on the process and treatment options, leading the couple to pursue options that were ultimately not appropriate for their situation. In the interviews, we saw more than one couple whose doctor led them to believe that repeating the IUI process over and over could lead to a successful outcome. As time marched on, and finances dwindled, it became painfully obvious, and later confirmed by a different doctor, that the IUI process had an extremely low chance of working for them. Trusting the doctor's knowledge and opinion, in this case, led to valuable time lost, further financial strain and numerous unsuccessful outcomes. These impacts from the Clinical and the Struggle Loops drove more negativity into the couple's Emotions and Relationship.

In an opposite scenario, with a realistic consultation with a good doctor, perhaps the couple would not have wasted valuable Time with an inappropriate Choice of treatment options, and proceeded straight to a more aggressive treatment earlier and may have had a greater chance of success. At very least, had the appropriate education been available to the couple, outside of blind trust of the doctor's opinion, even unsuccessful treatment outcomes would happen from a stronger mental position, would have ensured that the couple acted from a position of strength in

future Choices. This positivity in their Empowerment/Choices would have contributed positively to their Emotions and Relationship.

Conclusion of the Scenarios

We can follow the Infertility Experience System through various steps, or Affinities, to trace successful or unsuccessful Outcomes or Elements. Through development of the System, individuals and Medical Staff alike are able to identify key points as lessons-learned and in future development of interventions. The System shows that Medical Staff is perhaps the key driver in the entire treatment process, and their skills, abilities and communications can lead patients through a process that can enrich their lives and Relationships. Almost equally important is the access patients have to financial resources or appropriate lower cost options. Knowledge/Information, coupled with these elements can also lead patients to make Choices from a position of strength and understanding, increasing opportunities for successful Treatment Outcomes and a successful conclusion to the Roller Coaster Loop including Emotions and Relationships. This System is an important roadmap in understanding the infertility journey taken by couples in this study, as well as others across the country.

Predictions, Interventions, and Practical Implications

Understanding the Infertility System can help in targeting issues and problematic aspects of the experience. This system can be used by people in many areas, from doctors, to patients, to families and support groups, to analyze occurring problems and develop plans to solve those problems. When making decisions on developing solutions or interventions, knowing how all elements of the system work together as a phenomenon allows users to avoid assuming a one-to-one causation of the problem and to focus on only a single solution. Because systems are tools that help predict how an outcome might be affected given certain inputs, they are theory-generating, meaning researchers can identify a particular problem and can create an intervention to reach a favorable outcome.

In the following section, potential problems and solutions are identified in each loop based on the participants' input and the researcher's interpretation of the system. Findings of this research can help develop tools aimed at improving services to better connect with patients. Better services allow for supportive relationships to be built, and for tools to be developed to make the process of undergoing treatments easier.

The Clinical Loop

In the Clinical Loop, Medical Staff is the driver of the system and it is a predictor of how a patient will be engaged and will navigate the experience. Medical Staff is a critical element because they represent the starting point in the experience. Relationships built, and services offered during the initial clinical experience set the stage for the entire journey. Although many variables, including time, cost, biology and personal strengths and beliefs, might affect decision-making and whether the journey of starting treatments might occur, doctors' ability, personalities, and expertise strongly influence decision-making strategies and paths pursued.

The following diagram shows what issues are faced by the participants during this critical part of the journey, and the solutions proposed by this researcher.

Table 7.2: The Clinical Loop Solutions	
Problem	Solutions
Doctors projected a Business-like demeanor, they are Dismissing, Lacking empathy and They Rush through visits	Working toward developing a Patient-Centered Care model to: <ul style="list-style-type: none">◆ Provide more attention to patients◆ Become More approachable
Information given by doctors is unclear and/or incomplete and focus only on medical part	Doctors should provide <ul style="list-style-type: none">◆ Clear, comprehensive & easy-to-understand information◆ Resources for psychological care
Medical services are Disjointed	Care to patients should aim at Collaborative efforts – and at implementing a holistic approach

Problem: Doctors' Demeanor

Doctors determine the diagnosis and ultimately lead the decision to choose the type of fertility treatment. Once the treatment is chosen, other staff and resources come together to coordinate procedures.

When dealing with doctors, people have pointed out that, while some doctors seemed nice, in many cases they still did not feel completely satisfied, *“I really liked the guy personally, but he did not do very well by me medically.”* During the interviews, the majority of the respondents pointed out that doctors seemed too busy, too business-like and did not take time to get to know their patients,

“[You are] Just another case, just another number, No time to get to know you:

He is running a really big operation. It's not personal, it's business.”

“... the practice in itself was almost robotic, it is like herds of cows where they come and go”

In talking about this business-like impression that doctors projected, people also recounted how they felt pushed into buying a product with the promise of an easy journey ending with a positive outcome,

“There is certainly an element of sales involved from the doctors, almost like car dealers talking with folks, because they are trying to win your business in that sense.”

“Everyone said you will get pregnant, everyone essentially promises the same thing. You are Miss Fertile Myrtle.”

“I felt like I was at a car dealer and I was pushed for costly and heavy treatments quite early on.”

“Most of the doctors had crystal glasses and would always push you towards doing more fertility treatments.”

Additionally, interviewees pointed out that the demeanor of the doctors played a big role in the initial impression they had of the experience, and the subsequent steps, including decisions they made. Many described doctors as dismissive and not listening to patients’ concerns. Due to this lack of constructive communication, in many cases it took a long time, and many trials before doctors took patients’ concerns and points’ of views into consideration. People who described their doctors as dismissing, lacking of empathy, and in a rush, also described experiencing more negative feelings associated with anger and frustration, little hope and happiness, and higher levels of depression and stress when compared to those with more positive encounters.

“The initial doctors were rather dismissive or quick to put my experience in a box. The last doctor blew my symptoms off.”

“She was very lackadaisical about it and the more I have learned overtime, at 39 I was already pretty old so I felt she let me down by not being more pro-active early and giving me better information to spur me into action sooner. I felt that was wasted time.”

Solution: Patient-Centered Care Model

The first step toward ameliorating the fertility experience is to look at finding solutions to problems encountered in the clinical part of the journey. By starting with a series of steps aimed at enriching the patient-doctor relationship, each phase becomes easier to embrace. As previously mentioned in the exercising the model section, in Scenario 1, a comprehensive solution could be to implement a patient-centered model. A patient-centered model of care focuses entirely on the

patient. This type of care is built around the idea that the first step is to “assess patients’ reasons for the visit, their concerns, and their need for information, and then to seek an understanding of the whole person, emotional needs, and life issues.” (Stewart, 2001) When embracing this model, doctors aim at improving the quality of healthcare while reducing the costs associated with visits, testing, medication, and treatments. In this model, the objectives are to improve patients’ outcomes and satisfaction by establishing an optimum doctor-patient relationship.

In the past decade, more focus has been placed on developing and employing a patient-centered care model in the infertility arena. In these settings, the person’s emotional needs are valued, the formation of strong relationships with medical staff are emphasized, and the role of patients’ empowerment in making informed choices is highlighted (Dancet et al. 2011). Additionally, it has been recognized that a series of personal elements must be taken in consideration when caring for infertile individuals, such as their personal, social, familial and cultural background. This type of model calls for training and educating medical staff to recognize and place importance to the context when assisting patients’ with decision-making, choices, and treatments options (Cunningham & Cunningham, 2013). Indeed, research shows that a patient-centered approach is associated with positive health outcomes, such as less discomfort and improved mental health, with better and more efficient care, including less testing and referrals (Stewart, 2000), and it has positive effects on self-esteem, self-awareness and the quality of life in infertile couples (Amani, & Asadi, 2014). In this study, analyses of the affinities rating reported that people who experienced more positive emotions were more satisfied with medical staff ($r=.448$, $p<.05$), and those more satisfied with the medical staff reported more satisfaction with all the affinities (see Table 6.35) as well having a better overall Infertility Treatment Experience ($r=.345$, $p<.05$).

Problem: Poor Information

People expressed frustration when describing the information and knowledge affinity. Overall, respondents point out that the information they get from doctors and medical staff is incomplete,

often sterile, and piecemealed. Doctors tend to provide just basic information and only bits and pieces related to the step they are proposing to pursue.

“It comes down to communication of knowledge. I do not think they did a very good job of relaying information to us. They expect us to know”

“I always felt I had to be my own and my own doctor. I did not necessarily like that I had to. I thought the doctor should be more willing to do that, but the reality is a reality.”

“I think they do a good job of limiting your information. I think they could do much better. They do not tell you the whole story. They just piecemealed us the information as we went rather than giving up to us as a front.”

“I feel they are not very forthcoming with information, they know it but they are just not sharing it. It is really frustrating and sometimes it is that I have to ask the questions, “What will the next step be?” “We will talk when we get there.” “Well, I am going to need to plan ahead. I need to know what is around the corner. You cannot just say next month we will do IVF and then expect me to have that. What is the cost, what is the procedure?”

“Not overly informative, he does not volunteer a lot of information. He gives information as you go, but he is sort of vague, he is just very like surface. If you want any kind of detail you have to ask for it.”

Solution: Improving Doctors' Communication Skills

Clear and informative communication with doctors and other medical staff is fundamental in helping the patient understand their diagnosis, as well as the process in medical treatments and their costs, and in managing emotions and relationships. When people identify their doctors as

dismissive, or rushing through visits, and they perceive low levels of patient-centered communication, they are more likely to avoid or change their doctors and seek more complementary and alternative medicine (Faith, Thorburn, & Tippens, 2015). When the pool of infertility specialists is restricted, people facing this type of situation might feel trapped. These feelings might debilitate their empowerment and sense of control, and might negatively impact their emotions and their personal relationships. Additionally, patients who perceive they have reached common ground with their physicians, and have quality communication, report improved health statuses (Stewart, 2000).

As George (2015) points out, patients need to have access to clinical Knowledge that facilitates learning how to live with their medical condition. A shift needs to occur for knowledge to be transmitted. Instead of merely informing patients, doctors need to educate them. Education needs to start early on, before people even begin looking into forming families. During early checks at family doctors or OBGYNs, patients should be informed and counseled on the importance of understanding their physiology, their reproductive system, and on promoting healthy life-style habits. If patients are followed, informed, and screened early on, chances of discovering dysfunctions and of enhancing fertility outcomes can increase. In this study, 37% of patients are between 31 and 35 years old, followed by 23% ranging between 41 and 45 year of age, if these people were screened earlier in their lives or early in the fertility experience, the change of succeeding in treatments could be increased. Additionally, as already mentioned in the first scenario of this chapter, Medical Staff must move from only providing pamphlets, brochures, and Web resources, to also incorporating workshops and seminars as vehicles of information. Workshops and seminars can be offered periodically by different Medical Staff presenting information related to their areas of expertise, giving patients the opportunity to interact directly with doctors, technicians, and financial experts and learn about infertility, the technology used to address issues, the latest discoveries and procedures, and other resources they might need. These venues also offer the invaluable opportunity to meet other couples who have the same issues, and possibly form friendships or support systems. In this study, analyses of the affinities rating reported that people who were more satisfied with

Knowledge/information experienced more positive emotions ($r=.423$, $p<.05$) and they also were more satisfied with all the other affinities except for cost (Table 6.35).

Information provided by doctors is limited, or only informative of the medical aspects of the process. Little attention seems to be placed on the psychological aspects of treatment. When couples do seek help for infertility, they are typically presented, during the consultation visit, with some medical information, positive scenarios, and attractive statistics pointing to very encouraging outcomes. Therefore, many couples decide on fertility treatment with high expectations and underestimating the difficulties and challenges of the treatments. Ultimately, this lack of information fuels stress when couples' experiences are different than their expectations. To help couples, trained nurses and medical staff can be valuable in providing not only education, but also emotional support. With repeated failures, couples might experience great psychological distress underlined by feelings of guilt, self-blame, grief and sorrow, stress and anxiety. While nurses and medical staff can provide some support, fertility clinics should offer onsite professional counseling, or implement screening and evaluation assessments to identify people at risk of high distress so that they can be advised to undergo therapy (Massey, 2015).

Problem: Disjointed Medical Services

Finally, some people commented on how the field seemed disjointed. Due to the complexity of the condition, infertile individuals might need to consult with doctors from different fields, from endocrinologists, to male infertility specialists, to immunologists. Trying to set up appointments with specialists in different fields and locations, often out of town, takes away time and resources and increases stress and frustration. Additionally, in some instances, respondents reported experiencing different opinions and diagnoses, or resistance in reaching a common ground and finding the best approach to target issues.

“It is so un-integrated, these doctors are not able to work together.”

Solution: Holistic Approach

Ideally, this model would provide high-quality medical care in a multispecialty, integrated and patient-centered setting where several doctors with different expertise and specializations work closely together in the same buildings, or in close physical proximity, in order to offer a holistic approach. Mayo clinics are examples of this type of work and cooperation, where high-performing teams of experts come together to offer high-quality and efficient care and high-quality services at a reduced cost. Although able to be implemented in many settings, including hospitals, medical groups and independent practices, this type of work requires great efforts from different doctors to be willing to work as a team, as well as a substantial financial investment in tools and equipment that can facilitate sharing of resources and communication among providers (Berry, & Beckham, 2014).

While many pieces of the Infertility Experience can be improved, Medical Staff, and a positive experience with them, drives the positive outcomes more than any other. A more patient-centered care, including a deeper educational process than needs to be in place, could drive patients through a process that encourages more empowerment and options, and it will likely produce a much more positive experience. As with any business, focus on the customers' needs is key, and this study, albeit a medical and psychological product, proves the same outcome.

The Infinity Struggle Loop

Table 7.3: The Infinity Struggle Loop Solutions

Problem	Solutions
Lack of Transparency Regarding Costs	Cost should be disclosed on websites
Lack of Insurance Coverage	Insurance coverage & access
Out of pocket expenses are too high	Assistance with finding Loans/Grants
Time is the enemy of women's biological clock	Cooperation among Doctors & Early/Pre-Testing

In the Infinity Struggle Loop, cost is the central element. This is not only true of this loop, but also of the entire system, and it either directly or indirectly influences other Affinities.

According to The American Society of Reproductive Medicine (ASRM), the average cost of an IVF cycle is \$12,400, plus medications, and this does not include additional associated procedures that may be necessary or advisable, such as ICSI (Intra-cytoplasmic sperm injection), PGD (Pre-implantation Genetic Diagnosis) or donor/surrogacy programs. This cost varies, depending on the type of treatments, on the medication, and on the clinic and its location - clinics in large cities are often more expensive. Less aggressive treatments like IUI and ovarian stimulation are less expensive. The IUI procedure's average cost is \$865. Medication cost associated with infertility treatments generally can be as low as \$1500, but can reach up to \$7,000 based on the type of medicine, dosage, and the duration of the ovarian stimulation. Some people in this study reported to spend up to \$12,000 in medication alone. Gestational surrogacy cost starts at about \$70,000 and varies depending on the expenses associated with agencies and carrier fees, medical and insurance costs.

Problem: Unknown Costs

While some medications, diagnostic tests and some minor procedures sometimes are covered by medical insurance, most ART procedures are not, and therefore, patients must pay out of their

own pocket if they decide to undergo IVF treatments. Trying to find precise costs and out-of-pocket expenses is quite difficult because clinics do not disclose this information until a consultation occurs. The ambiguity of insurance coverage, along with the undisclosed costs, brings out lots of frustration, and the different costs associated with these treatments can become a financial burden and a source of high stress.

“Having a child is not a necessity so insurance does not cover any of it.”

“We paid tons of money. Sometimes I try to think how much money and it is scary to try to put it together. The IVFs are about 15,000. The IUIs, I bet by the time we were done we probably paid 15,000 for all of those together. Then the surgeries, the insurance covers the hysteroscopy, but I still have to pay a certain amount on those. Then if you think of everything that is on top of all of this, other stuff, for sure at least \$100,000.”

“We were blown away of the cost of medication. It was very very expensive. I was taking a thousand dollars a day on the second cycle. So that was for twelve days, \$12,000 gone. That was rough.”

“I always joke but I am not really joking that medicine is liquid gold. If people knew this tiny vial of medicine is \$6,000, it is outrageous.”

Solution: Cost Transparency

Whether couples enter the infertility experience with stable finances, or with less than adequate bank account balances, both monetary and non-monetary costs affect people in ways that shape the entire experience. In order to attenuate such difficulties and to lower cost-stress related issues, ideas are provided as preliminary solutions that could be implemented in the field.

Initially, particular attention should be paid to the monetary side of the issue, and solutions should address things such as insurance coverage, out of pocket expenses and medications cost. If ways are found to lift the heavy cost burden from patients' shoulders, immediate benefits will be realized by many couples with limited finances for whom pursuing treatments then becomes a reality. In the long run, benefits can be seen through improved well-being and in better relationships due to lower anxiety and stress levels. In this study, cost is positively predicted by positive emotions, meaning when people are more satisfied with how they are covering the cost they are more likely to experience more positive emotions ($r=.441$, $p<.05$). Additionally when people were more satisfied with how they were covering the cost they were more likely to be satisfied with their relationships ($r=.451$, $p<.05$), their choice ($r=.681$, $p<.05$), their medical staff ($r=.326$, $p<.05$); for a complete list refer to Table 6.35.

An easy and immediate solution to the undisclosed cost problem is in transparency in treatment prices, which would be readily available on clinics' websites and printed materials. Having prices available and upfront allows people to plan and seek financially wiser ways to avoid long-term financial burdens. When people have information upfront, they are more able to decide whether to seek options such as more comprehensive medical coverage, to plan their finances according to the necessary treatments, or to wait until they have the funds necessary to cover the expenses. When people first consult with doctors, the likelihood of receiving information with positive scenarios, attractive statistics, and positive outcomes is high. This positive feedback might inflate people's positive emotions in a way that individuals and couples may overestimate their chances of having a quick and positive outcome, and consequently they may also underestimate the chances of incurring extra costs, and the toll those costs might have on them.

Problem: Lack of Insurance Coverage & Access

Discussions and debates often surround insurance coverage. In the USA, currently only 15 states have passed laws requiring insurance coverage for infertility treatment, Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia. Having coverage laws set in place does not

necessarily mean that coverage is required. Often it only means that it is required to offer insurance not to provide it. Out of these 15 states, eight are required to provide and cover some level of procedures (RESOLVE: The National Infertility Association, 2015).

Insurance coverage for infertility and its treatments varies greatly. Even in the eight states where insurers and HMOs are required to cover the cost of procedures, there are many conditions, limitations, and requirements to be met. Some plans limit the number or type of procedures, including age, timeline, and preexisting conditions limitations. In Texas, laws set in place in 1987 require group insurers only to offer coverage, but does not require them to provide it as part of a regular plan, and employers can choose whether or not to include it in their employee health benefit package. Many do not due to the increased cost to carry the option. Even when offered, there are many requirements to be met. Limitation include a minimum of 5 years infertility associated with specific dysfunctions, such as endometriosis, DES, tubal issues, or Oligospermia; inability to get and stay pregnant with less expensive procedures also covered by same policy; marital status; sperm and egg donor procedures. In the best-case scenarios, plans would cover between \$10,000 and \$25,000 total. In general, insurance will cover diagnostics testing and treatment up to intrauterine inseminations. If fertility dysfunctions, i.e. ovulatory dysfunctions, are coded as medical conditions, blood and ultrasound tests are covered, but IVFs are not (<http://www.resolve.org>).

“That is probably the most disappointing thing for me. I work for the city. We have an amazing benefit package, the city is very progressive for the most part. We provide services for domestic partnership, we provide insurance for pets. All kinds of different things are available, so very progressive. But when it came to fertility treatment, it was lacking as a nice way to put it.”

Since coverage is scarce or unavailable, treatments are often possible only for those who have the financial means. Studies that have looked specifically into the cost and the financial impact of treatments show that a very small percentage of infertile women in the USA seek treatments, that they have usually mid to high incomes, and are predominately older, married, Caucasian

women (Katz, Nachtigall, & Showstack, 2002). These trends are confirmed in this study with a sample comprised of 76.7% of Caucasian, highly educated, with 18.6% reporting individual incomes ranging between 50,000 to \$74,999 and 58% reporting family incomes of \$100,000 and above. In this sample 93% of participants are married with 37.2% ranging between 31 and 35 and 23.3% ranging between 41 to 45 years of age (Table 6.1).

Additionally, research shows that financial burden might be a major reason to drop-out of treatments (Kulkarni, 2014). Recognizing infertility as a medical condition may be a first step to lowering the barriers. Having laws that require inclusion of infertility coverage in health plans, or having cost covered by national health services would then help in making parenthood a reality for many people, including those with limited finances, and it has the potential to reduce the cost of ART procedures across the nation.

“We feel very fortunate that we even had the money to do any of the stuff we have done, because I easily could not have had that money we would not be here.”

Solution: Treat Infertility as a Medical Condition

Research shows that outside of the United States infertility is considered a medical condition, and therefore covered by private or national health services, that the cost of treatments are lower, and that age limits are often higher. For example, IVFs are covered with public funds in many European countries: Australia, Austria, Denmark, Finland, France, Germany, Iceland, The Netherlands, Norway and Sweden. In these countries, IVF costs were also significantly lower, averaging at \$3,500 per IVF (Katz, Nachtigall, & Showstack, 2002). These realities are attracting a growing number of Americans to seek help outside the States (Lee, 2005; Tesoriero, 2008). In this study, some couples described their struggles with cost in the states, and their decisions to go overseas for treatments.

“It is expensive and we had to pay for the whole thing out of pocket. The American costs were much higher than those overseas. Then again just the whole

insurance process not knowing what your bill is going to be at the end of the day. You just have to be ready to write a check for how much they tell you."

"We went to Europe too and that was included in the overall. You have to pay for the travel, but the cost of flying, the treatment, the hotel was about half the cost of the procedure here in the States. It is five or ten grand and that includes plane travel, and also includes the donor and everything. Here the donor agency will charge you; I do not know what they will charge, but it was a lot. That just blew my mind away. I remember our doctor here was giving us the best he could give us and it was still twice as much as going overseas. That exceeded my expectations."

"Well you totally floored when they tell you how much it is going to cost. Even when they tell you thirty or forty thousand dollars, if you knew that was going to work you would say, "Where do I sign?" But when it is thirty or forty thousand dollar gamble and your biology is letting you down so much, you are like "oh my God. What are we getting ourselves into? What if it does not work?" That is part of the reason overseas was appealing to us because it is so much less. It was less than a regular IVF to do a donor cycle overseas."

In the USA, exclusion from coverage is justified by the argument that infertility is not viewed as a medical condition but rather as a "socially constructed need" and that IVF is an "experimental" technique. The three main arguments attributed to denying coverage included that, "1) infertility is not an 'illness,' 2) artificial insemination is not a 'treatment,' and 3) infertility treatment is not 'medically necessary.'" (Cardinale, 2012). In the largest international surveys conducted in several countries including Europe, Australia, and USA on the topic of infertility only 38% of respondents considered infertility as a disease with people showing little knowledge and understanding of the medical issues of infertility and its chances of treatments' success (Adashi, et al., 2000).

Working on revising perceptions and achieving medical condition status to influence policy changes could be the start. Khetarpal, & Singh, (2012) argue that in order to access services and change policies, infertility should be considered as a disability because it is a chronic condition that meets the “biopsychological, social role and legal criteria for disability.” Medically, it meets the criteria because it is a condition that includes the disorders of the reproductive and endocrine system and socially it impedes the realization of the parental roles. A federal mandate requiring insurance companies to provide coverage has the potential to lower health care costs and to provide medical services that could help with decreasing complications linked to multiple births such as prematurity, birth defects, and other similar disorders.

Problem: Out of Pocket Expenses

During the interviews, people described cost and time as some of the biggest stressors. In this study, although the majority of participants reported high income, and people were aware that fertility treatments are expensive, they described how dealing with the actual bills, out-of-pocket expenses, insurance coverage, and medication cost was a tolling experience. Indeed, the lowest positive experiences were reported within the Time affinity (4.7% positive), and the Cost affinity (14.0% positive), Table 6.13.

“It is hard to put a price on a baby. Cost is part of the decision-making that would lead to stress, because even though you feel you are advantaged and can afford it, you still feel this could be a terrible waste of money. And you feel guilty for being able to do it. I can afford to do this more than a lot of people and kind of mess with your emotions. I should be able to at least conceive for free, right? Even if children are expensive, that is the free part.”

“There is a lot of anxiety. It is because often the bills were presented to me, so it was like a shock [...] Every single month you are trying something, it is more money than you have paid, so I just adds up. It stressed me out thinking about future cost of it.”

“There was just a certain level of stress and sacrifice when you start thinking about that cost and how you are going to take care of it all. That takes you through a whole range of emotions at any time.”

Many felt they had no control or choices. Cost influenced decisions to pursue treatments, and limited the type of treatments some could afford.

“I felt we had no choice because we financially could not afford IVF and that is what panicked us.”

“The cost would dictate if we decided to do it or not. If cost was not an issue you would pursue treatments faster and more aggressively. If I could afford to go to the best clinic in the country, I might be more likely to have the best outcome.”

“Your choices are limited by how much you can afford and how much you are willing to spend. I knew how limited we were and how much we could do and that really tied our hands.”

Along with describing that cost influences emotions and choices, cost also posed many challenges to participants’ relationships. We noted this phenomenon earlier in our discussion of various scenarios and the impact that one Affinity may have on another. The Infinity Struggle Loop clearly was a major influencer on the Roller Coaster Loop, and challenging experiences with finances impacted the Roller Coaster Loop negatively and directly.

“Money is always the biggest thing and ruins most relationships. Money is a strain on any relationship. The cost that we incurred added a lot of stress to our relationship. I am like, “Oh my God, look at how much money we spent today [...] I would not be in this financial hole if it was not for you.” This is really stressful.”

“If it sounds expensive it is stressful. That was the number one thing for us. That is when the emotions come up in the relationship. My husband was more strategic. I was willing to go into debt for it. He was like, “We cannot do that; we need to think of the long term.” That is not easy to hear when you want something as badly as a child. Then you got the biological clock on top of that.”

Solution: Assistance Finding Loans and Grants

Another way to help people find funds for treatments is by assisting them with finding financial institutions that offer loans for medical reasons. In many of the doctors’ websites, or through printed material, patients can find information on several resources. Often, clinics offer their own Credit Care programs and options, or work closely with financial institutions that serve healthcare providers and patients, or they might have grant programs and opportunities for eligible families. Although these programs provide ways to help, it has been debated whether these types of partnerships between financial institutions and physicians constitute a conflict of interest, placing doubts on the ethical use of fertility loans (Hagel, 2013).

Narratives point to the distress caused by out-of-pocket expenses. In the only study addressing the direct out-of-pocket costs of infertility treatments, it was highlighted that couples who underwent IVF paid \$15,000 more out of pocket than couples who did IUI and paid an addition of \$7,000 out of pocket for any successive IVF. Even when people had insurance coverage, most of the costs were still undertaken by couples (Wu, Odisho, Washington, Katz, & Smith, 2014).

In this study, although out-of-pocket expenses were not quantified, narratives clearly show the distress that they procured.

“That was all out of pocket. A very negative experience because of the exorbitant cost and the impact that it had on our lifestyle.”

“Fear about out of pocket expenses is a big deal, because you just do not know about it. As you go through the process you really do not have any way of knowing how much is that costing you. You could be looking at 20,000 or 50,000 dollars if it takes, maybe you only need one course but if you need five maybe five does not even work, so I would say intimidation of it is more than the actual experience.”

“Insurance covered some things but most of it was out of pocket. I think probably the biggest thing was the difference in cost between America and foreign countries. So as we would like to go to a more expensive infertility process, the fact that you have to go overseas to do some of these things or you are driven there to save some money, it is challenging. But again it’s all out of pocket. You have to go into it willing to spend whatever it’s going to take and you know that certain things are going to be covered with insurance, but most of it is going to be out of pocket. But there is nothing good about writing the checks out”

“All the stuff for IVF and the meds were out of pocket. So out of pocket this year alone we have had twenty thousand dollars, just stuff that we had to pay not counting anything that the insurance covered. I liked knowing upfront how much we were paying, so that was good. But it was just very stressful even going in for things that were partly covered. Figuring out how much do I have to pay, how much is insurance going to pay for the laparoscopy or hysteroscopy.”

“They covered the diagnostics, his test and my test which I felt was a fraction of what the actually cost was, which all together was about seventeen thousands dollars out of pocket. It is ridiculous. There should be a better way to pay for it and it is crazy to me that insurance does not help at all.”

Many expenses are unavoidable when pursuing treatments, but getting information on what to expect, and where to find more affordable services, can offer a way to lower stress related to these costs. This type of information can help couples with the decision-making process.

Problem: Time is the Enemy of Women's Biological Clock

One final point to address in this loop relates to time, and how time was experienced by the infertile individuals in the study. Participants described their experiences as taking too long, that as time went by they felt more stressed due to the feeling of wasting their potential, particularly given the pressures of the biological clock.

"Four years. I think the time is the biggest thing for me. How long this took is the most frustrating part of it."

"Seemed long. In April it will be five; so four years, just under five years. That is a long time."

"So tried for three and a half years. It was very frustrating as time went by."

"Every time I added another year, that was pretty painful because we tried for five years. Even before we started with fertility doctors, we were trying on our own and then there was that one year that we were in this hole because of the uterine lining."

"That was really stressful trying to negotiate the time, it always takes longer than what I am willing to wait."

"So this just feels like so much wasted time. I feel I am wasting my potential."

“You feel you have been going through this for a long time, you are not getting any younger.”

“I feel I am getting older. I feel time is getting away from me and I can never get it back and it has never going to be ok. Things would be ok. Well one day I will have a crib in my house, and that will be ok. But this time, I can never get back my twenty seventh year when I was a parent because I am not.”

“I will be forty this year. So it is kind of getting to the point where it is time. You know what I mean. It is time already. Why do we have to have a biological clock?”

“I was really feeling this race against the clock and not only that, but also bitterness towards the first two doctors, I felt I wasted precious time.”

Research shows that couples who spent the most time on care were significantly more likely to experience fertility-related stress (Wu, Elliott, Katz, & Smith, 2013). In this study, analysis of ratings indicates that satisfaction with the pace of treatments positively predicts their satisfaction with every category, including the overall infertility experience (Table 6.35).

Another reason why participants felt their treatments took a long time was due to lack of comprehensive early testing. Many pointed out that doctors did not run enough or comprehensive tests, or no early testing was done in the majority of cases. People complained that they were given drugs or pushed into starting less invasive treatments with little, or no investigation, which increased the likelihood of not reaching a desired outcome, of wasting time and resources, and of having to repeat cycles of treatments before looking deeper into issues.

“He offered to put me on Clomid for several rounds unmonitored; just gave me the prescription and sent me home. It took years to know.”

“We went to one doctor, they said that IUI would be fine but they did not test me. They just did it. So, here we have been doing IUIs and timed intercourse for almost four years, and no one of the other doctors ever tested for the Antisperm antibodies, which basically will not allow you to get pregnant unless they do the ICSI.”

“One doctor continued to do the IUI process over and over again and it never worked and when we went to the next doctor, the next doctor said he does not understand why the other doctor was even continuing through that process, because it was a useless endeavor. I am still really mad at that doctor, because she did 7 IUIs on me, which is a lot. In retrospect you figure out that was too many, that was a waste of time.”

“...And you wonder, “Why did not we do this back there?” and that is where the discouraging part is. Every time I go in, it is like anything else we can look at? Is there anything else we are missing? Is there any other test that my husband and I can do to get us more information? “We recommend that you do this one test.” Then seriously why did we not do that in the beginning? We spent five hundred dollars apart for two IUIs and then you tell me about it?”

Solution: Cooperation Among Specialists & Early/Pre-Testing

Solutions proposed to enhance satisfaction with time include cooperation among different specialists, as well as early testing. As already previously mentioned, if people are counseled throughout their lives, and they are tested early during their annual checks, or at least early in the infertility treatment journey, chances of diminishing diagnostic time and enhancing rates of positive outcomes are more likely to occur. Participants described that, in many instances, it took a long time to discover the root of their problem, that paths were explored as they went through the experience and after failures, and that many test were not encouraged to be done early enough during the diagnostic time. Time is the enemy of women’s biological clock, thus if

professionals work together to evaluate the whole person and to run the most appropriate testing with the most cutting edge technology and equipment an accurate diagnosis can be reached in a timely manner while trying to minimize the costs. Therefore, it is important to reiterate and encourage a more integrated multi-specialty approach with several experts working closely together to provide better and faster medical care. Benefits of scheduling, consolidated appointments and locations, as well as an element of cohesive and integrated care all can play to the advantage of the patient and doctors alike, and significantly save time. As well, through a more comprehensive and cohesive treatment process, improved relationships with the medical staff will drive a more positive experience overall.

The Roller Coaster Loop

Table 7.4: The Roller Coaster Loop Solutions

Problem	Solutions
Negative emotions run high: Stress/Anxiety/depression, Sorrow & Grief	Need to develop Intervention Programs that incorporate Therapy & Body/Mind care
Relationships often suffer because People Isolate themselves due to the Stigma of being Childless	Increase Awareness & Provide Social Support

The Roller Coaster Loop represents the final outcome of the infertility experience. As previously pointed out, elements in the previous loops influence the final outcome and how infertile individuals move through the infertility treatment process. In this sample, the overall Infertility Treatment Experience satisfaction was positively predicted by positive emotions. People who experience more positive emotions are more likely to be more satisfied with all other affinities, including the overall Infertility Treatment Experience (Table 6.35)

Problem: Negative Emotions Run High

The overarching theme in this loop, which seemed to be at the root of many issues, and incorporated in all the different aspects, was the lack of regard for patients' psychological care. People were under an enormous amount of stress, and a variety of negative scenarios and distressing feelings during the experience, and they felt left alone to deal with their struggles.

“That is the biggest piece that was missing from the doctor, “How are you doing with this?” Instead of just this robot, “Keep doing this, this and this.” Like, “Let us stop for a second and how are you dealing with this? How are you coping with this? Are you taking care of yourself? Are the two of you doing ok?” There is none. There is no human connection there [...] There is no regard for the mental health component of it.”

As pointed out by research, infertility is ranked as one of the most stressful experiences in life along with death, divorce, and deadly diseases, such as HIV and cancer (Domar, Zuttermeister, & Friedman, 1993). The majority of studies suggest that infertility negatively affects adults' well-being (Shapiro, 1988; Cook, 1987; Mahlstedt, 1987; Wichman et al., 2011). Adults who experience infertility regard their inability to conceive as a prolonged life crisis (Lalos, 1999), and are more likely to suffer from depression, anxiety, feelings of loss and even marital problems both in the short and long term (Möller & Fällström, 1991; Lalos, 1999). People experiencing infertility have feelings of anger, hurt, fear, frustration, depression, sadness, grief, loss, isolation, lowered self-esteem, relationship distress, and sexual dissatisfaction (Daniluk & Tench, 2007). Anger toward people with children, toward abusive parents, or even toward medical professionals along with feeling pressure to have children and a lack of control seem to fuel some of the anguish experienced during this difficult time (Menning, 1980 & 1988; Cook, 1987).

Participants' narratives of this part of the experience support the above literature, and in fact they focused on stress and anxiety accumulating during their journey, and how it impacted their emotions, lives, relationships, and ultimately their well-being. Many people complained that the medical staff fueled a lot of their negative emotions. Doctors who took a long time to diagnose, or insisted on procedures that resulted in failures and waste of time and resources, was a predominant theme.

"I felt angry with the doctor who took a stand off path that we should not have been on in the IUI process where the doctor continued on and on, and when I later found that was a useless experience, I was extremely angry with that doctor."

"There are moments when I got angry. I think that is frustration boiled over. There were times when I would say we needed to do a couple of things differently here and then repeat myself, and I finally get angry and say this is stupid."

“I do get very angry with medical staff and that is really the only thing. I get angry at the hospital practices...”

“I was really frustrated by this. Just trying to figure out what the problem is and what exactly is going on, it is very difficult to get to the bottom of it and then very difficult to get answers on the best course.”

“I definitely felt anger, not with myself or my husband, just how difficult it is and in our society, you do not really talk about it and that the medical science is not where it should be. My lowest point is probably with the Doctor that screwed up the test. That was probably the angriest I ever got.”

“The loss of control over things makes you angry. I got really upset at the fertility clinic with the rude medical staff, because I expected it to be in an environment where someone is going to be supportive. I remember thinking “gosh. I came in a really good mood, what is wrong with this person?” Just anger at the out of control feeling with everything.”

Lots of frustration, depression, and stress were associated with failures, with the pace of treatments, and with feeling out of control and powerless.

“Frustration because nothing was working. Seems like you try and try and try and you try to fix things and nothing ever gets fixed. Usually, the harder you work the more you can succeed. This is one of those you work harder and harder and you do not necessarily succeed.”

“We are frustrated nothing has worked and what we are doing right now I do not consider as being working. We have had three complete strangers come together and have a child for us and it is not so completely less than ideal and I am so happy that it is working but I feel guilty and frustrated about that.”

“I was very angry because so much is unexplained and so much was out of my control. I think there were times that I was angrier than others, so I was not always angry. Anger and frustration probably did occur later on as more treatments failed...”

“You are frustrated that you are going through it. As a guy, you are frustrated that there is really not much you can change, frustrated that things that you are trying to change are not always the way you want them to be, frustrated that you are not as emotional generally as your partner, frustrated when it does not work, frustrated when you have to write that six thousand dollars check. I think that happens more often.”

Stress in this population runs high. Every story collected gravitated around stress. For every aspect of the journey, there was stress associated with it and this stress accumulated as people moved from one step to the next, and as time went by.

“I felt like I was on my max level of stress that I could possibly handle, and then it would get even worse during treatments or during negatives. Yes, treatments made it even worse.”

“It is one of the most stressful things that I have been through. Now it is less because of this decision to stop trying and just let it be like it really helps.”

“Stress is a big one definitely. Just because infertility is the first thing that I think of in the morning when I wake up and the last thing I think about before I go to bed at night. It is always in the back of my mind; it never goes away.”

“You are stressed financially, emotionally, and physically through the whole process. Trying to recuperate from surgeries and deal with the family and the job,

life goes on! Your life does not stop just because you are infertile; you have a lot more stress on top of your regular daily stresses.”

“Very stressful trying to calm my wife down, being in her shoes, she is upset and knowing that there is nothing I could do. It was very very stressful knowing that I could not do anything. You cannot just say, “be patient.” You cannot say, “it is going to be ok”. Those things do not accomplish anything. So it was more stressful, I mean that is the stress that it put on our relationship.”

Although loss and the process of grieving usually are associated with the death of a loved one, this feeling was felt strongly by this population. Not only that the diagnosis of infertility has been linked to models of bereavement or grief (Christie, 1997), but also when dealing with fertility issues and multiple failures to achieve a viable pregnancy, people must confront many types of loss that co-occur, including loss of self-esteem, loss of control over one's body, and the devastating loss of having one or more miscarriages (Shapiro, 1988; Cook, 1987; Mahlstedt, 1987; Menning, 1980).

Overcoming loss stemming from infertility involves acceptance of one's condition and coming to terms with the reality of permanent infertility and involuntary childlessness (Daniluk, 2001). Because society values norms and institutions that function under the assumption that couples should have children, and therefore focus on parenthood, most people view having a child as a natural and even an “inevitable part of the life cycle” (Daniluk, 2001). Children are thought to complete a family, provide later-life companionship, and are even regarded as enhancing status (Mason, 1993; Owens, 1982). Hence, the loss of a potential relationship with a child may be linked to a devaluation of the self and the loss of one's own status and position in society. People who find themselves unable to have children suffer feelings of exclusion from experiences considered of great significance in life and what gives a person a place and a precise identity.

Once infertility is diagnosed, it seems to creep up and strip people of their own identity “Foremost you are infertile, not a nurse, a physician, an engineer or a wife.” (Johansson & Berg,

2005). Women experience what Johansson & Berg (2005) identify as “life-grief.” Life-grief is conceptualized as overwhelming suffering due to the experience of infertility as it relates to the experience of childlessness. Monach (2006) points out that these people find themselves devalued as full members of society. They experience lower levels of self-confidence and self-esteem due to the fact that they cannot achieve what seems to be expected in adulthood -- to meet important life goals and ambitions and fully perform valued social roles. Lower levels of self-esteem are also due to a feeling of loss of one's healthy self-image and control over one's own body. Some women even perceive their own body as defective. In a qualitative study, Johansson and Berg report that their participants' respond to childlessness in the following way: “...Females must be able to give birth to children, that is why they have a uterus and ovaries... It is almost as if you cannot run with your legs – you have two legs but you cannot run with them.” Grieving over infertility, which produces involuntary childlessness, has a negative effect on women and is experienced as a major life crisis up to 20 years after termination of treatment (Johansson & Berg, 2005; Wirtberg et al., 2007).

Finally, couples might experience the loss of multiple pregnancies or even of their babies soon after birth. Coping with the loss of the potential baby, and/or the actual child is extremely burdensome on the individuals, especially when it is coupled with years of infertility and aggressive treatments. If the couples are not able to resolve these losses, the chance that they might exhibit signs of great distress is likely to increase. With increased distress due to a constant state of sorrow, chronic grief is likely to be triggered, and people may show signs of clinical anxiety, depression, and the onset of pathology. These negative outcomes might compromise a couple's decision to move on and to pursue other routes to achieve parenthood outside of IVF treatments.

This study supports previous research findings in that analyses of narratives reflect how participants experienced their grief and the type of losses they underwent. The following stories have been organized by the type of loss people recount experiencing.

Loss of Fertility

“When we got the diagnosis, I definitely had a mourning process, because you have envisioned your life a certain way and then you find out that it is not the way it is going to be, and you have to cope with that. It is almost like losing somebody.”

“I have after the last time when they removed the last tube, that moment when verdict was in. That week after I got out of the hospital, going shopping and everybody was pregnant. Every single one; every man, woman, child, pregnant trees. Everybody was just pregnant. I remember getting home, I was trying to be tough. I am handling this, I am fine, and my husband said, “You need to just cry and get it out.” This is like seven o’clock in the evening I started crying, and the whole night, that hold for like two days straight. I just do not think I have ever felt that kind of grief before. I had fallen from the sorrow in the grief but I knew at that point that was it. You know, it does not change.”

Loss of a Biological Family

“It has the grief in the morning that gets to me a lot. I remember very clearly lying in bed probably about six months ago and just thinking about the kind of family I want to have. I want to have four children like my mom and like my husband’s family. I want to home school them and I want them to all be close in age [...] I think my husband and I have really good genes to pass on. We are really smart, we value family. So I want to have genetic children and I want them to be close in age so they can all be friends. But I was thinking of the actual realities of that happening [...] thinking of the actual realities of being able to have the kind of family that I always thought I could have it felt like a sword in my stomach, just like a sharp sharp pain. And just feeling that like grief and mourning. I do not know if it is ever going to be ok.”

“That is high because is just hard. You have sorrow for what could have been, thinking about that. You know all of those things.”

“Just sadness for the fact that you lost the ability to have our family or we did not know how it was going to happen.”

“I think it is important to mourn the loss of those dreams that we had and to get yourself off of that. That was undervalued in our culture and I really wanted to give myself space to feel that. So I felt it, but I do not necessarily think that it was a negative thing like I should feel that and make room for that.”

Loss of Pregnancy

“Numerous occasions we lost a child and that was very depressing very great sorrow, great grief and there is just no getting over that sorrow and grief that you feel when you have a child and then again that causes more depression and that happened on a number of occasions.”

“Very high after every loss, but still a little bit now. I still feel like I am grieving a little bit even though I know that is inappropriate. I feel like the anticipation is tireless, some are treasured with that grief and that is wrong. I feel guilty about that.”

“Even if it is early in the pregnancy a loss is a loss, and that is always a grief and something that you are going to remember that there was a child.”

The Grief from Treatments not Working Time and Again

“I never really stopped to feel the sadness and the grief of this not working time and time again. So I really bottled it up for a long time, for years.”

“When there were failed IVF cycles and all these were really painful. And on the birthday, Getting older, yes there is lots of other triggers.”

“There was probably grief throughout the whole thing.”

“Each cycle I was kind of grieving that it did not work, during the month I would talk to my baby growing and then at the end of the month there will be nothing.”

“After getting the results that it did not work, that is when I also felt the sorrow and grief.”

“I grieved a lot. Just every time. Especially that one time I was on Femara and I was a week late I really thought I was pregnant but I was not. It is really devastating and then losing my relationship and going to the grief of that has been hard.”

Solution: Therapy & Body/Mind Care Intervention Programs

Because existing research overwhelmingly highlights the negative effects of fertility treatments, many researchers advocate psychosocial counseling to enhance quality of life in infertile women and support couples during fertility treatment (Ashraf, Ali, & Azadeh, 2014; Dooley, Dineen, Sarma, & Nolan, 2014), to help men feel more connected to the process (Mikkelsen, Madsen, & Humaidan, P. (2013), and to help with coping with life after treatments (Cunningham, 2014).

Given the negative psychological effects on those suffering from infertility and the strong calling for more counseling, this researcher advocated to move from merely referring patients to psychologists when, or if they inquire, to introducing and offering psychosocial counseling as

part of the treatment by developing effective psychological intervention programs.

A number of interventions have been devised over the years to address infertility. Interventions usually have been created and run by psychologists or nurses in clinical settings and rely heavily on therapeutic approaches such as psychodynamic-analytic interventions (Sarrell & DeCherney, 1985), cognitive-behavioral therapies (Noorbala et al., 2008), mind/body-orientated relaxation (Levitas et al., 2006), education (Chan, Ng, Chan, Ho, & Chan, 2006), and online counseling interventions (Cousineau et al., 2008). These interventions vary in format, single, couple or group, and in duration, ranging from 1 to 30 sessions. Each type of intervention presents its benefits. Understanding the benefits of these different types of interventions is very important in order to pinpoint the most advantageous aspects so that future interventions can be more effective in helping infertile persons.

Boivin's (2003) review of the psychological interventions in infertility provides valuable information on the benefits of each different type of program devised over the years. She examined the types of intervention that produced more positive changes and found that educational interventions were more effective than counseling interventions alone and produced twice as many positive changes.

The system in this study supports the importance of educational interventions. Specifically, in the Infertility Treatment Experience System the affinity Knowledge/Information directly influences Fertility Treatment & Process and indirectly influences Diagnosis. When the model is exercised, the system illustrates how the information and the type of information can affect, either positively or negatively, affinities in the same loop as well the adjacent affinities, producing a ripple effect that influences the rest of the system. In order to offer the best solution that addresses Knowledge/Information, the System teaches the user that the first step to cope with infertility could be educating couples about the condition itself. It is important that people understand the biological and medical conditions that underlie infertility so that they can make the best decision possible regarding which treatment to pursue. Trying to discover causes of infertility, however, is very demanding physically, emotionally, and psychologically. Couples

may need to understand more about the physical demands of undergoing many diagnostic procedures that often require surgeries. They should also be prepared for the emotional challenges that accompany increasingly aggressive treatments so that they can make a decision to terminate treatments if faced with continuous disappointment. Being informed on the medical and psychological challenges involved in this experience would set the stage for choosing the most appropriate treatment for the specific case. Finally, couples should be made aware of the economic hardships associated with IVF treatments, including the cost of diagnostic procedures, surgeries, and medications. Being properly informed allows people to choose treatments that can be done in the most timely and cost effective way. Being properly informed is also essential in helping couples gain control over their choices and future – it provides them with an opportunity to take a more active role in decision-making throughout the process and helps them cope with the stresses associated with treatment (Williams, Bischoff & Ludes, 1992). Once informed about infertility itself, counseling becomes more important and powerful. Combining educational and supportive counseling interventions have been proven effective in producing positive changes in mental health (Boivin, 2003; McNaughton-Cassill, Bostwick, Arthur, Robinson, & Neal, 2002). Therefore, a program that offers a combination of the two approaches could be very valuable.

Another important finding in this study was that people expressed appreciation for skills training, such as Stress Reducing/Managing and Coping strategies, as well as great interest for a body-mind holistic care as a way to learn to reduce stress. The infertility treatment experience is a very stressful one, and the narratives uncovered that negative emotions run high in this population. By tracing the systems' elements, the user learns that feelings are directly influenced by empowerment, and that they directly influence relationships. Thus, the system in the study suggests that providing people with tools and strategies for dealing with their infertility impacts their sense of empowerment and control over the situation. When people are taught strategies to enhance their well-being, they develop strategies that enable them to cope with stress and negative emotions, and to process and understand their condition in more effective and constructive ways. Feeling more in control influences their emotions enhancing satisfaction, not only with the experience itself, but also with their relationships.

Literature also supports the idea that coping training is an important component for infertility intervention (Schuth, Keck, Vogelgesang, and Breckwoldt, 1999) and a key determinant of participants' satisfaction (Holzle et al., 2002; McNaughton-Cassill et al., 2000).

Additionally, relaxation and mindfulness training has also been shown to be beneficial. Donnis (1984) believes that helping individuals learn compassion and forgiveness for themselves through mindfulness techniques is one way to help them learn to cope with guilt. Traditionally, mindfulness-based therapies, that teach people self-compassion and forgiveness strategies, have been used to treat distress in cancer patients (Foley et al., 2010). Originally targeted to help patients with chronic pain, Mindfulness-Based Stress Reduction (MBSR) interventions have been the foundation for several other mindfulness-related interventions, including Mindfulness-Based Cognitive Therapy (MBCT) and Acceptance and Commitment Therapy (ACT) to help with conditions as diverse as chronic pain, heart disease, stress and relationship problems, anxiety, eating disorders, sleep problems, and depression (Keng, Smoski, & Robins, 2011).

Since fertility patients present levels of distress comparable to those diagnosed with cancer (Domar, Zuttermeister, Friedman, 1993), Peterson & Eifert (2011) conducted a case study implementing Acceptance and Commitment Therapy (ACT) with one couple for 20 sessions. Findings have highlighted that undergoing ACT reduced all types of infertility related stress, increased levels of mindful acceptance, and reduced feelings of depression and psychological distress during the course of the study and in the one year post therapy.

Problem: Relationships Suffer

Research shows that isolation is one of the many facets of infertility. Infertile individuals find it very difficult to deal with the stigma associated with being childless and the societal assumption that all couples have children (Salzer, 1991). In most cases, infertile individuals do not feel fully understood, and they often feel judged by people who are not experiencing the condition. Often, couples have difficulties coping with friends and family members who express disappointment or insensitivity toward IVF procedures and failures, and often couples feel the pressure to produce a

child to please others (McNaughton-Cassill et al, 2000). Due to this lack of information and support, about 50% of these adults look for help by searching the internet for information, for answers, to share experiences, and to find support (Himmel, Meyer, Kochlen, & Michelmann, 2005; Haemmerli et al, 2008; Hinton, Kurinczuk, & Ziebland, 2010).

Confirming existing findings, isolation and lack of support were other themes that emerged during the interviews. Isolation was the result of a combination of factors. Feeling upset and angry at the situation often drove individuals into isolation, making it difficult to manage relationships. People would describe that they felt upset and angry on a daily basis, which affected or took away their ability to interact and enjoy others. Also, societal expectations of producing a child, along with pressure from family and friends, drove most of the participants away from others. Participants felt judged or misunderstood when trying to communicate their condition and the struggles they were having with becoming pregnant; they often faced people lacking sensitivity or empathy toward them. Additionally, this group described feeling unable to attend social activities where the presence of children, families or pregnant women could exacerbate their fragile emotional state. Consequently, many relationships with family members and friends became challenged and complex.

“It got to the point where I did not grocery shop because I did not want to go to the store where there were children. I would not go to restaurants ever because there were families there. We would watch TV, but only if my husband was actively holding the remote, and if a commercial that came on had a family, kids, anything, he would instantly change the channel. When I was out in public, if there were families or kids anywhere, I would consciously not look at them. I refuse to let my eyes connect with that person because I do not want to fill hate. I do not want to feel misunderstood. I do not want to feel different. I put all that on sacrifice because we sacrificed our social life, we lost touch with all of our friends. The few friends that we told what was going on, they just did not get it. They did not care. They were just like “Oh you will have a baby eventually.” And it is like “You do not understand what this is doing to us. It is killing us.” It would

make me furious when people go, “Hey, how are you doing?” when they knew we had just done IVF and it had failed. How could you ask me that? Our world is shattered. We do not know how we are going to go on. We do not know how, even if we found the emotional strength to go on, how we would pay for it. We are lost and angry and sad and you are just casually saying, how are you? It was maddening. We just stopped talking to people because we did not want to get that kind of treatment. I feel we sacrificed everything. We gave up everything we could give up. There was nothing left to give up except our love for God. Beside of that, we had nothing more to give up. We gave everything we had.”

“It was pretty lonely for us, just me and my spouse and I do not know whether I expected something different or not. But that was definitely an experience we had. There was not a lot of friends and family around. Some of that was by design. In case you have to go through the same process and before you get everyone excited about it you would want to believe for a good outcome. So some of it was by design but some of it was just because that is what happened.”

“So isolated, so lonely. Just cutting yourself from people and not talking about it.”

“I just pulled away and felt like I could not relate with anyone. Just feel so different and no one will understand. It is all you think about. But then if you talk about it they do not understand. So I pulled away, a lot, from people. It really does impact your relations. Even my best friend once I threw baby shower and it was hard. It is so very difficult.”

“That for me was the worst part of all the infertility because I told my husband I can go through anything, I can handle anything that life throws at me, but it would be nice if somebody was there to support me. Anything, any acknowledgement other than pretending like everything is normal and OK because I will tell you that is not normal, it is not OK. You need support. It is

impossible to survive alone. Everybody carries its burden alone. You lean on your husband and you know that you are leaning too much on him. I actually put together a list and sent it to my friends and family and they did not really respect it. It is like, "oh I did all I can do. Then do not talk to me. If you cannot follow these rules, then just do not talk to me.""

"One question that would just bother the hell out of me was, "Why do not you have any kids?" I knew they were not trying to be mean, but it just came off as like, "Really? You are really asking me that?" She would get really upset too."

"I would say it has affected my relationship with family negatively just because I can be isolative and same things for friends and co-workers. I do not share much, and then when I do I feel I am not understood, because they do not understand even though I try to share. I feel bad because they do not ask me anymore, because they know I do not want to be asked but I know that they still care. I only have another family who I talked to about this and who knows what we are going through right now because she did it."

"People say things because they feel they have to say something. It is not intentional but the dumb dumb things they say, "You should give up" and the really dumb one is "You should relax." Yes, it does not help. The only thing I wanted to hear was, "I am sorry. I love you." That is it. You cannot say anything, nothing else. Nothing is going to make me feel better."

"They tried to be supportive, but they failed miserably, and that was hurtful to me. I knew their intentions were good, they would say hurtful things."

"People either ask and you know how much you want to share and put yourself out there, and other people, other family members who are having babies, they do

not ask. You know they are looking at you or whispering about it, “How come they have not had kids yet?”

“Not supportive at all. So first it was just my mother and her comments. People knew we were trying but no support. My spouse needed more support from family members and they did not give a lot of support.”

“They all wanted to be supportive but they did not know how.”

“I think of my mom in particular, she does not get it at all. She would want me to keep doing fertility treatment. She wanted to fly me to Korea because some of her friends had success there; women over forty. I just want to say, “They are using egg donors, they are just not telling their parents,” but I do not tell her that. When I talk about adoption she says, “Oh you do not need to adopt.” So she does not understand. It is cultural. It is just cultural.”

“It was hard. My family felt like pressuring, they were just waiting for things to [happen]. It is not that they did not care it was just a lot of pressure because neither of my other sisters are going to have kids anytime soon. Both sides of parents, they were waiting and waiting and you feel you are letting people down but there is nothing that you can do; I am waiting too.”

Solution: Increase Awareness and Provide Social Support

Another way to help infertile people cope with their condition looks into increasing awareness and support. A support system is important in helping couples cope with the stress caused by infertility. Social support has been conceptualized as the mechanism by which interpersonal relationships buffer one against stressful events (Cohen & Wills, 1985). Over the years, many studies have found that social support might help prevent psychological and somatic disorders. It has been shown that support can minimize both adverse physiological and psychological side

effects among those undergoing treatment for certain medical conditions, such as cancer (Redd, Montgomery, & DuHamel, 2001), and provides a positive impact in areas such as sense of belonging, education, and having the strength to move on (Lentner & Glazer, 1991). Consequently, intervention programs aimed at offering social support have been devised to help people cope with a variety of issues, from illness, to disabilities, to loss, to relationships (Cohen & McKay, 1984).

The importance of social support for people coping with infertility is underscored by results from a longitudinal study of 38 infertile couples making the transition to permanent biological childlessness after undergoing unsuccessful fertility treatments (Daniluk & Tench 2007). Participants who received little or no support from significant others and medical personnel reported poorer adjustment 2.5 years after termination of treatments. Similarly, Wischmann and colleagues (2002) found that 15% to 20% of the individuals attending infertility clinics needed psychiatric help and over 60% intended to take up counseling. This finding indicates that couples struggle with a lack of social and institutional support from family members, friends, colleagues, and medical professionals. Therefore, perceived lack of support appears to be linked to poorer adjustment over time.

Medical staff, family and friends are often potential sources of support, however, in many cases, family and friends may respond in ways perceived as harsh, judgmental, or insensitive by the infertile couple because they do not fully understand the issues. As a result, couples often find it easier to isolate themselves from others who might not fully appreciate their hardship (Williams, Bischoff, & Ludes, 1992). Consequently, a group of peers, and led by a peer with similar issues and attitudes toward infertility, might be extremely powerful in helping couples cope with difficulties stemming from infertility and associated treatments. Group formats have proved beneficial because they offer peer support, new learning, personal insight, and stress reduction (Haemmerli et al, 2008). In a support group, participants feel less judged and better understood since the other people are undergoing similar experiences (Lentner & Glazer, 1991; Schuth et al., 1999).

Providing social support has been shown to help adults undergoing fertility treatment. In a study conducted by Dr. McNaughton-Cassill and colleagues (2000) to help couples process feelings and cognitions about the impact of infertility, and to explore expectations about future options, both women and men valued the group as a positive source of social support and stress management and underlined its role in helping them managing their stress during the treatment.

In the infertility arena, support groups started by RESOLVE are an example of this type of help offered to people (Menning, 1976). Many people found in these groups a great source of support. They build strong and lasting friendships with other women, and found it a great source of information.

“None of us were experts, but at least we were talking as someone who had been through. That is how I got so much of my information because they all had been through so much and hearing about other people’s stories made me aware of everything going on.”

“I was getting towards the end of my emotional rope, I was leaning on my husband a lot. Everyday coming home crying, falling apart and not knowing what to do. I have no friends left. I was just living this isolated life and I heard of RESOLVE from my web searching [...] I started going regularly and I made amazing friends. It was a place where I could, all the ugliness and all the hatred, I could share all that and not be judged for not being a good Christian. I could just tell them what I was feeling and I could seek advice on different treatment options or cheaper medication.”

“It was more than just supportive environment, people told you what to expect from a patient’s point of view as opposed to a doctor’s point of view. People had already had the test that I was about to go in for or had already experienced the treatment I was going in for and they were able to give you the girlfriend advice as opposed to just professionals. They told the truth. They said when it sucked or

what was not that bad, do not be scared of this, or worried about this. They also totally understood as opposed to family and friends. My husband was awesome, but no one else understands, even your best girlfriend tries to understand but if she is not going through it, and eventually once they have all had kids, they are afraid to ask you about it, they do not want to bring stuff up. So it was great. I suggest it to anyone who is open to it.”

“I finally found out about Resolve. Getting to that point was a little frustrating, because I kept asking the fertility doctors if there were places where they have other patients that are likely to speak with me about having a natural child and going through the donor process, in fact was very difficult for me to wrap my head around. It took forever but finally I had a doctor who referred me to RESOLVE. It is great to be around likeminded individuals and hear about other people struggles make you feel not so alone in the process. They were able also to hook me up or connect me with other women who had natural children and then donor. They were great sources on eliminating any concerns I have that this is my child I am carrying, and that they do not have feelings differently towards the children.”

Although extremely powerful and a great source of support, it is notable that this group is geared to women who are undergoing treatments. Although open to all, men are not participants of the meeting except during special gatherings when they organize couples' events. Additionally, a few women in this study felt somewhat out of place at times with certain support groups due to their different diagnosis or different feelings about treatments or timing of treatments. For instance women whose husbands were diagnosed with infertility, and women who had decided to stop treatments and live child-free, felt the group was not quite addressing their situations and needs. Therefore, a call for differentiated types of infertility groups is still unfulfilled. Following are some of the narratives underlying the issues:

A Man's Point of View

"I only went once to the support group my wife goes to. They had one occasion where the partners came and that was a positive experience. I also had a positive experience with my wife going to those groups even without me. I thought that was good for her even though I know it is very painful for her to talk about.."

"I did not complain about it, but it does not seem like there are infertility support groups for men. If there was one, something along the line as what women have, granted it will be different, but they talk about things. As the husband you are like, "My wife is going through all of this, what can I do? Or you know sometimes I feel completely helpless because she is having to do this stuff, what can I do? What are the things you would have done when you all get stressed out? What do you all do?" You know just talk about things. You may not get anything solved but it is like there is someone else going through what you are going through. See actually, if you can take one, you are going to take many things from your research, that will be one thing."

A Different Point of View

"I found RESOLVE after the second IVF, and I wanted to meet people who were like me, who went through this terrible ordeal and try to make the best of their lives. Get through the hard, get through this and then move on, but what the support group felt like was that this group of women is pushing each other not to give up. It felt sort of unhealthy [...] I liked that they are there for each other and if you are going through treatment I think it is good, it is great. But, maybe there is almost too much focus on the end goal being a baby [...] I felt sad that this industry is telling us we should not stop, we should not stop until we have a baby [...] I feel that not accepting infertility as a potential outcome is damaging to our society in several ways, making women and couples feel they must have a child

and that they can with new technology. I just feel it is creating a lot of unhappy people and a lot of false expectations [...] It feels that the support group was keeping up that image. It was not actually supporting people to try to be healthy and move on and do what they needed to do to have a healthy life. It was supporting them to keep trying, keep trying, keep trying. That was really sad. I felt sad because I thought it means that this is going to perpetuate. I also felt sad because nobody else out there is like me. How can I find people like me who want to try to move on with their lives, live with their hurt, but then move on? I could not find that. If there were support groups focusing on coping on this type of decision to stop treatment and just accept the situation and just move on and live childfree I would join in a heartbeat. I would be an active member. I would be a leader. I feel we do not only owe it to ourselves but society is pushing this image. Hollywood is pushing this image. It is just exhausting. These treatment centers are pushing this because that is how they are making money. In the past when science and technology could not allow many of these procedures, people got on with their lives, and I think people could have happy lives. Everybody understood that a certain percentage of couples did not have children for some reason and that was ok. But now, it is just not ok. I was very disappointed that the support groups did not accept healthy minds over having a baby.”

“I definitely feel the minority in that group because I am not doing IVF. It is not female factor for me as far as we know. So some of the women are like, “You can just get sperm somewhere and be fine. So it is not as bad as...” But a lot of the emotional components of it are the same regardless of what we are doing or how we are going through it and what caused our infertilities. So on that, there is a lot of united front and being able to talk to somebody about that. A support group that was more similar to my situation, I would really like to experience that. Yes, that would be useful. There are unique things that I feel would not be as well received by a group that is predominantly female factor infertility. Like that nagging feeling of, “If I had picked somebody else, I would not be having this problem.” That is a

horrible thought, and I judge myself a lot for that feeling because I picked the perfect guy to have kids with. I am getting everything lined up and figuring all these things out and so it then hits me all of a sudden, it is not fair. It is not fair. I worry that I have so little time left and the only reason that this is not easy is because I picked the broken guy. It is horrible; I hate that feeling. In those moments, it is just like shouting, screaming, punch the walls you know, not that I do all these things, but inside. I feel like disclosing that with women where they are the infertile one in the couple, they would feel like, "Well, maybe my husband feels that way about me because I am the "broken one.""

There are several causes, and thus different solutions that can be advocated to cope with some of the emotional challenges associated with the impacts and outcomes of infertility. Certainly, education and knowledge help anyone deal with most medical situations through understanding of the diagnoses, future related necessary decisions, and through having the ability to share with others. This researcher also advocates the need for more psychosocial counseling as part of the treatment process through developing effective psychological intervention programs. By combining education with appropriate counseling, effective interventions can be developed.

Relaxation and mindfulness training can also be beneficial to those suffering from infertility and should be considered as a useful tool in any intervention program being developed. Patient-centered approaches can help in this regard.

As noted in this section, isolation and a sense of lack of empathy creates a heavy emotional burden for infertility patients. Through more social interaction, particularly with others who have had similar experiences, patients can begin to heal on a psychological level. Support groups such as RESOLVE can provide a much-needed base of support for those experiencing infertility. Support systems have proven to be a critical measure in the healing process.

The Total System Solution

While the problems and solutions above are properly identified and solutions contain some consensus, all miss the point of looking at the Infertility Treatment Experience as a system. They assume that one problem can simply be identified, an intervention put in place, and a good outcome will result. The Infertility Treatment System indicated that this sort of thinking is naive and shortsighted. In a complex system, many things can go wrong and spiral downward in a vicious cycle. Yet while sometimes things can go wrong, they can also self-correct and create a more positive result. Assuming that one problem can be identified and paired with a solution does a disservice to all. For this reason, the entire system should be examined as a whole for each and every individual or couple involved in the process.

This researcher recommends an Infertility Treatment Experience Counselor position be created and be involved in the entire process from the beginning. They would most likely work with the Medical Staff, in essence, attaching themselves as a driver to the experience. The Infertility Treatment Experience Counselor's role would be similar to a coach throughout the process, tracking problems and finding solutions. Those seeking infertility treatments would visit the Counselor very early in the process. The Infertility Treatment Experience Counselor would interview the patient using the Infertility Treatment Experience Interview Protocol, noting in detail in which sub-affinity the patient might experience negative effects. For each sub-affinity, there are several things that have the potential to go wrong, and several possible solutions. The Infertility Treatment Experience Counselor must be an expert on how The Infertility Treatment Experience System works, and how to apply it. Once the problematic sub-affinities are identified, a Protocol of solutions would be quickly available for use.

An example of an interaction between the Counselor and the patient might be seen in a couple visiting the Counselor, noting that they are struggling through the process. During the consultation, the Infertility Treatment Experience Counselor would conduct a detailed 1-2 hour interview with questions such as - "tell me about...(each affinity)" - and the Counselor would have them rate their experience. We might also assume a scenario in which, during the interview,

the Infertility Treatment Experience Counselor notes that the couple is struggling with money, and that their relationship is strained. The Infertility Treatment Experience Counselor would bring the couple back to discuss the analysis, and an individualized plan would be presented to provide interventions and solutions to mitigate the identified concerns. Perhaps a list of financial and insurance resources and professionals, along with appropriate contact information would be provided. Additional counseling sessions would be set up to help the couple in their relationship. The intervention package presented to the couple would utilize the system to identify potential future roadblocks and concerns, and provide detailed solutions for those challenges. As interventions are put in place, the Infertility Treatment Experience Counselor would continually monitor the couple into the future and adjust the individualized plan as needed. The addition of the Infertility Treatment Experience Counselor is meant to address issues holistically, rather than one problem at a time. Through a holistic approach, the likelihood of missing negative triggers in the experience would be greatly reduced because a comprehensive, systematic and rigorous analysis would take place using The Infertility Treatment Experience System.

Statistical Discussion

Although this research was originally conceived as a qualitative study, the IQA methodology chosen for it enabled the collection of both qualitative and quantitative data, and allowed for the expansion of the original investigation, as well as to put in place a tentative mixed-method study. Mixed-method studies are gaining more attention and are becoming more used because of the strengths that each approach brings. By using a combination of interviews and surveys, this researcher was able to gather rich stories of the infertility experience, but also was able to measure participants' satisfaction with each aspect of the experience as well as with the entire experience.

Ten elements (affinities) were identified by participants of this study as main components of the Infertility Treatment Experience: Medical Staff, Diagnosis, Fertility Treatment & Process, Cost/Finances, Knowledge/Information, Treatment Outcome, Time, Empowerment/Choices, Relationships, Within each element sub-categories (sub-affinities) were identified as well as components of the main category. Surveys measuring participants' satisfaction with each of the ten affinities and their respective sub-affinities were created. Since this study was originally conceived as an exploratory qualitative study, hypotheses were not developed. Therefore, analyses conducted on the survey responses are exploratory.

Exploratory analyses were conducted using SPSS version 23.

The first step was to identify the perceptions of the participants with each element of the infertility experience. Overall experience scores from each affinity category were averaged across participants to determine which overall experiences were most positive. Although many individuals have generally negative or neutral experience with infertility, and during the interviews they recount more negative episodes, there are some aspects of the infertility process that were rated more positive than others.

Results indicating that cost and time are rated as the least positive perceived experiences perfectly align with the narratives of participants and support the qualitative findings that dissatisfaction with cost and length and pace of time spent in treatments are predominant themes. Surprisingly, results indicating that the other elements are rated as being more positive experiences do not align with the majority of the narratives. A reason for these finding might lie in the tendency of respondents to assign more positive final ratings to the categories and they tend to give a better evaluation when asked to assign a number versus when they are asked to give examples of their experiences as they applied to each of the themes.

A main goal of this investigation was to determine agreement between the specified affinities and their sub-scales as well as to determine the specified affinities and the overall infertility experience agreement.

To determine the extent to which the items in each affinity measure the same variable, reliability analyses were conducted to evaluate the psychometric properties of the scales. These analyses revealed strong associations among the Medical Staff, Fertility Treatment & Process, Cost/Finance, and Negative Emotions. For the remaining affinities, low reliability indicated that scales are not measuring the same constructs or that there might be few numbers of items in the scale.

To confirm the above findings, and to determine agreement between the specified affinities and their sub-scales, inter-item correlations were examined. First, a series of inter-item correlations were conducted to determine which items are strongly related to the overall experience satisfaction with that affinity. Results indicated that most of the inter-item correlations with the overall experience question were weak positive relationships. This denotes that, although each of the items of each subcategory is related to the overall experience, it is not just one item or aspect that determined individuals' overall satisfaction with each affinity. For example, having a positive experience with doctors will not necessarily mean a positive overall medical experience, because other factors contribute to that overall satisfaction with the medical affinity. However,

having high positive experience with doctors increases that chance that one will have an overall highly positive medical experience.

The second aim was to explore whether the “overall experience” item alone (the last question of each affinity) captures all the information obtained by the other sub-items scale. A factor analysis showed that reducing the subscales to one item would not capture as much information. In other words, each item in each subscale captures a significant amount of unique information that would be lost if the scale was to be reduced to one item. An additional factor analysis was carried out to determine whether it is reasonable to treat all the items as one scale. Based on the factor analysis, the emerging factors are not highly correlated enough to be considered one scale.

Considering that this is an exploratory study, and given that surveys were developed by the researcher to measure the constructs identified by this particular population, the above findings have provided important information for attributing some validity to these measures, so that the same surveys can be used in future applications.

These results are highly important for future replications of this study. Results indicating that each category and sub-category is capturing unique pieces of information within each specific aspect suggest that reducing the surveys to contain only the main questions, rating the experience with the overall category, would not allow gathering the same rich information of the unique aspects in each category than asking the sub-questions.

To find the relationships between each of the subscales, a series of correlations were examined. Positive emotions was significantly (positively and moderately) correlated with all other subscales, except negative emotions, which could indicate that all the other components play as a factor in positive emotions.

While it was expected that people who experienced more positive emotions were more likely to be more satisfied with all the other affinities, it was surprising to find a lack of statistical significance in negative emotions. This result contradicts the narrative of the participants, which

clearly described how distressing emotions such as stress, anxiety, anger, and depression were constant parts of each step of their experience.

However, since positive and negative emotions were not significantly correlated, it points out that in regards to the fertility treatment experience, having positive emotions does not necessarily mean the absence of negative emotions. The experience of infertility treatments is filled with mixed positive and negative emotions. In fact, many pointed out that they consistently tried to balance the stress and disappointment of the experience by leaning on their partner, keeping their hopes up, and accepting the circumstances.

Reasons why negative emotions do not result statistically significant could be due to a possible over-fitting problem due to low sample size. With small samples, there could be the chance of getting higher correlations because the variance is small due to the few points that can deviate from the fit line, with a larger sample, the error variance increases and the correlation goes down.

In order to answer the question of which components are most important for individual's rating of the overall infertility treatment, a correlation analysis indicated that overall experience is positively predicted by positive emotions, choice/empowerment experience, time, medical experience, and fertility treatment experience. All these relationships were positive, so as one increases, the other increases as well. In other words, people who experienced more positive emotions, those who were more satisfied with their choices, with the pace of treatment, with medical staff, and with the treatment were more likely to be more satisfied with the overall Infertility Treatment Experience.

A series of correlations were run to explore demographics differences.

In regards to gender, it was found that females have significantly higher positive emotions and significantly better diagnosis experience compared to males. The reason for these findings could indicate that women have higher expectations of the ultimate outcome and that they might be

more accepting of their condition. Traditionally, infertility has been labeled as a woman's condition, therefore, it is more expected that women are the one in the couple that carry the issue.

In regards to marital status, the empirical data support the qualitative finding that those who are married have significantly higher positive emotions, more positive experiences when receiving the diagnoses and better experiences with the medical staff compared to those who were not married. Being in a stable relationship might buffer negative circumstances surrounding the infertility experience.

In regards to education level, higher education was correlated with higher relationship satisfaction, better medical experience and better fertility experience supporting these relations found in the qualitative data. The reasons for this finding might be that education enables people to understand issues surrounding the experience. Higher levels of education allow one to entertain more engaging and inquisitive questions with doctors and medical staff, and might help in understanding both the medical part of the issue as well as giving some flexibility in how to find resources, information and help during the experience.

Lastly, with regard to individual income: lower individual income was correlated with higher negative emotions. This finding supports the narrative of this group. Many described how cost impacted their emotions, empowerment and decisions. For many in this sample, limited finances were the determining factor in their decision not to pursue, or continue pursuing more aggressive treatments.

One last set of correlations was conducted to explore the emotional reactions to the satisfaction (or lack thereof) with each aspect of the fertility treatment experience. It was expected that more negative emotions would be related to less satisfaction with cost, treatments, outcomes, time, choices, and relationships. Results met the expectations of the researcher except for cost.

Specifically, people who reported high level of isolation also reported low levels of satisfaction with relationships which is corroborated by the examples given during the interviews. People

who reported lower treatment satisfaction also reported higher levels of depression confirming previous finding that with repeated unsuccessful treatments and failures depression increases (Lalos, 1999; Klonoff-Cohen, 2008; Verhaak et al. 2005). Individuals' coping was positively related with satisfaction with choices and sense of empowerment. People in the study recounted that when they had some control over some of the factors and when they had access to resources they felt better equipped to face the struggles associated with the treatments. Finally, higher excitement and acceptance are both related to higher satisfaction with the pace at which the treatment is going. For most of the women in this study, time was the enemy of their biological clock and time was always associated with cost. Each time treatments failure was associated with waste of precious time and financial resources. Contrary to the expectation, cost did not yield statistical significance. Cost was negatively correlated with all negative emotions and positively correlated with positive emotions, however, no statistically significant with any of these emotions perhaps due to the small sample size..

Limitations and Future Directions

Every study comes with certain limitations, and this one is no different. Limitations provide a guidepost by which to direct future studies, or future expansion of the subject study.

Although the sample size was more than adequate for the qualitative portion, this study was limited by a relatively small sample size for the quantitative part and should be replicated with a larger sample. The small number of participants limited the statistical part of the study, impacting the likelihood of finding significance that was explored by the investigator. Additionally, a combination of low N and missing data eliminate the possibility of running more sophisticated regression or factor statistical analyses.

In addition to the sample size, the demographics of the participants lacked enough diversity. This study included mostly Caucasian, middle class people with mid to high incomes and with college educations. High income is directly tied to the possibility of pursuing treatments, and a high education level in participants could explain the reason why some of these participants reported higher satisfaction in choices, medical staff and knowledge. It is possible that higher levels of education enabled these participants to easily understand the medical side of their condition, to engage in more inquisitive and comprehensive dialogue with their doctors, to feel more confident in their abilities to seek resources and to find ways to navigate through the experience. It is important to note that it would be relevant and beneficial to look further into different income-based populations, particularly lower income adults. However, since low-income adults often do not have a regular doctor, and due to their limited resources they are less likely to inquire or consult about infertility, a new approach may be needed to recruit this population. One method could be to target, advertise and recruit individuals and couples at hospital emergency rooms since many low-income families visit with doctors not only during emergencies but also when they are ill. Another method could be to team up with other ongoing health-related studies through research centers to develop multi-level testing protocols, or even separate approaches with the same individuals. These approaches will increase both the diversity and the sample size.

It is also possible that another limitation with this population is that they may have answered the surveys more positively than expected in order to enhance social desirability. It is also possible that these people were motivated to depict themselves as well-functioning individuals despite the fact that this experience was very tolling on them. In fact, Demyttenaere et al. (1998) noted that infertility patients hide their stress because they want to show that they are functioning well both socially and psychologically. Therefore, a more complete evaluation of the patients' experiences was obtained from the interviews.

Additionally this study did not look into comparing systems generated with other populations of interest. For example, similar studies could be conducted to compare and contrast experiences of women versus men, or to compare experiences of fertile people versus infertile people pursuing a child.

Another limitation of this study was that it included participants in different stages of their journey, from the newly diagnosed, to newcomers to IVF, to people who were in treatments for years. Having a large range of experiences could impact the responses and might have contributed to the differences found between the interviews and the surveys. Newcomers to IVF might have more positive attitudes and higher expectations that in vitro will help them bear children. Usually, new patients are not aware of the difficulties associated with the procedure. With repeated tries, the treatments typically become increasingly more aggressive, and women become more aware of the possibility that they will never bear children, elevating their levels of distress (Domar et al., 1992; Kee, Jung, & Lee, 2000). Thus, this study should be replicated by comparing different experiences of people at different stages of their journey. This replication may yield different impacts within the System itself from participants at different stages as compared to results from a study that combines participants who have traveled through the entire System. It would be valuable for a future study to determine whether the System continues to hold constant by comparing populations who are at certain specific stages within the System.

As discussed prior, other ways to improve on this study could be to replicate it with samples

including other cultures and ethnicities, as well as low-income families, and a more diverse sample with a wide range of educational backgrounds. Including a larger and more diverse sample would allow the researcher to examine how environmental factors or factors external to the systems, such as culture, social class, or socioeconomic status affect the systems. For example, a person's culture's traditions and beliefs could impact the decision regarding the type of treatment to pursue or even to pursue treatments altogether.

Finally, replication of this study should incorporate a more solid mixed-methodology. Although this researcher was able to develop surveys and measure the satisfaction of the respondents, incorporating an array of questionnaires measuring depression, coping skills, and other dimensions of well-being will create the opportunity to bring more rigor into the research and gain high validation between questionnaire responses and interviews.

While these limitations should be considered, they do not, in any way, compromise the integrity of the conclusions. These limitations, if addressed, are likely to provide a richer and deeper perspective of a broader array of the representative sample.

Conclusion

Assisted Reproductive Technology and, in particular, In Vitro Fertilization, has revolutionized the meaning of conceiving, and contributed to reshaping the lives of many who otherwise would be unable to bear children. However, coping with infertility and associated treatments can be very challenging.

This study was conceived with the intent to examine and compare the infertility experience of individuals who have difficulty bearing children and/or who undergo fertility treatments. To achieve this goal, this study sought to identify the elements that make up the infertility treatment experience.

The Interactive Qualitative Analysis (IQA) grounded framework (Northcutt & McCoy, 2004) was the method of choice. Although IQA is essentially qualitative, in that it allows researchers to gain insights into people's experiences, and to draw a picture from the participants' words of how they construct their realities, this methodology also provides the opportunity for gathering quantitative data. Therefore, the use of this methodology allowed this researcher to implement a mixed-method approach. Advantages of using a mixed-method approach include increasing the comprehensiveness of the findings by showing how the qualitative data corroborated the statistical data; expanding the research by enabling investigation of different research questions; and comparing of findings from each method to check for consistency and increase methodological rigor (Chow, Quine, & Li, 2010).

Fifty individuals who were experiencing infertility and were undergoing treatments, or had already been through treatments, were originally recruited. Participants were recruited using flyers placed in medical clinics, as well as advertising online and through the RESOLVE community (a national infertility support group). About thirty of these people participated in three focus groups. The first two focus groups were designed to identify the elements of the infertility treatment experience. A third focus group was used to refine and validate the final

categories' names, and provide data for sub-categories.

Analysis of the data gathered in the focus groups revealed ten main categories that make up the infertility treatment experience. These categories, called Affinities in the IQA methodology, are: Medical Staff, Diagnosis, Fertility Treatments & Process, Cost / Finances, Knowledge / Information, Treatment Outcomes, Time, Empowerment / Choices, Relationship, and Emotions. Each one of these categories comprised a series of sub-categories. For example, the affinity labeled Time includes Years Trying, Schedules / Cycles, Waiting, and Biological Clock. Each Affinity was also comprised by sub-affinities. A total of seventy-six sub-affinities were identified.

Using these ten elements, their respective seventy-six sub-affinities, and the Overall Infertility Treatment Experience the research team developed surveys and a semi-structured interview. The interviews provided participants' rich stories about each affinity and how they relate to each other, while the surveys measured satisfaction of experiences with each of the affinities and their respective sub-affinities. Theoretical coding of the affinities, and their relationships, allowed to build a system made of the affinities and their interactions. In this system, the relationships connect all the elements so that change in one affinity leads to changes among all affinities, and in the system itself.

Thematic analysis of the System's elements, and their interactions, enabled this researcher to pinpoint the more difficult aspects of both the condition and the process, and therefore contributed to the understanding of the quality of treatments, as well as the quality of experiences. Examination of the system, in several ways, provided insight and solutions into common problems and allowed the researcher to identify how certain conditions could produce positive outcomes in the system. These positive outcomes can be used to draw conclusions and develop solutions and intervention programs geared toward improving the overall Infertility Treatment Experience.

This study revealed some very interesting points that may not have been obvious prior to the

results becoming clear. Medical Staff showed itself as the most important Affinity of the Infertility Experience System, with Costs as a close second. All drivers and influences produce outcomes as the Emotions and Relationships.

The System produced three “Loops,” each with its own drivers and influences. The Clinical Loop, consisting of the medical process, creates an influence on the Infinity Struggle Loop, which primarily revolved around costs of the infertility experience, both monetary and non-monetary. These two Loops impact the ultimate outcome, The Roller Coaster Loop.

Positive experiences with the critical Affinities, such as Medical Staff, can lead to an overall positive experience, while negative experiences can produce the contrary affect.

While there are limitations to this study, there are also very tangible elements that one can take away and consider as they experience infertility treatments. The infertility experience is already highly emotional, and the emotions impact one’s relationships directly. While not the only element of a relationship, the heightened sensitivity of infertility can have an acute influence, negative or positive. Given the various drivers and influencers of the System, the study makes clear that having a positive experience with one’s Medical Staff can directly impact one’s relationship with their spouse, family and friends, therefore, fertility clinics and medical practitioners should understand that their role is not only that of medical treatment, but also an influencer of the psychological well-being of patients, couples and their social networks. As one solution, patient-centered treatment regiments should be developed to include not only medical considerations, but also psychological treatments as well. It is clear that education and knowledge also play a role in any patient-centered treatments, as empowerment through knowledge is a critical element of the System, greatly influencing patients’ emotions and relationships.

Medical Staff also should be alert to the need to balance initial and less-aggressive infertility treatment methods with the realities and probabilities that a patient may be experiencing. Participants of this study noted that doctors continued to attempt the lowest impact treatments,

often IUI, several times, only to find out later that this time and money should have been better spent directly through more aggressive treatments, or even alternative options, including adoption or surrogacy or even the harsh reality of choosing to stop pursuing a child. Almost as important an element as cost is time. Manifesting itself through the relentless biological clock, or even time spent in the emotional roller coaster, reality-based treatments should greatly consider the impacts that Time has on the overall experience.

Clearly this study highlighted that monetary and financial concerns need to be addressed going forward. Lack of access to capital creates hardships, particularly given the sometimes cost-prohibitive nature of treatments. Very few people have limitless access to capital to fund necessary treatments, and in fact, the financial burden is often very acute, as seen in the System. Access to capital can be pursued through access to more infertility coverage in insurance plans, either through voluntarily-provided coverage in an employer's plan, or even through government-sponsored plans. Lobbying for insurance coverage can be a takeaway of the study for interest groups or individuals seeking more access to capital. Otherwise, active engagement by Medical Staff with the patients to help seek out grants and loans can be very helpful, and provide positive influence in the overall System.

The System is not only to be used by those undergoing treatments, or developing new programs, instead, it can and should also be used by family, friends and others within the social network of those undergoing the treatments. One clear obstacle to experiencing positive emotions is that others are not understanding of the psychological and physiological impacts that the infertility experience has on those getting treatments. Having positive interactions with a broad social network can be one of the more important overall tools that a patient may have, and those individuals can assist them through empathy, knowledge and interactions. Understanding the System, and the intersection of the elements can help raise awareness among the public in general, and provide for positive outcomes.

This study is only one step toward the continued development of the Infertility Treatment Experience System, and clearly is able to be refined in the future, either by this researcher, or

others. Replication of this study is advisable in order to ensure that the System holds true with a larger sample size. As seen in the Limitations section, more exploration of a broader and more diverse demographic, both race and ethnicity as well as socio-economic status, could be pursued to optimize the impact of the participants' results. Furthermore, more consideration should be given to developing more inputs from males, and determining how, if any changes exist through a gender-specific perspective.

Previous studies, both qualitative and quantitative, have identified some aspects of concern and produced work on single elements of infertility. For example, a plethora of studies underline the psychological side effects of infertility and call for psychological counseling therapies. Few studies look into costs associated with treatments or diagnoses of treatments. The majority of the research is geared toward the medical aspects of the issue, and they are exclusively quantitative. In fact, many of the qualitative work is from overseas. No study has gathered this type of information from the participants' points of view and built a system that allows the visualization of the conditions within each element of the experience, noting the elemental interaction, and pin-pointing solutions to ameliorate various negative conditions and concerns. This study identifies the specific elements and their interactions among the others, and it opens the way to future research investigating each element alone as well as together.

In addition to paving the way for future investigations, this study offers the opportunity to create a new important counseling professional position (The Infertility Treatment Experience Counselor) missing in the field. By utilizing the interview protocol, and the System, this research allows one to develop a package of solutions that can be used to help individuals and couples undergoing treatments. Specifically, an intervention checklist can be developed using all the affinities and sub-affinities, and it can be used when counseling infertile people to identify where targeted problems or concerns lie. Then a list of solutions can be targeted based on the particular needs of the patient. Finally, a package offering a plan that addresses the issues, and that specifies ideas and solutions can be customized for each consultation.

A very important point to remember is that, although problems within an affinity seem to be individual problems for which to find single type of solutions, the experience needs to be looked at, and evaluated as a whole. In a system, all the relationships among the affinities are interconnected parts of a whole, so a change in one part leads to changes among all parts, and in the system itself. In the Infertility Treatment Experience System there are 10 affinities, 76 sub-affinities, and the one Overall affinity. Thus, when consulting, there are at least 87 total elements that need to be analyzed to fully understand the whole picture of a person. This means that there are at least 87 data points to consider throughout the entire experience, and the job of a counselor would be to understand what can go wrong in any of the elements and to effectively be able to find solutions for each problem to improve the experience. New programs, educational tools, psychological treatments, financial and psychological counseling, as well as many other solutions discussed herewithin can be addressed by using the System and by creating new positions and staff dedicated to a more patient-centered, solutions-based methods to help patients throughout the nation, and to target all demographics and populations.

This Dissertation study is a groundbreaking approach to an emerging medical and psychological issue of increasing importance throughout America, and across the globe. Through the identified Infertility Treatment System, we are able to develop solutions and approaches to future programs and interventions. The Study will, no doubt, be expanded upon in the near future.

APPENDIX A: OVERVIEW OF INTERACTIVE QUALITATIVE ANALYSIS PROCESS

by Norvell Northcutt and Danny McCoy

Northcutt, N. and D. McCoy, (2004), "Interactive Qualitative Analysis: A Systems Method for Qualitative Research," Sage Publications.

McCoy, Danny. *Interactive Qualitative Analysis: How to do Qualitative Research* Unpublished Manuscript 2014.

The following, subsequent descriptions of methodology were written by and used with the permission of Northcutt and McCoy.

IQA Methodology

What is IQA?

Developed by Northcutt and McCoy at The University of Texas and published in their groundbreaking book, *Interactive Qualitative Analysis: A Systems Method for Qualitative Research*, Interactive Qualitative Analysis (IQA) is a systems approach to qualitative research, which seeks to advance upon phenomenology and grounded theory. Where grounded theory falls short, IQA picks up with systematic, protocol driven procedures and the ability to draw a system of influence. IQA utilizes protocols to develop research design, identify themes and draw systems. IQA was developed to take the mystery out of research and to provide graduate students with a tool chest for dissertation research. IQA integrates the identification of the nature of the problem with solutions, even when you are not sure what the problem is.

IQA is the art of seeing what is invisible to others and naming it. IQA identifies connections between all causes of a problem with the ability to draw a system of influence, an easy to understand visual representation of the phenomenon. IQA integrates the identification of the nature of the problem with solutions, even when one is not sure what the problem is.

IQA also reconciles quantitative TQM rigor to a qualitative design of data collection and analysis. IQA seeks to capture the lived reality of people, actively involving participants in the mapping of their stories. IQA identifies relationships among self-identified components of an issue. IQA integrates the identification of the nature of the problem with solutions, even when you are not sure what the problem is. IQA builds consensus among the focus group participants. IQA builds strategies around the nature of the problem.

The purpose of an IQA study is to allow a group to create its own interpretive “map” then to similarly construct individual “maps” of meaning: together, the two levels of meaning are used by the researcher as the foundation for interpretation. The “map” is represented as a system of states (affinities) held together by roadways (relationships among affinities). In plain language, an IQA study prompts the participants to examine these issues with respect to a phenomenon important to them:

- ◆ What does this mean to you?
- ◆ What led to this?
- ◆ What are the results?

IQA begins with a group process methods adapted from the Total Quality Management (TQM) movement to produce and analyze qualitative data. IQA seeks on the one hand to capture the "lived reality" of people and involve the participants in the study in the meaning of their stories, the identification of constructs and relationships, and the development of theory; and on the other hand to produce high-level abstraction of this reality that captures the participants' "cognitive map" or their "theory in perception."

The systems perspective views relationships as interconnected parts with the whole being greater

than the individual parts. Change in one part, leads to changes among all parts and the system itself. IQA combines the tradition of phenomenology, which asks what is the structure and the essence of the experience of the phenomenon for the people in the study, and systems theory whose central questions is: how and why does this system function as a whole. So IQA asks two broad questions: 1) What are the dimensions of the phenomena from the participants' point of view; and 2) How do the dimensions relate to one another?

The dimensions are the result of both inductive and deductive group processes and are called "Affinities" or textual references or terms related around a common meaning or theme. After Affinities are defined by being grouped inductively (from the particular to the general) and then assigned a range of meanings deductively (from the general to the particular), their relationships are explored systematically to produce a comprehensive picture. The analysis of the textual data is done by three kinds of coding activities and the participants both generate the data and analyze it.

A theoretical framework will emerge through the coding activities of the participative research method. This theoretical framework will depict a "theory of action" or a "theory-in-use" or what the participants actually experience.

Hence, IQA is a method of qualitative research, which relies upon group processes, interviews, and observation to understand and explain naturally occurring phenomena in a naturally occurring state. In addition, data collection and much of the data analysis are socially constructed by the participants under study; resulting in a theory grounded in the data. The collaborative nature of the processes helps manage the influence of organizational politics and protects minority voices and perspectives.

IQA seeks to balance the paradigms. IQA is an approach to qualitative research that attempts to integrate and reconcile some of the disjuncture in theorizing about the purposes and methods of research.

IQA is the art of seeing what is invisible to others and naming it. IQA identifies connections between all causes of a problem with the ability to draw a system of influence, an easy to understand visual representation of the phenomenon. IQA integrates the identification of the nature of the problem with solutions, even when one is not sure what the problem is.

Understanding a System

Systems have two components: *elements* and *relationships among the elements*. The elements may be as disparate as physical objects (parts in a manufacturing process, for example), mathematical constructs (acceleration, profit, loss, or IQ, for that matter), or for the purposes of this approach to qualitative research, categories of meaning. Understanding a system means:

- ◆ Identifying the elements of the system
- ◆ Describing the relationships among the elements
- ◆ Understanding how the elements and relationships dynamically interact to result in different *states* of the system, which implies
 - Interpretation – What is the nature of the unity represented by the system?
 - Making intrasystemic inferences – What are the logical effects of changes of state of some elements on others?
 - Making extra-system inferences – Analyzing the effects of outside influences (interventions) on the system – What may we logically expect the effects of extra-systemic effects to be?

The three major inquiries above apply to a single system. By *single system*, we mean the systemic representation of a phenomenon from one person or group's viewpoint. If we have more than one system, a fourth very useful inquiry is possible:

- ◆ How do two (or more) systems compare in terms of elements and relationships, and what are the interpretive implications, both intra- and extra-systemic, of the comparison?

IQA Phases

IQA research flow has four distinct phases: Research Design, Focus Group, Interview, and Report (Results/Analysis and Interpretation/Implications). Research Design provides a series of tools to help articulate problems of interest, to identify constituencies that have an interest in the problem, and to state research questions that are implied by the problem statement. IQA then uses focus groups to identify the “map pieces” (affinities) of a system or systems that will ultimately represent the group's experience with the phenomenon. The group next identifies the “states,” or the relationships between each of the affinities. Using a set of protocols or rules stemming from IQA systems theory, a system is drawn that represents a “mind-map” of the group's reality. Affinities defined by the group are then used to develop a protocol for interviews, which are invaluable in to further explore the meanings of the affinities and their systemic relationships. A comprehensive system diagram is developed from the interviews to explain the phenomenon. The final report allows the researcher to describe the affinities and their relationships, to make comparisons among systems and individuals, to make inferences (predictions) based on the properties of the system(s). Following is a summary of each of the stages in the research flow.

Research Design

- ◆ Identify the “problem” or phenomenon of study (what you want to study)
- ◆ Identify the constituencies (who you want to study)

- ◆ Identify comparisons (for strength of analysis)
- ◆ Produce an Issue Statement and Focus Group Warm-up Exercise

Focus Group

- ◆ Identify themes or “affinities”
- ◆ Draw a crude system
- ◆ Produce an interview protocol

Interview

- ◆ Obtain rich descriptions of each theme
- ◆ Obtain rich descriptions of each relationship
- ◆ Identify relationships between each theme
- ◆ Produce a system

Report (Results/Analysis and Interpretation/Implications)

- ◆ Describe each theme
- ◆ Describe each relationship
- ◆ Describe the system
- ◆ Compare groups
- ◆ Make predictions
- ◆ Identify other theories that resemble or support the researcher’s findings

It is important to note that each of the phases in the IQA research flow is represented by a protocol, and each protocol is supported by a document or set of documents, resulting in a public data collection and analysis audit trail for the entire study. In other words, issues of credibility and trustworthiness are addressed at least in part not only by a standard analytical protocol that is dependent neither on the subject matter (the nature of the affinities) nor on the inclinations of the researcher, but by the standardization and documentation of each step in the research process. Below is a system summarizing the phase of an IQA study. Note that for each element in the research flow, which represents a particular protocol in the first system diagram, there is a supporting document or a set of documents that serves two purposes: First, an audit trail of both data gathering or generation and analysis is created, that is, open to public inspection; and second, information and analytical results from each step feed to the next.

IQA Research Flow

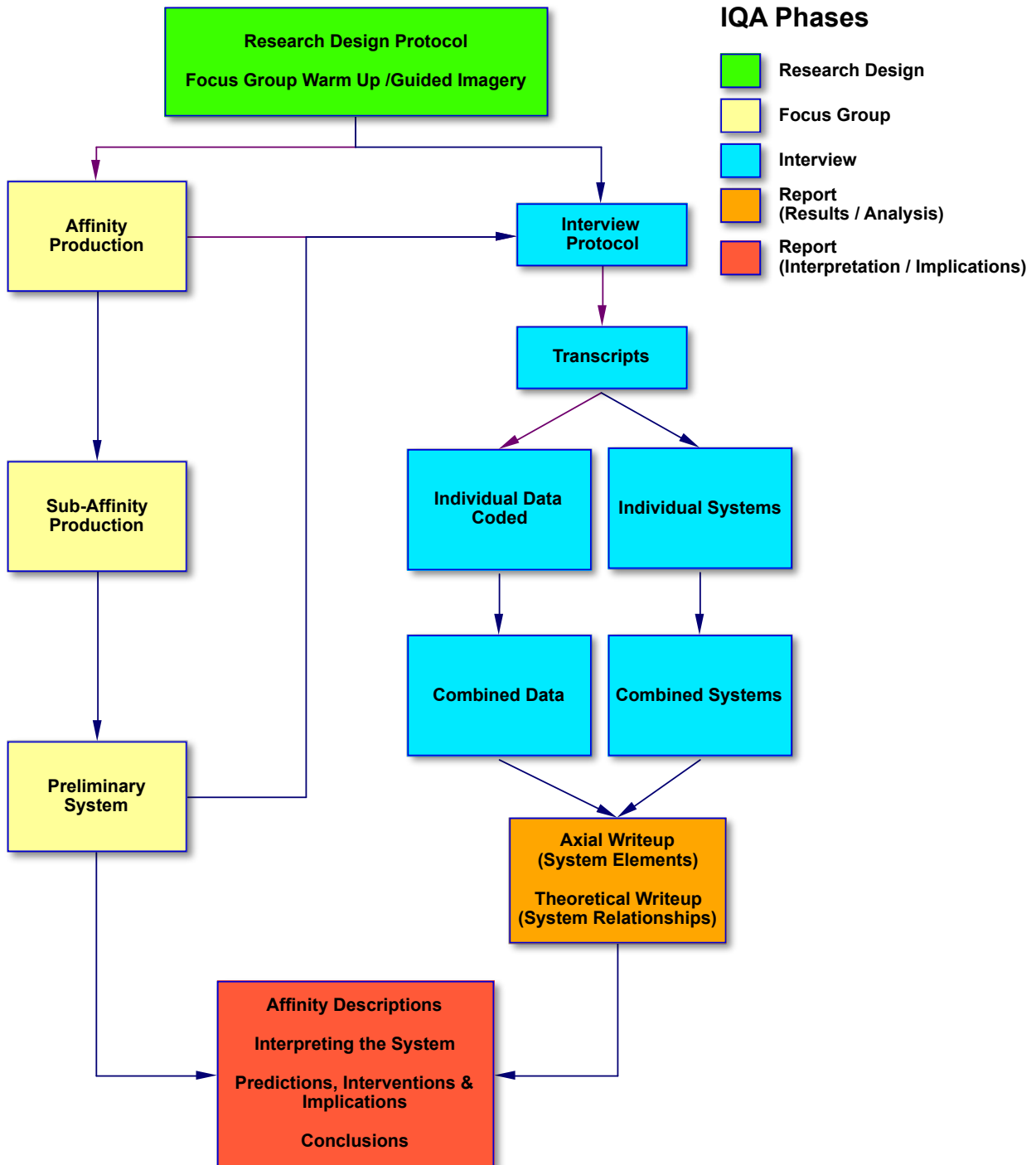


Figure A1: IQA Research Flow

IQA Research Design

Thinking about the design for a study typically begins with a problem statement, which at the early stages of design may be no more than a vague concern; a desire to know more about an ill-defined and poorly-understood phenomenon; or a need to correct or ameliorate a situation, the nature of which is not fully circumscribed. This initial lack of clarity is probably the most difficult hurdle for researchers to overcome, and the literature from both the quantitative and qualitative streams tends to give this element of research design less than meticulous attention. If the collection (or generation, or creation, depending on one's point of view), analysis, and interpretation of qualitative data can be approached from a systems point of view, it follows that the question of how to think about doing qualitative research can itself be the subject of an IQA systems analysis.

IQA research design starts with what is traditionally called a “problem.” By “problem” we mean nothing more dramatic than an issue someone thinks is either interesting or needs attention. Often at this stage, a solution to some perceived problem is sought, but it is difficult to articulate what the problem really is. By its very nature, the problem is not clearly defined at this point. Rather than simply demanding that the problem be made explicit or simply hoping that a well-defined problem will somehow rise from the chaos of our activity, the IQA research flow presumes that ambiguity is a characteristic of the early thinking about a project and deals with this ambiguity, reducing it with every recursion around the IQA design cycle. IQA research design starts with the vague problem and seeks to identify those who have something to say about the problem (constituencies) and what question to ask them (an issue statement). Next research design seeks to identify comparisons of constituencies useful to understanding the phenomenon.

There are three universal research questions. It might be useful at this point to restate the section above, which describes the issues that may be addressed through systems representation of phenomena, in more conventional language. If we have only one system, two research questions are possible:

1. What are the components of the system?
2. How are the components related to each other?

If we have a minimum of two systems, then a third question can be asked:

3. How do the systems compare?

Note that the three questions are in a requisite sequence. One cannot answer a question about relationships without having first identified the things (components) that are in relationship to each other. Neither can the third question be answered unless the first two have been addressed with respect to at least two systems.

IQA research design is not conceived of as a linear get-it-right-the-first-time process; rather, it is circular in nature, as implied by the process graphic, which is shown below. However, while going in circles is a metaphor for getting nowhere, the recursive feature of IQA design allows for successive refinements of each of the following:

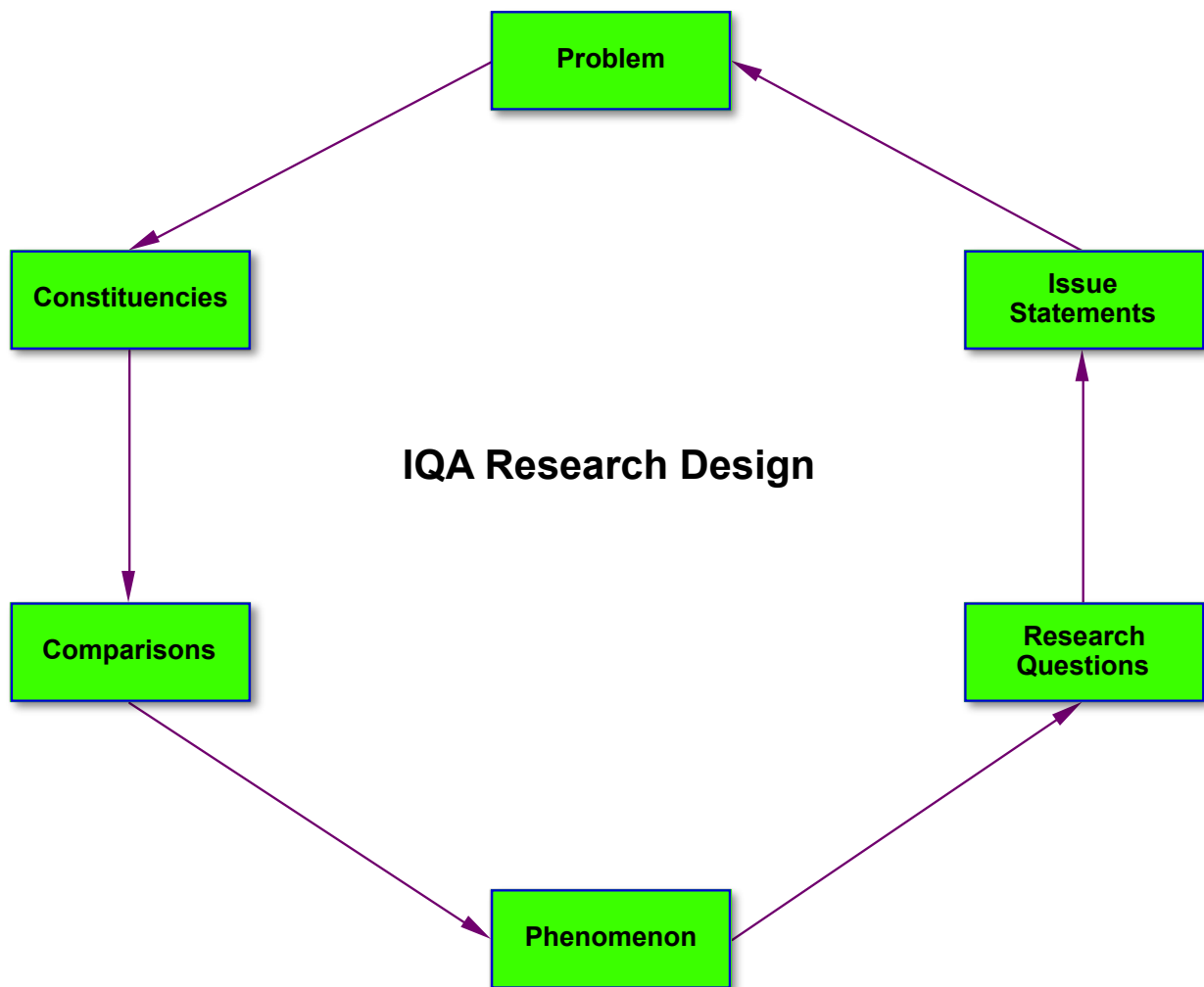


Figure A2: IQA Research Design

Problem - The problem reflects a simple observation or concern that the researcher is interested in further exploring. The problem seeks answers to *How* and *Why* questions.

Constituencies - Constituency is a term reflecting both an interest (perceptual or phenomenological distance) and power over the phenomenon, which is at the center of the problem. A constituency is anyone who

- ◆ Has something to say about the phenomenon
- ◆ Can do something about the phenomenon

Comparisons – Comparisons generate research questions.

Phenomenon - The phenomenon is an abstract idea (but a simple name) capable of producing a system with elements and relationships that not only describe the phenomenon, but how it works.

Issue Statement - Different constituencies have different perspectives on the same phenomenon, so the issue statement must be meaningful to each. The issue statement is quite simple and is always a variation of *Tell me about the phenomenon* but it must be presented in terms that are real to a given constituency. The issue statement is the question we ask to get the audience to speak about the phenomenon.

Research Questions – There are three universal research questions. If only one constituency is involved two, and only two, questions can be answered from a systems point of view:

1. What are the elements that make up the Phenomenon?
2. How do these elements relate in a system of influence?

If more than one constituency comprises the study, a third systemic inquiry is possible:

3. How do the experiences of constituency 1 compare to constituency 2?

Research Design Protocol

Problem		
Scenario		
<i>Identify the Scenario. The Scenario outlines a simple observation or assumption for which the researcher is interested in knowing more about.</i>		
Role of the Researcher	Purpose of the Study	
<input type="checkbox"/> Academic Researcher	<input type="checkbox"/> Academic Research	
<input type="checkbox"/> Graduate Student	<input type="checkbox"/> Dissertation	
<input type="checkbox"/> Consultant	<input type="checkbox"/> Solving a Problem	
<input type="checkbox"/> Internal Organization Research	<input type="checkbox"/> General Understanding of a Problem	
<input type="checkbox"/> Other _____	<input type="checkbox"/> Other _____	
Readers/Users of the Study Results		
<i>Identify any potential readers or uses of the results of the study and why they will need it.</i>		
Problem Question		
<i>Identify the Problem Question. The Problem Question reflects a simple observation or concern that the researcher is interested in further exploring. The Problem Question often takes the form of a how or why question.</i>		
Domain		
<i>Identify the Domain. The domain reflects the very general topic or area in which the problem resides.</i>		
Potential Causes of the Problem or Success		
<i>Brainstorm potential causes of the problem as possible.</i>	<i>Do not censor your ideas.</i>	<i>Identify as many as possible.</i>
◆	◆	◆
◆	◆	◆
◆	◆	◆

Constituencies		
Constituency	Distance (Close to Far)	Power (High to Low)
Individual		
Intermediary		
Authority		
Comparisons		
Individual	VS.	
	VS.	
Intermediary	VS.	
	VS.	
Authority	VS.	
	VS.	
Cross Constituency	VS.	
	VS.	VS.

Phenomenon		
Constituency		Phenomenon
Location of Events		
Individual	Intermediary	Authority
Where Does This Take Place?	Where Does This Take Place?	Where Does This Take Place?
◆	◆	◆
◆	◆	◆
◆	◆	◆
Range of Time		
Individual	Intermediary	Authority
When Does It Take Place?	When Does It Take Place?	When Does It Take Place?
◆	◆	◆
◆	◆	◆
◆	◆	◆
Constituency	Research Questions	Issue Statement
	3. What are the elements that make up <u>the Phenomenon</u> ? 4. How do these elements relate in a system of influence? 5. How do the experiences of <u>constituency 1</u> compare to <u>constituency 2</u> ?	Tell me about <u>the Phenomenon</u> .
	1. What are the elements that make up <u>the Phenomenon</u> ? 2. How do these elements relate in a system of influence? 3. How do the experiences of <u>constituency 1</u> compare to <u>constituency 2</u> ?	Tell me about <u>the Phenomenon</u> .
	1. What are the elements that make up <u>the Phenomenon</u> ? 2. How do these elements relate in a system of influence? 3. How do the experiences of <u>constituency 1</u> compare to <u>constituency 2</u> ?	Tell me about <u>the Phenomenon</u> .

Final Answer	
Problem:	
Constituency:	
Comparisons:	
Phenomenon:	
Research Questions:	
Issue Statement:	

IQA Focus Groups

Focus Group Warm-up Exercise

The final result of the IQA Research Design Phase is the Focus Group Warm-up Exercise. This protocol is used in the Focus Group Phase and uses guided imagery to ask the constituent groups to think about the phenomenon and provide a “dump” of thoughts.

IQA studies usually begin with a focus group, which is a group of people who share some common experience, work or live within some common structure, or have a similar background. This definition suggests that the researcher should think first about commonalities rather than differences when designing the composition of the group; IQA focus groups are formed with groups of individuals who may certainly have varied opinions and experiences with the system under study, but who more critically share a common perspective.

The Focus Group Phase of IQA begins with a guided imagery exercise using the Focus Group Warm-up Exercise produced in the Research Design Phase. From the researchers prospective, the IQA Focus Group Process is designed to identify the themes or affinities that make up the phenomenon. The focus group is asked to reflect on their experiences of the phenomenon and give a “dump” of all thoughts. The researcher next facilitates a “clumping” and “naming” exercise in order to identify the affinities. The final result of the Focus Group Phase is to identify the affinities that will be used to develop the Interview Protocol.

Focus Group Warm-up Exercise

I would like you to think for a while about the phenomenon—Very brief definition of the phenomenon

In a few minutes, I am going to ask you to tell me about your experience with the phenomenon.

So let's begin.

- Please allow yourself to be as comfortable as possible.
- Put your thoughts from the day aside to allow your attention to focus on the phenomenon.
- Close your eyes to increase your state of relaxation and your ability to focus on the phenomenon.
- Now imagine yourself in the environment of the phenomenon. See yourself in all of the places the phenomenon occurs. (long pause)
- Imagine yourself in the time frame the phenomenon occurred. (long pause)
- See all of the places, events and people the phenomenon. (long pause)
- See yourself engaging in the activities of the phenomenon. (long pause)
- Notice your surroundings. (long pause) Looking around you, take in the sights, the sounds that are associated with being in the environment of the phenomenon. (long pause)
- Allow yourself to become aware of your environment with all of your senses.
- Focus on what it feels like to be totally absorbed in the environment of the phenomenon. Be there in your mind. (long pause)
- Review all your recollections up to this moment. (pause)
- Allow all these thoughts to remain calmly in your consciousness and ready to be revealed.

Thank you for allowing these valuable observations and recollections to come forward.

Please allow yourself to gently allow your consciousness back to this time and place and when you are ready, open your eyes.

Good. Thank you.

And now, with all that you remember—and that is all that you just noticed—please write down your thoughts on these cards.

Write one thought or experience per card. Feel free to record a word, a phrase, a sentence, or a picture to capture that thought . . . and. . . Tell me about the phenomenon.

Identification of Affinities

The first step for an IQA focus group is silent brainstorming. During this phase a focus group is asked to write their experiences about the subject on note cards, one thought per card. After producing as many cards as possible, the focus group is asked to tape the cards along a wall. The researcher reads each card and the group comes to a consensus as to the meaning of the card, thus the foundations are laid for constructing, through discourse, a shared reality among group members. The facilitator then asks the group to silently organize the cards into groups of meaning, an activity referred to as inductive coding. Grouping is followed by the affinity naming and revision phase (axial coding), which consists of giving a name to the group (affinity) and sorting any cards that may have been mis-categorized into the proper group.

IQA data collection/analysis techniques originated from Total Quality Management (TQM) processes designed to capture knowledge from organizational members to solve problems and improve processes. A major TQM assumption is that people who are closest to the job best understand what is wrong and how to fix it. Similarly, IQA data collection techniques assist members of a group close to a phenomenon of interest in describing and labeling their experiences, and in articulating perceived relationships among these experiences to produce a theory in perception or a conceptual map, which is a systems representation of how a person or a group understands a particular phenomenon. This system consists of categories of meaning called *affinities* and the perceived causal relationships among the affinities.

The first step in creating a mind map is to assist the focus group members in organizing their thoughts into a manageable number of categories or affinities, sets of textual references that have an underlying common meaning or theme, synonymous to *factors* or *topics*. During affinity production, the constituents are given an opportunity to reflect upon their experiences and then express their thoughts and feelings. The thoughts of the group as a whole are combined and organized into common themes or affinities by the group itself with the aid of a facilitator. The group collectively names the affinities and helps the researcher create a detailed written description or definition of each affinity. The goal is to produce the smallest number of affinities with the greatest amount of detail or “richness.”

Axial coding seeks to name, reorganize, clarify, and refine the affinities. While the first kind of coding is, as the name implies, almost exclusively inductive, axial coding cycles back and forth from inductive to deductive. Once the affinities are refined and often reorganized by the group participants, they are encouraged to narrow down the meanings of the affinities and their categories. Major categories of affinities are reviewed and then may be combined or divided into hierarchical systems of sub-affinities.

An affinity name is a general term that represents an experience to a particular group or individual when probed. The purpose of an affinity is to explore the range of meaning to any one group. An affinity typically has a range of meaning as well as a range of timbre. Further, both the meaning and timbre are not necessarily unidimensional (such as temperature, which can range

only from hot to cold) and therefore can require sub affinities that exist in multiple dimensions. A common example is emotions. Emotions may have a range of timbre described by the group as positive (happy) to negative (sad). At the same time, there are possibilities of sub affinities within this affinity that show a range of meaning: such words as “frustration” “ecstasy” and “challenging” all point to differences in meaning as well as differences in timbre.

Once again, this process is achieved through group discussion and consensus. The descriptions are refined and narrowed by the group until each participant agrees that the definition accurately reflects the meaning of the affinity. Affinities are given titles that accurately reflect the meaning of the affinity. Affinities are given titles as determined by participants, which are documented on header notepads and placed at the top of each vertical column. An example is provided below.

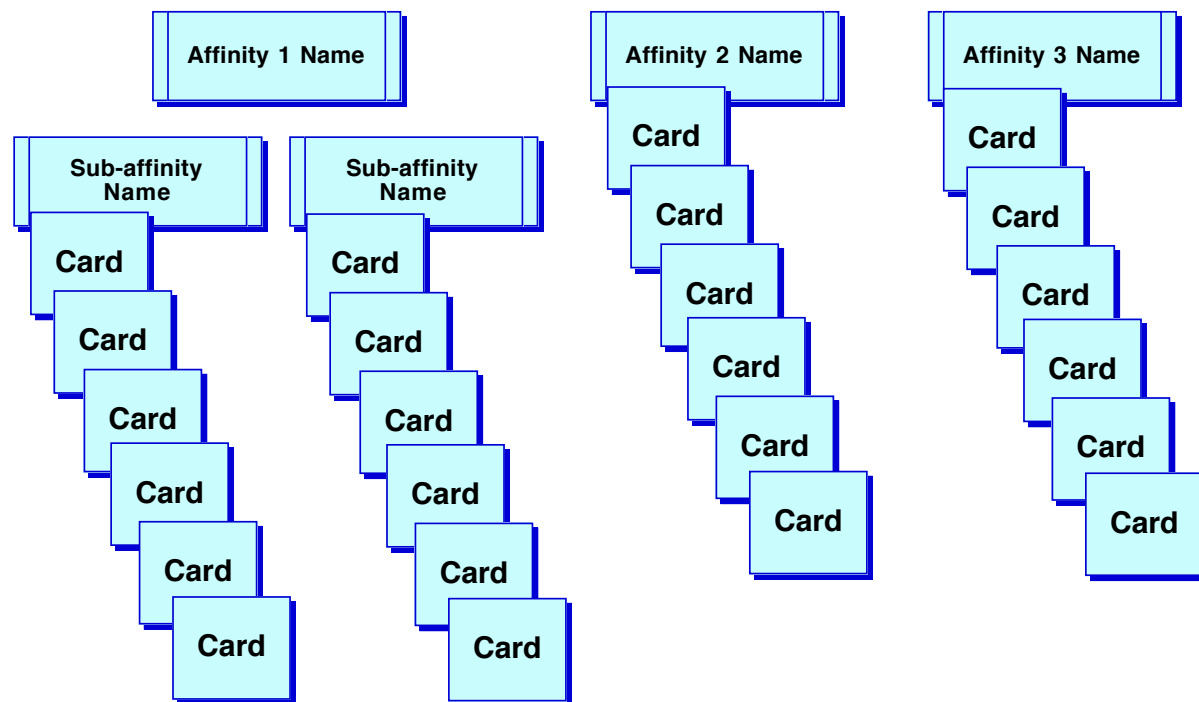


Figure A3: Affinity Naming

Renaming and Reconciling Affinities for the Interview Protocol

Renaming affinities is often necessary when using focus group work to build an interview protocol. Sometimes focus group affinity names are either too specific or metaphorical, or too abstract: in either case, the focus group name acts as a barrier rather than a facilitator to communication with an audience. For example, sometimes the group may put a qualifier on an affinity name. A very common one is “negative emotions” or “positive emotions.” The two “affinities” are much more usefully and accurately represented as two subaffinities of the more general category of “emotions,” as are other labels such as frustration, anger, fun, and happy. As another example: A focus group produced the category (among others) they called “external context.” An interviewee who did not participate in the focus group, when asked to talk about

“external context” within the general subject of student achievement would probably have no idea of the reference for the name. An Affinity name should be simple enough to immediately trigger a response with a minimum of explanation by the interviewer. In this sense, the “best” affinity name requires the interviewer to say nothing other than, “Tell me about (affinity name)”.

The whole idea of IQA is to allow members of a constituency to define the meaning and the range of the elements of the phenomenon and to articulate how these elements are connected in their understanding of the phenomenon. The researcher only facilitates drawing descriptions out of the group and organizing the descriptions into similar chunks: therefore, affinity descriptions in an interview protocol should only help to define the name and not indicate a “preferred” timbre or meaning of the category. A good affinity and description is a neutral presentation: It avoids any bias and does not lead the respondent down only one timbre path. For example, if you ask graduate students “Tell me about stress,” they will tell you all about stress as a graduate student. But if you say, “Tell me about emotions,” graduate students will tell you about stress, anxiety, fear, satisfaction, enervation, exhilaration, and perhaps even about even a few moments of contentment and relaxation. Leading a respondent down too narrow a path will rule out the possibility of describing all the other paths. A good affinity allows for the full range. A particular group may only experience one path, but that is what research often is about, to identify how one group compares to another. Ask a group of graduate students who are at risk of quitting about emotions and you will probably get an overwhelming set of negative descriptions, but a group who are about to graduate will very likely have a different understanding of negative emotions while at the same time remembering some as satisfying or happy

Some may fear that some affinities may be overlooked by the focus group. There is nothing wrong with adding additional affinities to the system if it gives more explanatory power to the topic. IQA recommends conducting 2 focus groups with different participants who are members of the same constituency and reconciling the two sets of affinities. Often the researcher will note that both groups generate nearly the same affinities. Naming may be different but affinities could be paired off as having the same meaning. On occasion, one group might identify an affinity, whereas the other group might identify a category of meaning that they believed to be a sub-affinity, or the dialectic, of a larger category of meaning. While many of the affinities may have the exact same name between both groups, there may be a few that on first appearance seem to be unique to one group. In order to check to see if an affinity is unique to just one group, the researcher must go back to the cards to see if there were any references to that affinity in the other group. The researcher must reconcile whether it was an affinity or sub-affinity, the two groups had produced similar categories. The researcher resolves the issue by compiling a new affinity list that took into account both focus group responses.

Identification of Sub-Affinities

Sub-Affinities can be developed as a part of interview transcript analysis or through additional focus groups. To identify sub-affinities using interview transcripts the researcher conducts the interviews based on the affinities. Transcripts are examined and each affinity is coded to identify sub-affinities. Conducting additional focus groups may also be used to identify sub-Affinities. Using the same guided imagery process used to identify affinities, the researcher asks *tell me*

about each affinity. Cards are generated, sorted and names. The process is repeated for each affinity.

Interview Protocol

The final result of the Focus Group Phase is to identify the affinities to be used in the Interview Protocol.

IQA Interviews

IQA Interviews

The IQA interview is a semi-structured interview. It is designed to capitalize on the consistency afforded by highly structured interview and the level of detail offered by open-ended or emergent interviews. The interview questions are designed and based on the affinities developed by the focus group members. An IQA interview protocol is designed to achieve specific objectives, each of which relate directly to the research questions of the study. The affinities produced by the focus group are used to create an interview protocol. The interview protocol is used to elicit descriptions of affinities created by the focus group and to identify and elicit descriptions of relationships among the affinities. In particular, IQA interviews serve to:

- ◆ Add richness and depth description of the meaning of affinities that is not possible with a focus group alone
- ◆ Allow for individual mind-maps, which can be used in a debriefing session as an interpretive aid to the investigator

Structuring the interviews with the same questions around affinities that are discussed in a prescribed order (although follow-up questions or probes in the first phase will naturally vary) allows the researcher to ensure that each affinity is explored thoroughly and consistently. Following this carefully prepared protocol then frees the researcher to focus attention on eliciting and responding to each interviewee's distinct responses. This careful, procedural preparation supports the interviewer's art in engaging and eliciting each person's experience. This process enables the researcher to achieve several critical purposes with the IQA interviews:

- ◆ To provide data representation the respondent's experience with the phenomenon
- ◆ To provide data representing the respondent's personal mind map
- ◆ To help the researcher code the impact and influences of these affinities in order to create a systems influence diagram
- ◆ To provide data representing the group's collective SID (mind-map)

The creation of an IQA interview protocol is straightforward. The interview protocol consists of two parts: 1) the open-end *axial interview* designed to provide rich description of affinities by the respondents; and 2) the structured *theoretical interview* designed to identify relationships between affinities. The axial interview section is derived from the affinities identified by the focus group, while the theoretical interview is presented through an Affinity Relationship Table.

The focus group affinity identification is the basis of the open-ended questions of the axial interview. The interviewer need only address the affinity names themselves. The interviewer seeks to address, "What does the affinity mean to you? Tell me about your experience with the affinity?"

The Affinity Relationship Table (ART) is the basis for the theoretical interview. The table provides a quick reference of all of the possible relationships between affinities. Presented with a copy of the table, the respondents are asked if they believe there is a relationship between each

affinity and to explain why they believe so. They are probed to provide their experiences with the relationship. Each respondent is asked to determine the nature of the relationship between all possible pairs of affinities. For any two affinities A and B, there are only three possible relationships: either A directly influences B, or B directly influences A, or there is no direct influence between A and B. These *Rules for Hypothesizing* are summarized as follows:

For any 2 affinities A and B, either

$A \rightarrow B$ (A influences B)

$A \leftarrow B$ (B influences A)

$A \times B$ (No relationship)

They are asked to record their responses in an ART, which is a matrix containing all the perceived relationships in the system.

Affinity Name	
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	

Possible Relationships
$A \rightarrow B$
$A \leftarrow B$
$A \times B$ (No Relationship)

Affinity Relationship Table					
Affinity Pair Relationship				Affinity Pair Relationship	
1	←	2		3	→ 5
1	←	3		3	→ 6
1	←	4		3	→ 7
1	←	5		3	→ 8
1	←	6		4	→ 5
1	←	7		4	→ 6
1	←	8		4	← 7
2	←	3		4	→ 8
2	←	4		5	→ 6
2	←	5		5	← 7
2	←	6		5	← 8
2	←	7		6	← 7
2	←	8		6	← 8
3	→	4		7	→ 8

Interview Transcripts

The final result of the Interview Phase is a collection of transcripts for each respondent.

IQA Report

The last phase of an IQA or any study is that of the report, which in the case of an IQA study proceeds not only from the descriptions of the affinities produced by the respondents, but from two other sources as well: (1) the respondents' judgments of the cause-and-effect relationships among the affinities and the system these judgments create; and (2) comparison of mind-maps, both at an aggregate level (composite SIDs from interviews for different constituencies) and at an individual level (examining individual mind-maps or the variability within a constituency). While there are several choices of formats for an IQA study, the dissertation format is most frequently used.

Affinities and relationships are described with the words of the group. Since IQA is designed to describe the perceptions of the phenomenon or the lived reality of the group, it makes sense to describe the affinity purely in the words of the group. Comparison is the fuel for the interpretive machine, and systems as represented by mind-maps or SIDs, provide multiple opportunities for comparison.

The IQA systems approach is designed to be of the greatest possible assistance in interpretation. The focus group is used to identify the affinities, each of which is well documented as part of the focus group protocol. Interviews then expand on the descriptions of the affinities. Since the primary result of an IQA study is a picture of a system or systems, it is no accident that the process that produced these systems is designed to aid in the writing process. The typical IQA report accomplishes three goals:

1. Naming and describing the elements of the system
2. Explaining relationships among elements of a system (system dynamics)
3. Comparing systems

To systematically approach the report, IQA splits the process into two phases (1) Results / Analysis and (2) Interpretation / Implications. These two phases are reflected in the typical Chapter 4 and 5 of the dissertation. "Results / Analysis" on the one hand and "Interpretation / Implications" on the other is arguably a distinction without a difference. These terms have a strong positivist flavor, and indeed the ontological barrier between our findings and the meaning we give them is much more permeable than the names imply. Nevertheless, the distinction can be useful for presentational purposes, and IQA makes a distinction that is consistent with the one described above. "Results / Analysis," in IQA terminology, refers to describing the affinities and the systems. "Interpretation / Implications" refers to comparing systems and setting these comparisons into the two larger contexts of theory (conceptual implications) and application (pragmatic implications).

The IQA Results / Analysis chapter provides the researcher the opportunity to describe the phenomenon in the participants voice and to present the data free of commentary, interpretation or opinion by the researcher. Through a rigorous use of protocols, transcripts are coded and systems are drawn. The story of each constituency group is told by aggregating axial codes of each affinity to tell the story of the group as a whole. The system is built one relationship at a time by aggregating theoretical codes to tell the story of the group as a whole. The resulting

report (dissertation Chapter 4) is an Axial Write-up, Theoretical Write-up and presentation of the SID.

The IQA Interpretation / Implications chapter (dissertation Chapter 5) provides the researcher the opportunity to describe the phenomenon in the researcher's voice. The researcher is free to interpret the data, suggest interventions and introduce other literature that reinforces the researcher's results. In Chapter 5, the researcher re-engages with the literature to accomplish two goals: first, to re-interpret the literature reviewed in chapter 2 in the light of what has been learned and second, to identify other areas of literature that now have relevance in the light of what has been learned. The applications section of this chapter is the investigator's response to the question of pragmatic utility: What is the study good for?

IQA Report (Results / Analysis)

The results section provides to the reader the facts to be used in later discussion. This section should be as free from researcher interpretation and opinion as possible. By presenting only the facts, the researcher adds credibility to the data. This also provides an audit trail for later arguments. Providing just the data allows the reader to draw his or her own conclusions, free from researcher bias.

- ◆ System Elements (Describe each Affinity)
 - Composite affinity descriptions (affinity write-up)
 - Describe each affinity from the point of view of the group as a whole
- ◆ System Relationships (Describe each Relationship)
 - Composite theoretical descriptions (theoretical write-up)
 - Draw the cluttered SID one affinity at a time while describing the relationships
 - System influence diagram (SID)
 - Present the uncluttered SID

The Results / Analysis Phase of the IQA Report is primarily an exercise in organization and presentation. Raw transcripts are processed through a series of protocols designed with the purpose identifying the meaning of each affinity by telling the composite story of each constituency. This phase also produces the relationship-by-relationship building of the composite system while telling the group story of how each affinity is related to the others.

Transcripts

All interviews are transcribed word for word. The transcript is formatted to provide the researcher quick identification of the sections. The researcher then edits the transcripts to remove all spoken word stumbles and poor grammar. Personal identifiers are removed or generalized.

Axial Coding

Axial Code Table (ACT)

Once the transcripts had been prepared, the researcher analyzes the text for axial codes, which are specific examples of discourse that illustrate or allude to an affinity. The researcher then documents the reference for retrieval by recording the affinity number on the line of transcript that refers to the affinity and by documenting the line numbers and affinity numbers in the Individual Interview Axial Code Table (ACT). The ACT is the primary documentation for all utterances that illustrate the range of meaning of each affinity for each respondent.

The structure of the interview is designed to make this step very easy. The meaning of each affinity is explored with each respondent according to a standard (but flexible) protocol and the respondent's descriptions are transcribed line-by-line. The researcher examines the particular section of the interview transcript that addresses the affinity and looks for phrases or statements that define and provide examples of a specific affinity. These examples may be symbolic or metaphorical statements concerning the affinity, clearly stated descriptions of how the affinity becomes manifest in the experience of the respondent, or proximate descriptions of other affinities in the context of the one being addressed.

Quotes relating to a specific affinity are cut and pasted into the third column of the ACT, along with the line(s) of the transcript that are the source of the axial quote. There will usually be multiple axial quotes for any given affinity; each quote represented by another row in the ACT. Once all interviews are coded, the data from the interviews are summarized to create a composite of the individuals' experience with the phenomenon.

Sample Individual Interview Axial Code Table			
Affinity	Transcript Line	Axial Quotation	Researcher Notes
1.			
2.			
3.			
4.			
5.			
6.			

Combined Interview Axial Code Table

Once all interviews have been coded, the data from the interviews are summarized to create a combined Axial Code Table that represents a composite of the individuals' experience with the affinities of phenomenon. Axial data are transferred from each Individual Interview Axial Code Table to a Combined Interview Axial Code Table. By combining all interviews into one table,

the researcher creates a database for the entire set of respondents containing all Axial Codes for all affinities, with each code containing a link or a reference to the transcript and line numbers that produced the code. This table is very similar to the one used to record axial codes for an individual interview except that it also contains a link to the transcript that produced the code.

Composite Affinity Descriptions: The Affinity Write-up

The IQA Affinity Write-up is a composite story of the group. The researcher is tasked with organizing the multiple interviews so that they tell the story of the group as a whole. The researcher seeks to identify what “does the affinity mean?”, “what are the sub components?” and “what is the range of meaning?” for each affinity. Since the group is the best source of describing their experience, why not describe it purely in their own words? Much like the process used to identify affinities with a focus group, quotes can be organized into common themes using a “Dump, Clump, Name, Organize” procedure. With all the quotes for a particular affinity contained in a Combined Interview Axial Code Table for that affinity, the meaning of the affinity can begin to take shape. IQA takes the stand that the researcher should have little voice in the Results / Analysis. The role of the researcher is to organize the data so that it tells the groups story and is interesting to the reader. The researcher is tasked with combining, naming and organizing the quotes. The researcher introduces the affinity and sub affinities to the reader but avoids any temptation to add the researchers voice and interpretation to the story. For this reason, only a few introductory sentences are written in the voice of the researcher while the bulk of the Affinity Write-up is in the words of the group.

Once all interview have been organized and coded and system have been build all that is left to do is present the material in a manner that is informative, organized and fun to read. Since we are all prolific writers, this step is easy and need no further explanation. But for that rare researcher who looks at a blank piece of paper and has no idea where to start, IQA once again take a systematic approach to writing up the study. Knowing the data that IQA produces makes the writing process much less difficult. The transparent nature of the IQA process allows the researcher to present the results in an open forum and allows the reader to examine the data along with the researcher. Presenting the data in an open manner allows the reader to draw their own conclusions about the study. Most researchers work so hard and become so involved in the study that they cannot resist drawing conclusions and making predictions. But all too often researchers blur the line between presenting the data and interpretation. A systematic approach can help to avoid the pitfalls by drawing distinct lines between describing the data and interpreting the data.

In the “Dump” phase, each Combined Interview ACT is cut into strips of paper representing a single individual quote. The research in effect creates cards for a sub-affinity analysis. In the “Clump” phase, the researcher next examines all quotes for that affinity. Similar themed quotes are clumped together in piles. In the “Name” phase, the researcher examines each theme and gives it a meaningful name. These themes are called sub-affinities. They represent the overall range of meaning of the affinity. They often describe the affinity in either a range of timbre or tone or as a list of attributes that describe the affinity. In the “Organize” phase, multiple quotes

for each sub-affinity are then woven together to develop a composite quote. The researcher organizes the quotes so that they tell a story about each sub-affinity.

While the resulting paragraphs of quotes are made up of quotes taken from individuals, the result is an affinity description that represents a composite story of the group as a whole. While this process may seem strange to qualitative researchers who are used to seeing quotations being treated in traditional ways, the process is not unusual. It is very common for a researcher to interview an individual many times over a period of time about the same subject. Researchers often compile quotes on a topic and report the results so that the story reads as a continuous piece.

Theoretical Coding

The purpose of IQA is to draw a picture of the system (Systems Influence Diagram or SID) that represents the perceptual terrain or the mind-map of an individual or group with respect to a phenomenon represented by the issue statement. The SID is a picture drawn using a set of rules for rationalization on a summary of the theoretical codes called an Interrelationship Diagram (IRD) produced by the respondents. Theoretical Coding refers to ascertaining the perceived cause and effect relationships (influences) among all the affinities in a system. In the interview setting, this is accomplished by facilitating a systematic process of building hypotheses linking each possible pair of affinities.

All possible direct links between the affinities are investigated by developing hypotheses grounded in the data. IQA provides participants with a formal protocol to determine whether or not there is a direct influence between every possible pair of affinities in the system. If so, the respondent then determines the directionality of influence. The goal is to identify the underlying (and generally hidden) structure of the group mind map, which is summarized in a SID.

Theoretical Coding can serve two purposes, first to present an individual SID for each participant and second to produce a composite SID representative of the group as a whole. To produce a SID for an individual the researcher examines the transcripts for Theoretical Codes. Theoretical Codes are recorded in an Individual Interview Theoretical Code Table (TCT), which captures both directionality of relationships as well as descriptive explanations of how the relationships work in the respondent's words. In preparation for drawing an individual system the relationships are transferred to an Affinity Relationship Table (ART), which was described in the interviews section. The relationships are then processed through another protocol called an Interrelationship Diagram (IRD). Next, a Cluttered SID, one that contains all relationships identified by the respondent, is produced. The Uncluttered SID is the final version of the system in which redundant links are removed. Each of these protocols will be explained in detail to follow.

In order to build a composite system representative of the group as a whole a few extra steps are performed. For each interview an Individual Interview Theoretical Code Table (TCT) is produced. As each interview is processed an accounting of each affinity pair relationships is tallied in a Theoretical Code Frequency Table. The Theoretical Code Frequency Table captures

the frequency of “votes” for each affinity pair for all members of the group. IQA uses a Pareto Protocol, which is used operationally to achieve consensus and analytically to create a statistical group composite of the group. The Pareto Protocol identifies which relationships the researcher should use to build the Composite SID. The relationships to be used are recorded in an ART. Following the same steps as an Individual System an IRD, Cluttered SID and Uncluttered SID is produced. The Composite SID process is described in detail following the process for the individual SID.

The SID Assignments Protocol

The purpose of the SID Assignments Protocol is to allow the researcher to analyze the entire set of relationships identified in the ART and determine the basic flow of the system from Driver to Outcome. The SID Assignments Protocol contains four tables, The Affinity Relationship Table (ART), The Interrelationship Diagram (IRD), The Sorted IRD and the Tentative SID Assignments Table. The SID Assignments Protocol is completed by examining the number relationships a particular affinity influences and is influenced by. In other words, the researcher examines the number of OUT arrows (Drivers) and IN arrows (Outcomes) of each affinity. The difference between OUT and IN arrows determines if the affinity is a relative driver or outcome. Affinities are then sorted from drivers to outcomes. The results of the sorted IRD are examined to determine the tentative order of the affinities in preparation for drawing the SID. Below is the blank SID Assignments Protocol.

Affinity Name	
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	

Possible Relationships
$A \rightarrow B$
$A \leftarrow B$
$A \times B$ (No Relationship)

Affinity Relationship Table				
Affinity Pair Relationship			Affinity Pair Relationship	
1	2		3	5
1	3		3	6
1	4		3	7
1	5		3	8
1	6		4	5
1	7		4	6
1	8		4	7
2	3		4	8
2	4		5	6
2	5		5	7
2	6		5	8
2	7		6	7
2	8		6	8
3	4		7	8

IRD											
	1	2	3	4	5	6	7	8	OUT	IN	Δ
1											
2											
3											
4											
5											
6											
7											
8											
Total											

Count the number of up arrows (\uparrow) or *Outs*

Count the number of left arrows (\leftarrow) or *Ins*

Subtract the number of *Ins* from the *Outs* to determine the (Δ) *Deltas*

$$\Delta = \text{Out} - \text{In}$$

Error Check

Add both the *Outs* column and the *Ins* column. The numbers should be equal.

Add the Δ column. The value should be zero.

Paste the contents of the IRD into the table below and sort by Δ

IRD – Sorted in Descending Order of Δ											
	1	2	3	4	5	6	7	8	OUT	IN	Δ
1											
2											
3											
4											
5											
6											
7											
8											

Directions

Copy and paste the sorted affinity number column over the affinity numbers in the Tentative SID Assignments Table.

Examine the Sorted IRD Table for the following possibilities and change the Tentative SID order to reflect the rule.

Zero IN, Zero OUT Rule: If there is a *Zero In* within the system it must be moved up to a pure primary driver. If there is a *Zero Out* it must be moved down to a pure primary outcome.

Equal Delta Flip Rule: If there is a tied delta value, examine the relationship pair and identify which is the driver. The driver of the pair goes first in the table. Make changes to the SID order in the table below.

Tentative SID Assignments	
1	
2	
3	
4	
5	
6	
7	
8	

Primary Driver
 Secondary Driver
 Neutral
 Secondary Outcome
 Primary Outcome

The Cluttered SID

The first version of the SID contains each link present in the IRD and is referred to as the Cluttered SID. The system is saturated with links, a term appropriated from organic chemistry. Just as saturated hydrocarbons are composed of carbon atoms linked to as many hydrogen atoms as their structure will allow, the cluttered SID contains all of the links identified by participants in the protocol leading to the IRD.

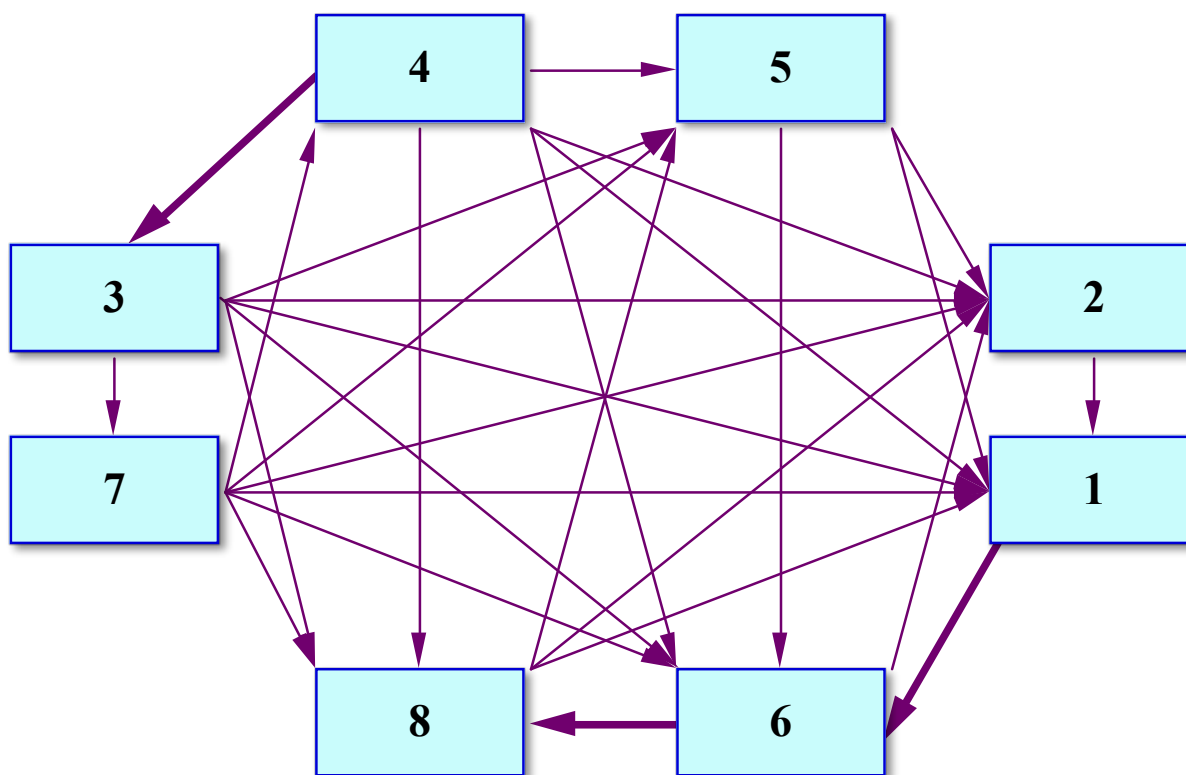


Figure A4: Sample Cluttered SID

The Uncluttered SID

The Cluttered SID deserves its name. The problem with saturation is that a Cluttered SID, while being comprehensive and rich, can be very difficult to interpret, even for a modest number of affinities that are highly interlocked or embedded within the system. While the Cluttered SID is extremely rich in descriptive capability, it serves better as an *objet d'art* (depending on one's sense of aesthetics) than as an interpretive device. In other words, many systems have so many links that the explanatory power of the system becomes bogged down in the details of the relationships. Comprehensiveness and richness are certainly objectives of the SID; on the other hand, so is parsimony. A way to reconcile the richness–parsimony dialectic is to produce an Uncluttered SID, one that has redundant links removed. Redundant links are those between two affinities in which, even if removed, a path from the driver to the outcome can be achieved

through an intermediary affinity. Redundant links can be thought of as the paths of least resistance. The Uncluttered SID has all redundant links removed. The Uncluttered SID is the simplest possible representation consistent with all the relationships contained in the IRD.

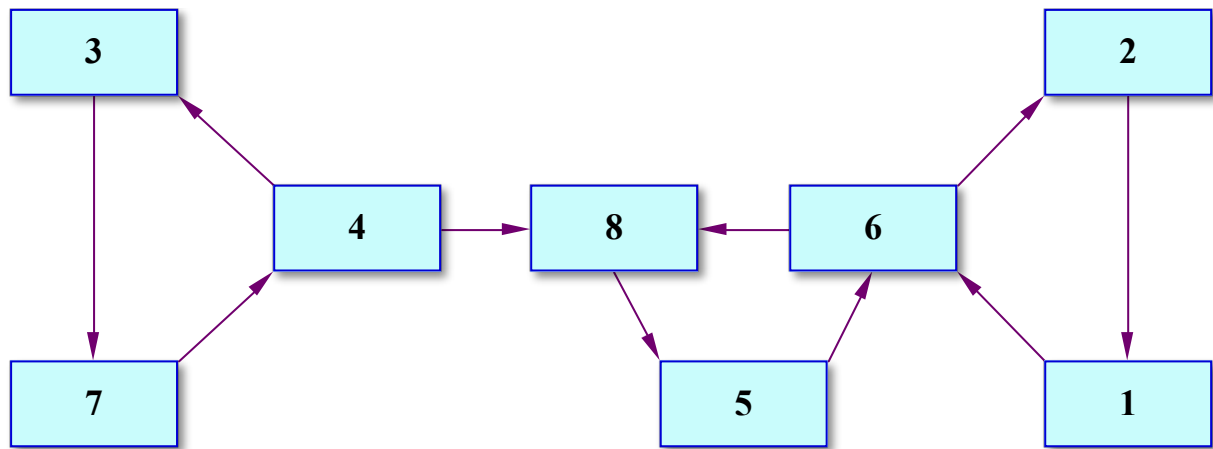


Figure A5: Sample Uncluttered SID

The Composite SID

Using the same procedure used to develop an Individual SID, a Composite ART, IRD and SID can be created for the group. Once all interviews have been coded, the data from the interviews are summarized to create a combined SID that represents a composite of the individual's experience with the phenomenon. A count of each theoretical code is entered into the Combined Interview Theoretical Code Frequency Table. Because individual respondents may have defined relationships differently, and may in fact disagree about the direction of a relationship, IQA provides a protocol (the Pareto Protocol with MinMax Criterion) to constructing a composite SID from individual interview SIDs.

The Pareto Principle

Selecting a protocol for representing the consensus or the “preponderance” of the group's analysis of relationships is similarly independent of the level of detail or group organization. A reasonably rigorous and powerful technique for achieving and documenting the degree of consensus in a group is the Pareto Principle, named after the 19th century economist Wilfredo Pareto (1843-1913), and popularized among management and systems theorists by Joseph Juran (1988). Pareto wrote of the “trivial many and the significant few” in his analysis of productivity and economics. The principle has been used in quality management to help focus priorities by providing an easy-to-remember rule of thumb. Put in systems terms, the Pareto Principle states that something like *20% of the variables in a system will account for 80% of the total variation in outcomes* (such as productivity or profit). Other (sometimes tongue-in-cheek) incarnations of the Pareto Principle are:

- ◆ Addressing the most troublesome 20% of your problem will solve 80% of it.
- ◆ In any organization, 20% of the personnel will cause 80% of your headaches.
- ◆ *80 percent of all work that is completed is really the result of 20 percent effort.*
- ◆ 20 percent of all potential solutions will solve 80 percent of the problem

Whether the split is 20/80 or 70/30 or some other ratio depends upon the nature of the system, but the essential utility of the Pareto Principle is this: a minority of the relationships in any system will account for a majority of the variation within the system. Depending upon the variation of theoretical coding used, it is quite likely that there will be some disagreement among either individuals or subgroups about the nature of a given relationship. IQA uses the Pareto rule of thumb operationally to achieve consensus and analytically to create a statistical group composite.

The Pareto Protocol provides an efficient and, to group members who find themselves in an initial stage of disagreement, satisfying method for achieving consensus. A Pareto Composite System requires an exact count of each relationship code but has distinct benefits in that it takes into account close votes and identifies conflicting relationships not addressed in a simple vote. The frequency of each relationship is determined and recorded on a spreadsheet by tallying all of the relationships identified by each member of the group and recorded in an ART. The total number of “votes” (we omit the quotes from now on) for each relationship is calculated, and the relationships are sorted out in descending order. Cumulative percentages are then calculated for each relationship, which is to say a Pareto Protocol is constructed. The cumulative frequencies are used for two purposes:

- ◆ To determine the optimal number of relationships to comprise the composite system. “Optimal” is used in the sense that the researcher’s goal is to use the fewest number of relationships (for parsimony’s sake) that represents the greatest amount of variation (for the sake of comprehensiveness and richness). Relationships that attract a very low percentage of votes are generally excluded from the group composite.
- ◆ To help resolve ambiguous relationships, which are relationships that attract votes in either direction.

IQA Report (Interpretation / Implications)

The last phase of an IQA or any study is that of Interpretation / Implications, which in the case of an IQA study proceeds not only from the descriptions of the affinities produced by the respondents, but from two other sources as well: (1) the respondents’ judgments of the cause-and-effect relationships among the affinities and the system these judgments create; and (2) comparison of mind-maps, both at an aggregate level (focus group SID, composite SIDs from interviews for different constituencies) and at an individual level (examining individual mind-maps or the variability within a constituency).

In the Interpretation / Implications chapter, the researcher begins to make comparisons and draw conclusion based on the data. Composite systems for each constituency are compared to each other. Individual respondent systems are compared to show typical or atypical variation from that

of the group. The researcher draws inferences based on theoretical perspective. Finally, the researcher can make predictions based on the model or suggest interventions one may attempt to change the outcome of the system.

Comparisons

Comparisons can be made at two levels: A qualitative analogue to the statistical concept of variation is possible by comparing individual mind-maps to each other and to the composite; and a qualitative analogue to post hoc group comparisons is possible by comparing the composite mind-maps of different constituencies. These two interpretive protocols are the logical results of the dialectical nature of IQA research, as revealed in the following:

1. Individuals are unique in meaningful ways. Individual perspectives or voices are important and should not get lost in our attempt to find patterns. However ...
2. Patterns or communalities in perceptions do exist within constituencies. These patterns or abstractions are useful for both theoretical and practical purposes. Furthermore...
3. Comparison is the primary method of interpretation, both from the participant's point of view and from the investigator's. IQA focus group and interview protocols are designed to encourage constant comparison by the participants; and for the investigator, the following comparisons are provided by following the IQA research design process:
 - Among individuals within and across constituencies (comparing individual mind-maps to each other and to composites)
 - Comparisons among constituencies (comparing composites)

Scenarios Examined

A mind-map or SID, whether it is the map of a group's or an individual's perception, is a system, and systems are made to be "exercised." Systems may be exercised (or scenarios may be cast) in three basic ways:

1. The researcher may ask the model to "predict," based on its internal logic, the ultimate state of the outcome affinities given known states of its antecedent affinities.
2. The researcher may do the opposite, which is to ask what antecedents might, by the logic of the system, lead to a particular state of its outcomes.
3. The researcher may ask what might be the effect of extra-systemic influences or those forces not named or accounted for in the system.

In other words, IQA methodology allows for a representation of both individual and group realities, comparisons of which allow the researcher to ask the two great interpretive questions: "What is ...?" and "What if ...?"

Interpretation & Implications: Chapter 5 Guidelines

The implications section provides a forum for the researcher to analyze and interpret the data as well as draw conclusions based on the data. How one chooses to make comparisons is a matter of choice. IQA chooses to analyze the composite system first. Next, IQA chooses to identify

opposing individual experience and compare them. Finally, IQA chooses to treat the system as a theoretical model that can be applied to other situations and make predictions based on the model.

- ◆ Composite System (Describe the System)
 - Brief tour through the system.
 - Describe overall placement of the affinities in the systems. Describe links, building the model from left to right. Give examples (you can put theoretical quotes directly onto your SID) of each link.
 - Highlight and *name* any feedback loops. Give an example, in the manner just above, of how each loop works; in particular, how it can *implode* or go negative. Describe way(s) to escape from a negative feedback loop.
 - Zoom out by substituting the feedback loop names for the affinities comprising the loops, working from right (outcomes) to left (drivers).
 - *Exercise the model* by presuming some given states or conditions of the drivers and then examining what the expected results would be (prospective scenario). Then, do the reverse (retrospective scenario) by assuming some states or conditions of the outcomes, and then examine the model to see what conditions or states of the drivers could have produced these outcomes.
- ◆ Valence (Describe the Valence)
 - Describe the overall valence (hot to cold, positive to negative, bad to good, pleasant to unpleasant, lots of variation, little variation) of each affinity. Analyze the interviews based on valence and quotes.
- ◆ Predictions and Interventions
 - Describe how the system can be used outside the context of the study.
 - Describe how each Constituency (from Power/Proximity analysis in Research Design) could use the system
- ◆ Practical Implications (Provide Solutions to Identified Problems)
- ◆ Revisit the Literature
 - Identify other theories that resemble or support the researcher's findings

Additional Interpretative Techniques

- ◆ Compare Groups (Compare System of Different Constituencies or Comparison Groups)
 - Compare and contrast drivers to outcomes, loops and the overall placement of the affinities in the systems.
 - Compare and contrast the timbre of the individual's affinities to that of the composite.
- ◆ Individual System (Describe an Atypical and Typical Individual)
 - Discuss each affinity in the context of an individual interview.
 - Discuss each relationship in the context of an individual interview.
 - Describe links, building the model from left to right. Give examples (you can put theoretical quotes directly onto your SID) of each link.
 - Describe overall placement of the affinities in the systems.

- Highlight and *name* any feedback loops. Give an example, in the manner just above, of how each loop works; in particular, how it can *implode* or go negative. Describe way(s) to escape from a negative feedback loop.
- Zoom out by substituting the feedback loop names for the affinities comprising the loops, working from right (outcomes) to left (drivers).
- *Exercise the model* by describing the individual's path through the system.
- Describe the overall valence (hot to cold, positive to negative, bad to good, pleasant to unpleasant, lots of variation, little variation) of each affinity. Analyze the individual interview based on valence and quotes.
- In the individual SID, identify the affinity, which, if its valence becomes negative enough, will likely lead to a decision to abandon the doctoral program. (This step is particular to our case study.)

APPENDIX B: THEORETICAL CODING

**Table B1: Combined Interview Theoretical Code
Frequency Table**

Affinity Pair Relationship	Frequency	Affinity Pair Relationship	Frequency	Affinity Pair Relationship	Frequency
1 → 2	17	2 → 9	22	5 → 6	12
1 ← 2	13	2 ← 9	2	5 ← 6	11
1 → 3	24	2 → 10	32	5 → 7	12
1 ← 3	9	2 ← 10	0	5 ← 7	8
1 → 4	16	3 → 4	22	5 → 8	28
1 ← 4	9	3 ← 4	9	5 ← 8	4
1 → 5	25	3 → 5	8	5 → 9	17
1 ← 5	5	3 ← 5	22	5 ← 9	6
1 → 6	17	3 → 6	23	5 → 10	28
1 ← 6	7	3 ← 6	6	5 ← 10	2
1 → 7	17	3 → 7	21	6 → 7	12
1 ← 7	8	3 ← 7	8	6 ← 7	13
1 → 8	17	3 → 8	9	6 → 8	11
1 ← 8	10	3 ← 8	18	6 ← 8	8
1 → 9	9	3 → 9	21	6 → 9	26
1 ← 9	6	3 ← 9	6	6 ← 9	1
1 → 10	27	3 → 10	27	6 → 10	31
1 ← 10	2	3 ← 10	4	6 ← 10	1
2 → 3	31	4 → 5	4	7 → 8	18
2 ← 3	1	4 ← 5	13	7 ← 8	7
2 → 4	27	4 → 6	18	7 → 9	17
2 ← 4	4	4 ← 6	7	7 ← 9	3
2 → 5	22	4 → 7	5	7 → 10	26
2 ← 5	8	4 ← 7	12	7 ← 10	3
2 → 6	21	4 → 8	19	8 → 9	11
2 ← 6	4	4 ← 8	9	8 ← 9	16
2 → 7	16	4 → 9	18	8 → 10	16
2 ← 7	4	4 ← 9	4	8 ← 10	12
2 → 8	25	4 → 10	25	9 → 10	14
2 ← 8	2	4 ← 10	6	9 ← 10	17

SID Assignments Protocol

Affinity Name
1. Medical Staff
2. Diagnosis
3. Fertility Treatments & Process
4. Cost / Finances
5. Knowledge / Information
6. Treatment Outcomes
7. Time
8. Empowerment / Choices
9. Relationships
10. Emotions

Possible Relationships
$A \rightarrow B$
$A \leftarrow B$
$A \times B$ (No Relationship)

Table B2: Affinity Relationship Table				
Affinity Pair Relationship		Affinity Pair Relationship		Affinity Pair Relationship
1 \rightarrow 2		3 \rightarrow 4		5 \rightarrow 10
1 \rightarrow 3		3 \leftarrow 5		6 \leftarrow 7
1 \rightarrow 4		3 \rightarrow 6		6 \rightarrow 8
1 \rightarrow 5		3 \rightarrow 7		6 \rightarrow 9
1 \rightarrow 6		3 \leftarrow 8		6 \rightarrow 10
1 \rightarrow 7		3 \rightarrow 9		7 \rightarrow 8
1 \rightarrow 8		3 \rightarrow 10		7 \rightarrow 9
1 \rightarrow 9		4 \leftarrow 5		7 \rightarrow 10
1 \rightarrow 10		4 \rightarrow 6		8 \leftarrow 9
2 \rightarrow 3		4 \leftarrow 7		8 \rightarrow 10
2 \rightarrow 4		4 \rightarrow 8		9 \leftarrow 10
2 \rightarrow 5		4 \rightarrow 9		
2 \rightarrow 6		4 \rightarrow 10		
2 \rightarrow 7		5 \rightarrow 6		
2 \rightarrow 8		5 \rightarrow 7		
2 \rightarrow 9		5 \rightarrow 8		
2 \rightarrow 10		5 \rightarrow 9		

Table B3: IRD													
	1	2	3	4	5	6	7	8	9	10	OUT	IN	Δ
1		↑	↑	↑	↑	↑	↑	↑	↑	↑	9	0	8
2	←		↑	↑	↑	↑	↑	↑	↑	↑	8	1	7
3	←	←		↑	←	↑	↑	←	↑	↑	5	4	1
4	←	←	←		←	↑	←	↑	↑	↑	4	5	-1
5	←	←	↑	↑		↑	↑	↑	↑	↑	7	2	6
6	←	←	←	←	←		←	↑	↑	↑	3	6	-3
7	←	←	←	↑	←	↑		↑	↑	↑	5	4	1
8	←	←	↑	←	←	←	←		←	↑	2	7	-5
9	←	←	←	←	←	←	←	↑		←	1	8	-7
10	←	←	←	←	←	←	←	←	↑		1	8	-7
Total											45	45	0

Table B4: IRD – Sorted in Descending Order of Δ													
	1	2	3	4	5	6	7	8	9	10	OUT	IN	Δ
1		↑	↑	↑	↑	↑	↑	↑	↑	↑	9	0	8
2	←		↑	↑	↑	↑	↑	↑	↑	↑	8	1	7
5	←	←	↑	↑		↑	↑	↑	↑	↑	7	2	6
3	←	←		↑	←	↑	↑	←	↑	↑	5	4	1
7	←	←	←	↑	←	↑		↑	↑	↑	5	4	1
4	←	←	←		←	↑	←	↑	↑	↑	4	5	-1
6	←	←	←	←	←		←	↑	↑	↑	3	6	-3
8	←	←	↑	←	←	←	←		←	↑	2	7	-5
9	←	←	←	←	←	←	←	↑		←	1	8	-7
10	←	←	←	←	←	←	←	←	↑		1	8	-7

**Table B5: Tentative SID
Assignments**

1	Primary Driver
2	Secondary Driver
5	Secondary Driver
3	Secondary Driver
7	Secondary Driver
4	Secondary Outcome
6	Secondary Outcome
8	Secondary Outcome
10	Secondary Outcome
9	Primary Outcome

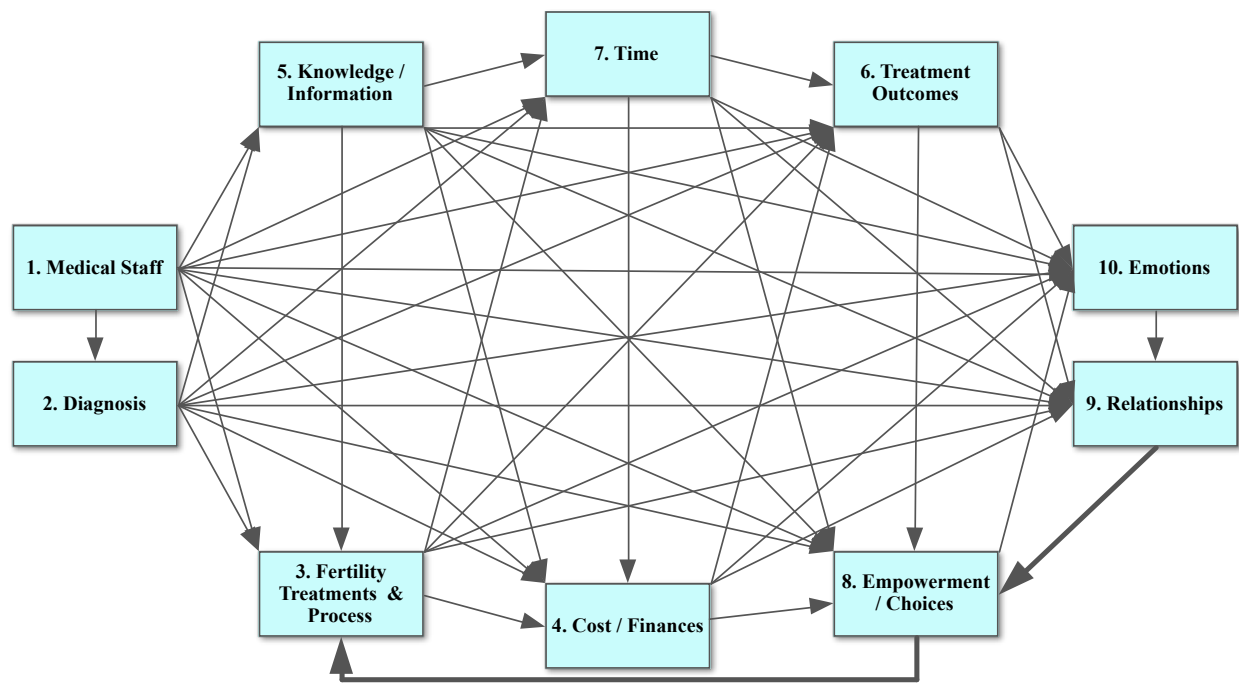


Figure B1: Cluttered SID

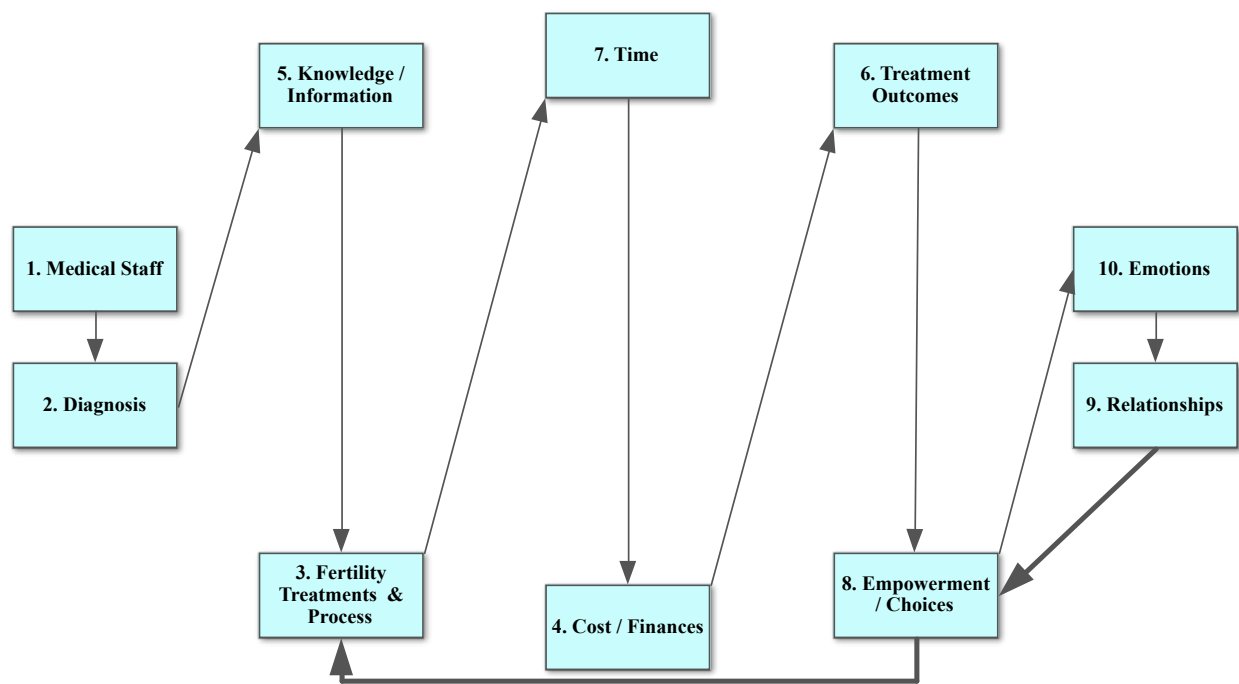


Figure B2: Uncluttered SID

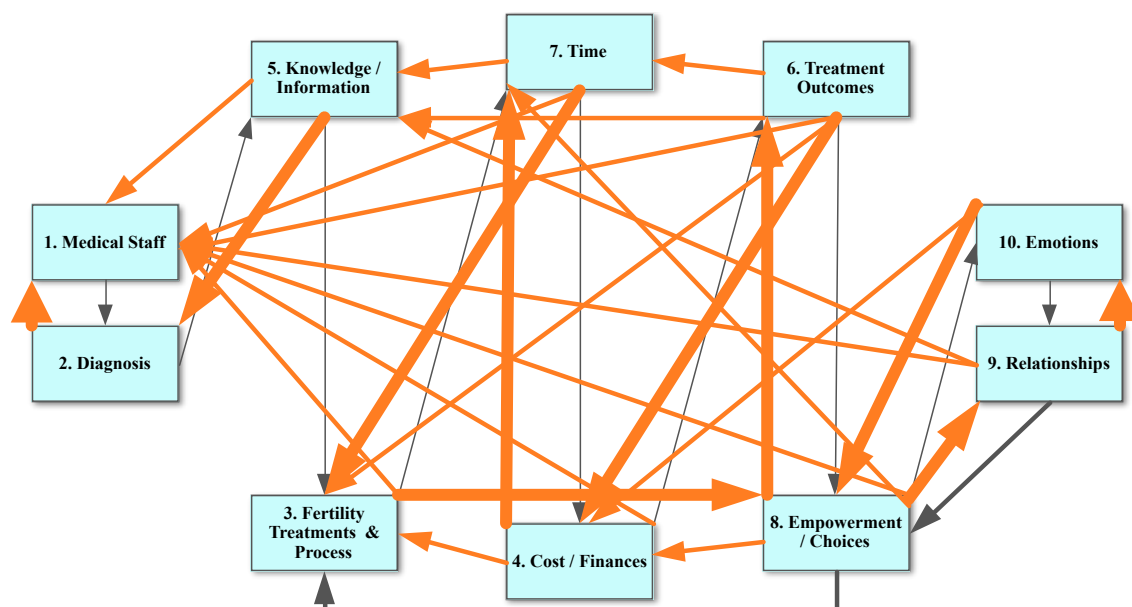


Figure B3: Pareto Reconciled Cluttered SID

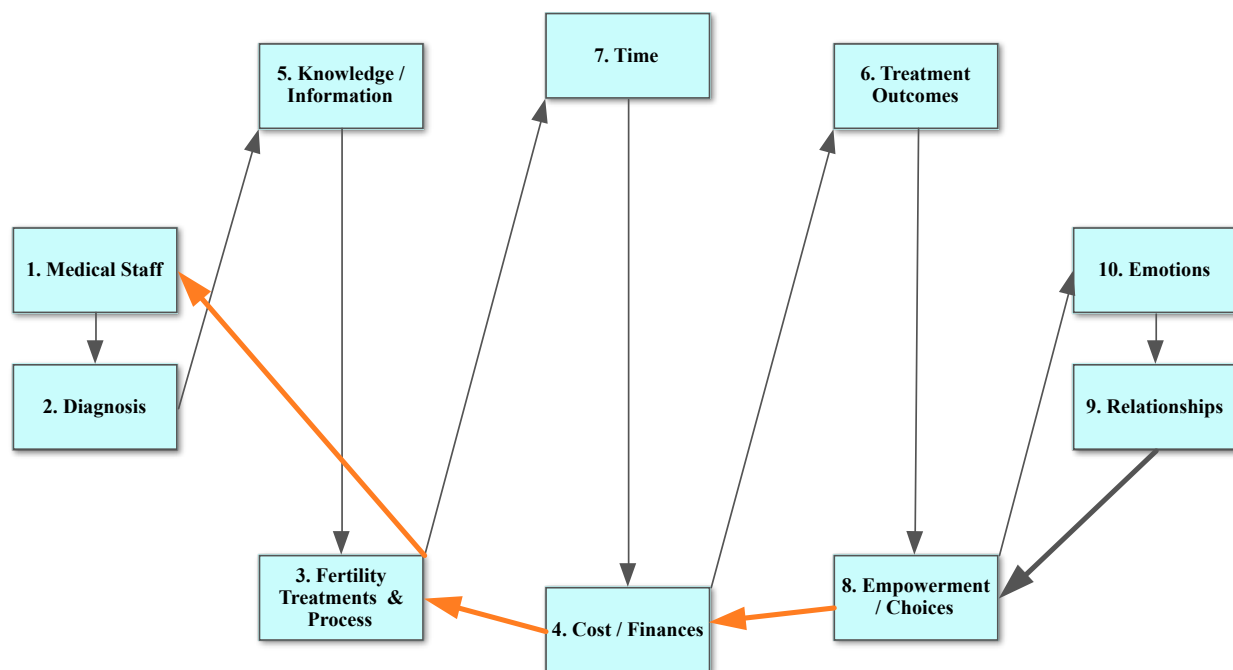


Figure B4: Pareto Reconciled Uncluttered SID

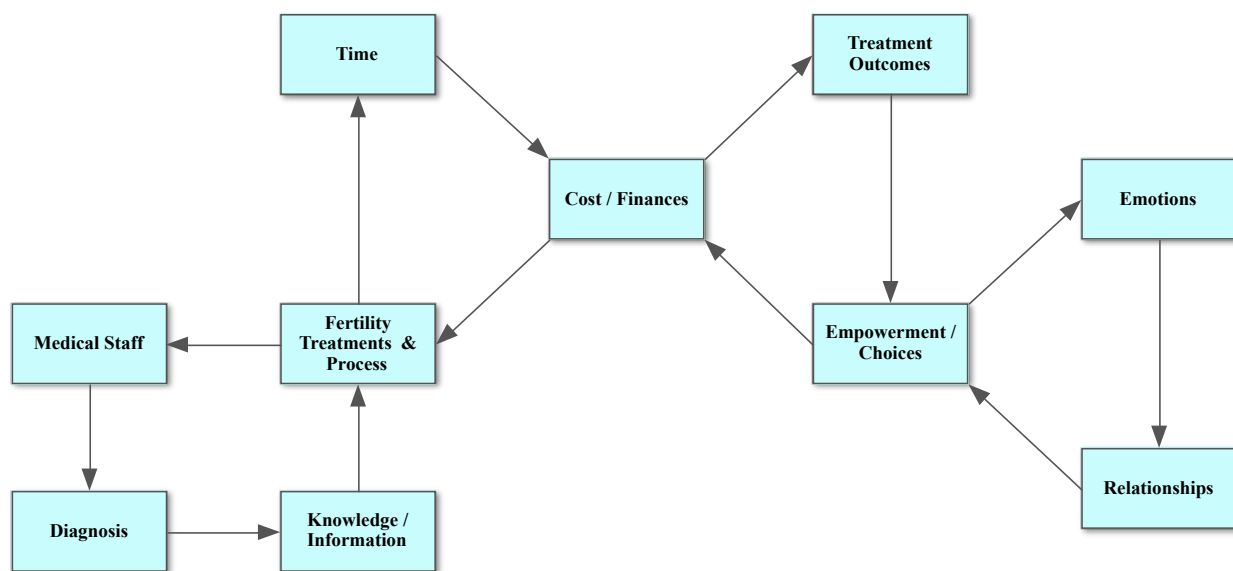


Figure B5: The Infertility Treatment Experience

REFERENCES

- Adashi, E. Y., Cohen, J., Hamberger, L., Jones, H. J., de Kretser, D. M., Lunenfeld, B., & ... Van Steirteghem, A. (2000). Public perception on infertility and its treatment: an international survey. The Bertarelli Foundation Scientific Board. *Human Reproduction (Oxford, England)*, 15(2), 330-334.
- Amani, H., & Asadi, M. (2014). Psychology of Infertility: a healthy experience in the treatment of infertility. *Journal Of Jahrom University Of Medical Sciences*, 11(2).
- Anderheim, L., Holter, H., Bergh, C., & Möller, A. (2005). Does psychological stress affect the outcome of in vitro fertilization? *Human Reproduction*, 20(10), 2969-2975.
- ART Fact Sheet. (n.d.). Retrieved June 21, 2015, from <http://www.eshre.eu/Guidelines-and-Legal/ART-fact-sheet.aspx>
- ART Success Rates. (2015, May 21). Retrieved June 21, 2015, from Centers for Disease Control and Prevention website: <http://www.cdc.gov/art/reports/index.html>
- Assisted Reproductive Technology. (n.d.). Retrieved October 10, 2012, from Centers for Disease Control and Prevention website: <http://www.cdc.gov/art/>
- Ashraf, D., Ali, D., & Azadeh, D. (2014). Effect of Infertility on the Quality of Life, A Cross-Sectional Study. *Journal Of Clinical & Diagnostic Research*, 8(10), 13-15. doi:10.7860/JCDR/2014/8481.5063
- Baird, D., Collins, J., Egozcue, J., Evers, L., Gianaroli, L., Leridon, H., & ... Tarlatzis, B. (2005). Fertility and ageing. *Human Reproduction Update*, 11(3), 261-276.
- Beaurepaire J, Jones M, Thiering P, Saunders D, Tennant C. (1994). Psychosocial adjustment to infertility and its treatment: male and female responses at different stages of IVF/ET treatment. *J Psychosom Res*, 38, 229-240.

- Berg, B., & Wilson, J. (1991). Psychological functioning across stages of treatment for infertility. *Journal Of Behavioral Medicine, 14*(1), 11-26.
- Berry, L. L., & Beckham, D. (2014). Team-Based Care at Mayo Clinic: A Model for ACOs. *Journal Of Healthcare Management, 59*(1), 9-13.
- Bianchi, S., M., Milkie, M., A., Sayer, L., C., & Robinson, J., P. (2000). Is anyone doing the housework? Trends in the gender division of household labor. *Social Forces, 79*(1), 191-228.
- Boivin, J. (2003). A review of psychosocial interventions in infertility. *Social Science & Medicine, 57*, 2325–2341.
- Budig, M. J. (2001). England P. The wage penalty for motherhood. *American Sociological Review, 66*(2), 204-225.
- Butler, R. R., & Koraleski, S. (1990). Infertility: A crisis with no resolution. *Journal Of Mental Health Counseling, 12*(2), 151-163.
- Cardinale, J. R. (2012). THE INJUSTICE OF INFERTILITY INSURANCE COVERAGE: AN EXAMINATION OF MARITAL STATUS RESTRICTIONS UNDER STATE LAW. *Albany Law Review, 75*(4), 2133-2149.
- Chan, C.H.Y., Ng, E.H.Y., Chan, C.L.W., Ho, P.C., & Chan, T.H.Y. (2006). Effectiveness of psychosocial group intervention for reducing anxiety in women undergoing in vitro fertilization: a randomized controlled study. *Fertility and Sterility, 85*, 339-346.

- Chandra, A., Copen, C. E., & Stephen, E. H. (2013). Infertility and impaired fecundity in the United States, 1982–2010: data from the National Survey of Family Growth. *National health statistics reports*, 67, 1-19.
- Chen, T., Chang S.P., Tsai C., Juang K. (2004). Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic. *Human Reproduction*, 19, 2313-2318
- Chow, M. K., Quine, S., & Li, M. (2010). The benefits of using a mixed methods approach - quantitative with qualitative - to identify client satisfaction and unmet needs in an HIV healthcare centre. *AIDS Care*, 22(4), 491-498. doi:10.1080/09540120903214371
- Christie, G. (1997). Grief management in infertile couples. *Journal of Assisted Reproduction and Genetics*, 14, 189–191.
- Cibula, D. (2008). Women's contraceptive practices and sexual behaviour in Europe. *European Journal Of Contraception & Reproductive Health Care*, 13(4), 362-375.
- Cohen, S., & McKay, G. (1984). Social support, stress, and the buffering hypothesis: A theoretical analysis. In A. Baum, J. E. Singer, & S. E. Taylor (Eds), *Handbook of Psychology and Health* (Vol 4) Hillsdale, NJ: Erlbaum.
- Cohen, S., & Willis, T. (1985). Social support, stress, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310-357.
- Cook, E. P. (1987). Characteristics of the biopsychosocial crisis of infertility. *Journal of Counseling and Development*, 65, 465-470.
- Connolly, K., Edelmann, R., Cooke, I., & Robson, J. (1992). The impact of infertility on psychological functioning. *Journal Of Psychosomatic Research*, 36(5), 459-468.

- Corson, S. L. (1999). *Conquering infertility: A guide for couples* (4th ed.). Vancouver, British Columbia, Canada: EMIS.
- Cousineau, T.M., Green, T.C., Corsini, E., Seibring, A., Showstack, M.T., Applegarth, L., et al. (2008). Online psychoeducational support for infertile women: a randomized controlled trial. *Human Reproduction*, 23, 554-566.
- Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. *Handbook of mixed methods in social and behavioral research*, 209-240.
- Cunningham, N., & Cunningham, T. (2013). Women's experiences of infertility - towards a relational model of care. *Journal Of Clinical Nursing*, 22(23/24), 3428-3437. doi:10.1111/jocn.12338
- Cunningham, N. (2014). Lost in transition: Women experiencing infertility. *Human Fertility*, 17(3), 154-158. doi:10.3109/14647273.2014.930517
- Curry, L. A., Nemhard, I. M., & Bradley, E. H. (2009). Qualitative and mixed methods provide unique contributions to outcomes research. *Circulation*, 119(10), 1442-1452.
- Dancet, E. F., Van Empel, I. H., Rober, P., Nelen, W. M., Kremer, J. M., & D'Hooghe, T. M. (2011). Patient-centred infertility care: a qualitative study to listen to the patient's voice. *Human Reproduction (Oxford, England)*, 26(4), 827-833. doi:10.1093/humrep/der022
- Daniluk, J. C. (1997). Gender and infertility. In S. Leiblum (Ed.), *Infertility: Psychological issues and counseling strategies* (pp. 103-125). Oxford England: John Wiley & Sons.

- Daniluk, J. (1988). Infertility: intrapersonal and interpersonal impact. *Fertility And Sterility*, 49(6), 982-990.
- Daniluk, J. C. (2001). Reconstructing their lives: A longitudinal, qualitative analysis of the transition to biological childlessness for infertile couples. *Journal Of Counseling & Development*, 79(4), 439-449.
- Daniluk, J. C., & Tench, E. (2007). Long-term adjustment of infertile couples following unsuccessful medical intervention. *Journal of Counseling & Development*, 85, 89-100.
- Demyttenaere, K., Nijs, P., Evers-Kiebooms, G., & Koninckx, P. (1989). The effect of a specific emotional stressor on prolactin, cortisol, and testosterone concentrations in women varies with their trait anxiety. *Fertility And Sterility*, 52(6), 942-948.
- Domar, A., Broome, A., Zuttermeister, P., Seibel, M., & Friedman, R. (1992). The prevalence and predictability of depression in infertile women. *Fertility And Sterility*, 58(6), 1158-1163.
- Domar, A., Zuttermeister, P., & Friedman, R. (1993). The psychological impact of infertility: a comparison with patients with other medical conditions. *Journal Of Psychosomatic Obstetrics And Gynaecology*, 14 Suppl45-52.
- Domar, A. D. (1997). Stress and infertility in women. In S. R. Leiblum (Ed.), *Infertility: Psychological issues and counseling strategies* (pp. 67–82). New York: Wiley.
- Donnis, S. (1984). Common themes of infertility: A counseling model. *Journal of Sex Education and Therapy*, 10(1), 11-15.

- Dooley, M., Dineen, T., Sarma, K., & Nolan, A. (2014). The psychological impact of infertility and fertility treatment on the male partner. *Human Fertility*, 17(3), 203-209. doi:10.3109/14647273.2014.942390
- Edelmann, R. J., Connolly, K. J., & Bartlett, H. (1994). Coping strategies and psychological adjustment of couples presenting for IVF. *Journal Of Psychosomatic Research*, 38(4), 355-364.
- Eugster, A., & Vingerhoets, A. (1999). Psychological aspects of in vitro fertilization: a review. *Social Science & Medicine*, 48(5), 575-589.
- Faith, J., Thorburn, S., & Tippens, K. M. (2015). Examining the association between patient-centered communication and provider avoidance, CAM use, and CAM-use disclosure. *Alternative Therapies In Health And Medicine*, 21(2), 30-35.
- Freeman, E., Boxer, A., Rickels, K., Tureck, R., & Mastroianni, L. (1985). Psychological evaluation and support in a program of in vitro fertilization and embryo transfer. *Fertility And Sterility*, 43(1), 48-53.
- Foley, E., Baillie, A., Huxter, M., Price, M., & Sinclair, E. (2010). Mindfulness-based cognitive therapy for individuals whose lives have been affected by cancer: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, 78, 72–79.
- George, M. (2015). Integrative medicine is integral to providing patient-centered care. *Annals Of Allergy, Asthma & Immunology: Official Publication Of The American College Of Allergy, Asthma, & Immunology*, 114(4), 261-264. doi:10.1016/j.anai.2015.01.001
- Gibson, F., Ungerer, J., Tennant, C., & Saunders, D. (2000). Parental adjustment and attitudes to parenting after in vitro fertilization. *Fertility And Sterility*, 73(3), 565-574.

- Goldin, C., & Katz, L. F. (2002). The Power of the Pill: Oral Contraceptives and Women's Career and Marriage Decisions. *Journal Of Political Economy*, 110(4), 730-770.
- Golombok, S., Cook, R., Bish, A., & Murray, C. (1995). Families created by the new reproductive technologies: quality of parenting and social and emotional development of the children. *Child development* 66,(2), 285-298.
- Greil, A. L., Porter, K. L., & Leitko, T. A. (1990). Sex and intimacy among infertile couples. *Journal Of Psychology & Human Sexuality*, 2(2), 117-138.
- Hagel, A. (2013). Banking on Infertility: Medical Ethics and the Marketing of Fertility Loans. *Hastings Center Report*, 43(6), 15-17. doi:10.1002/hast.228
- Hammarberg, K., Astbury, J., & Baker, H., W., G. (2001). Women's experience of IVF: a follow-up study. *Human Reproduction*, 16(2), 374-383.
- Haemmerli, K., Znoj, H., Burri, S., Graf, P., Wunder, D., & Perrig-Chiello, P. (2008). Psychological interventions for infertile patients: A review of existing research and a new comprehensive approach. *Counselling & Psychotherapy Research*, 8(4), 246-252. doi:10.1080/14733140802292895
- Himmel, W., Meyer, J., Kochen, M. M., & Michelmann, H. (2005). Information Needs and Visitors' Experience of an Internet Expert Forum on Infertility. *Journal Of Medical Internet Research*, 7(2), doi:10.2196/jmir.7.2.e20
- Hinton, L., Kurinczuk, J. J., & Ziebland, S. (2010). Infertility; isolation and the Internet: a qualitative interview study. *Patient Education And Counseling*, 81(3), 436-441. doi:10.1016/j.pec.2010.09.023

- Holzle, C., Brandt, U., Lutkenhaus, R., & Wirtz, M. (2002). Solution-focused counselling for involuntarily childless couples. In B. Strauss (Ed.), *Involuntary childlessness: Psychological assessment, counselling and psychotherapy* (pp. 105–126). Seattle: Hogrefe & Huber Publishers.
- Johansson, M., & Berg, M. (2005). Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment. *Scandinavian Journal Of Caring Sciences*, 19(1), 58-63.
- Johansson, M., Adolfsson, A., Berg, M., Francis, J., Hogström, L., Janson, P., & ... Hellström, A. (2009). Quality of life for couples 4-5.5 years after unsuccessful IVF treatment. *Acta Obstetricia Et Gynecologica Scandinavica*, 88(3), 291-300.
- Katz, P., Nachtigall, R., & Showstack, J. (2002). The economic impact of the assisted reproductive technologies. *Nature Cell Biology*, 4s29-s32.
- Kaufman, G. (2000). Do gender role attitudes matter? Family formation and dissolution among traditional and egalitarian men and women. *Journal of Family Issues*, 21(1), 128-144.
- Kee, B. S., Jung, B. J., & Lee, S. H. (2000). A Study on Psychological Strain in IVF Patients. *Journal of Assisted Reproduction and Genetics*, 17(8), 445-448.
- Keng, S., Smoski, M. J., & Robins, C. J. (2011). Effects of mindfulness on psychological health: A review of empirical studies. *Clinical Psychology Review*, 31(6), 1041-1056.
- Khetarpal, A., & Singh, S. (2012). Infertility: Why can't we classify this inability as disability? *Australasian Medical Journal*, 5(6), 334-339. doi:10.4066/AMJ.2012.1290
- Klonoff-Cohen, H. (2008). The role of procedural vs. chronic stress and other psychological factors in IVF success rates. In A. B. Turley, G. C. Hofmann (Eds.) , *Life style and health research progress* (pp. 67-85). Hauppauge, NY US: Nova Biomedical Books.

- Kulkarni, G., Mohanty, N. C., Mohanty, I. R., Jadhav, P., & Boricha, B. G. (2014). Survey of reasons for discontinuation from in vitro fertilization treatment among couples attending infertility clinic. *Journal Of Human Reproductive Sciences*, 7(4), 249-254. doi:10.4103/0974-1208.147491
- Lalos, A. (1999). Breaking bad news concerning fertility. *Human Reproduction (Oxford, England)*, 14(3), 581-585.
- Lentner, E., & Glazer, G. (1991). Infertile couples perceptions of infertility support-group participation. *Health Care for Women International*, 12, 317–330.
- Levitas, E., Parmet, A., Lunenfeld, E., Bentov, Y., Burstein, E., Friger, M., et al. (2006). Impact of hypnosis during embryo transfer on the outcome of in vitro fertilization embryo transfer: a case- control study. *Fertility and Sterility*, 85, 1404–1408.
- Lippa, R. A. (2005). *Gender, nature, and nurture (2nd ed.)*. Mahwah, NJ US: Lawrence Erlbaum Associates Publishers.
- Mahlstedt, P. P. (1987). The crisis of infertility: An opportunity for growth. In G. R. Weeks & L. Hof (Eds.), *Integrating sex and marital therapy: A clinical guide* (pp. 121-148). New York: Brunner/Mazel.
- Markestad, C., Montgomery, L., & Bartsch, R. (1998). Infertility and length of medical treatment effects on psychological, marital, and sexual functioning. *International Journal Of Rehabilitation & Health*, 4(4), 233-243.
- Martin, S. P. (2000). Diverging fertility among U.S. women who delay childbearing past age 30. *Demography*, 37(4), 523 – 533.

- Mason, M. C. (1993). *Male infertility – Men talking*. London: Routledge.
- Massey, M. T. (2015). Managing infertility in primary care. *Practice Nurse*, 45(3), 32-37.
- Matthiesen, S.M.S., Frederiksen, Y., Ingerslev, H. J., & Zachariae, R. (2011). Stress, distress and outcome of assisted reproductive technology (ART): a meta-analysis. *Human Reproduction*, 26(10), 2763 – 2776.
- Mays, N., & Pope, C. (1999). Quality in qualitative health research: qualitative research in health care. *BMJ Publication Group, London*.
- McNaughton-Cassill, M.E., Bostwick J.M., Vanscoy, S.E., Arthur, N.J., Hickman, T.N., Robinson R., & Neal, G.S. (2000). Development of brief stress management support groups for couples undergoing in vitro fertilization treatment. *Fertility and Sterility* 74, 1, 87-93.
- McNaughton-Cassill, M. E., Bostwick, J. M., Arthur, N. J., Robinson, R. D., & Neal, G. S. (2002). Efficacy of brief couples support groups developed to manage the stress of in vitro fertilization treatment. *Mayo Clinic Proceedings*, 77(10), 1060-1066.
- McPhee, S. J., Papadakis, M. A., & Tierney, L. M. (2008). *Current Medical Diagnosis & Treatment, 2008*. McGraw-Hill Medical.
- Menning, B. (1976). Resolve: a support group for infertile couples. *American Journal Of Nursing*, 76258-259.
- Menning, B. E. (1980). The emotional needs of infertile couples. *Fertility and Sterility*, 34, 313-319.

- Menning, B. E. (1988). *Infertility: A guide for the childless couple* (2nd ed.). New York: Prentice Hall.
- Möller, A., Fällström, K. (1991) Psychological consequences of infertility: A longitudinal study. *Journal of Psychosomatic Obstetrics & Gynecology*, 12(1), 27-44.
- Mikkelsen, A. T., Madsen, S. A., & Humaidan, P. (2013). Psychological aspects of male fertility treatment. *Journal Of Advanced Nursing*, 69(9), 1977-1986. doi:10.1111/jan.12058
- Mills, M., Rindfuss, R., McDonald, P., & te Velde, E. (2011). Why do people postpone parenthood? Reasons and social policy incentives. *Human Reproduction Update*, 17,(6), 848-860. Advanced Access publication on June 7, 2011 doi:10.1093/humupd/dmr026.
- Noorbala, A.A., Ramazanzadeh, F., Malekafzali, H., Abedinia, N., Forooshani, A.R., Shariat, M., et al. (2008). Effects of a psychological intervention on depression in infertile couples. *International Journal of Gynecology and Obstetrics*, 101, 248–252.
- Northcutt, N., & McCoy, D. (2004). *Interactive qualitative analysis: A systems method for qualitative research*. Thousand Oaks, CA US: Sage Publications, Inc.
- O’Cathain, A., Murphy, E., Nicholl, J. (2007) Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. *BMC Health Services Research*. 7(85).
- Owens, D. (1982). The desire to father: Reproductive ideologies and involuntary childlessness men. In L. Mckee & M. O’Brien (Eds.), *The father figure* (pp. 72–86). London: Tavistock.
- Peterson, B. D., & Eifert, G. H. (2011). Using Acceptance and Commitment Therapy to Treat Infertility Stress. *Cognitive And Behavioral Practice*, 18(4), 577-587.

Redd, W.H., Montgomery, G.H., & DuHamel, K.N. (2001). Behavioral intervention for cancer treatment side effects. *Journal of the National Cancer Institute*, 93, 810–823.

Resolve Insurance Coverage. Retrieved July 13, 2015, from Resolve website: http://www.resolve.org/family-building-options/insurance_coverage/state-coverage.html

Ruble, D. N., Martin, C. L., & Berenbaum, S. A. (2006). Gender development. In W. Damon & R. M. Lerner (Eds. In Chief) & N. Eisenberg (Vol. Ed.), *Handbook of child psychology, Vol. 3. Social, emotional, and personality development* (6th ed., pp. 858-932). Hoboken, NJ: Wiley.

Salzer, L. (1991). *Surviving infertility*. New York: Harper Collins.

Sarrel, P. M., & DeCherney, A. H. (1985). Psychotherapeutic intervention for treatment of couples with secondary infertility. *Fertility and Sterility*, 43, 897–900.

Schuth, W., Keck, C., Vogelgesang, D., & Breckwoldt, M. (1999). Psychosoziale Bewältigung der ungewollten Kinderlosigkeit: Konzept, Inhalte und Evaluation von 27 Wochenendseminaren mit 288 sterilen Paaren. [Psychosocial coping with unwanted sterility: Concept, contents and evaluation of 27 weekend seminars with 288 sterile couples]. *Geburtshilfe and Frauenheilkunde*, 59, 225–231.

Shapiro, C. H. (1988). *Infertility and pregnancy loss: A guide for helping professionals*. San Francisco: Jossey-Bass.

Slade, P., Emery, J., & Lieberman, B. A. (1997). A prospective, longitudinal study of emotions and relationships in in-vitro fertilization treatment. *Human Reproduction*, 12(1), 183-190.

- Smeenk, J. M. J., Verhaak, C., M., Eugster, A., van Minnen, A., Zielhuis, G. A., & Braat, D. D. M. (2001). The effect of anxiety and depression on the outcome of in-vitro fertilization. *Human Reproduction*, 16(7), 1420-1423.
- Stewart, M. J. (2000). The Impact of Patient-Centered Care on Outcomes. *Journal Of Family Practice*, 49(9), 796-804.
- Stewart, M. (2001). Towards a global definition of patient centered care. *BMJ (Clinical Research Ed.)*, 322(7284), 444-445.
- Tenenbaum, H. R., & Leaper, C. (2003). Parent-child conversations about science: Socialization of gender inequities. *Developmental Psychology*, 39, 34-47.
- Tesoriero, H. W. (2008, February 19). Infertile Couples Head Overseas For Treatments. *Wall Street Journal - Eastern Edition*. pp. D1-D2.
- Valentine, D. (1986). Psychological impact of infertility: Identifying issues and needs. *Social Work in Health Care*, 11(4), 61-69.
- Verhaak CM, Smeenk JMJ, van Minen A, Kremer JAM, Kraaimat FW. (2005). A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment cycles. *Human Reproduction*, 20, 2253–2260.
- Wagenaar, K., Huisman, J., Cohen-Kettenis, P., & Delemarre-van de Waal, H. (2008). An overview of studies on early development, cognition, and psychosocial well-being in children born after in vitro fertilization. *Journal Of Developmental And Behavioral Pediatrics: JDBP*, 29(3), 219-230

- Wagenaar, K., Ceelen, M., van Weissenbruch, M., Knol, D., Delemarre-van de Waal, H., & Huisman, J. (2008). School functioning in 8- to 18-year-old children born after in vitro fertilization. *European Journal Of Pediatrics*, 167(11), 1289-1295.
- Wagenaar, K., van Weissenbruch, M., Knol, D., Cohen-Kettenis, P., Delemarre-van de Waal, H., & Huisman, J. (2009). Behavior and socio-emotional functioning in 9-18-year-old children born after in vitro fertilization. *Fertility And Sterility*, 92(6), 1907-1914.
- Westoff, C.,F., & Higgins, J. (2009). Relationships between men's gender attitudes and fertility: response to Puur et al.'s 'Men's childbearing desires and views of the male role in Europe at the dawn of the 21st century'. *Demographic Research*, 21, 65-74.
- Wichman, C. L., Ehlers, S. L., Wichman, S. E., Weaver, A. L., & Coddington, C. (2011). Comparison of multiple psychological distress measures between men and women preparing for in vitro fertilization. *Fertility & Sterility*, 95(2), 717-721.
- Williams, L., Bischoff, R., Ludes, J. (1992). A Biopsychosocial model for treating infertility. *Contemporary Family Therapy*, 14(4), 309-322.
- Wirtberg, I., Moller, A., Hogstrom, L., Tronstad, S., E., & Lalos, A. (2007). Life 20 years after unsuccessful infertility treatment. *Human Reproduction*, 22(2), 598-604.
- Wischmann, T., Stammer, H., Gerhard, I., & Verres, R. (2002). Couple counseling and therapy for the unfulfilled desire for a child: The two-step approach of the 'Heidelberg Infertility Consultation Service'. In B. Strauss (Ed.), *Involuntary childlessness: Psychological assessment, counseling, and psychotherapy* (pp. 127-149). Ashland, OH US: Hogrefe & Huber Publishers.

- Wright, J., Duchesne, C., Sabourin, S., Bissonnette, F., Benoit, J., & Girard, Y. (1991). Psychosocial distress and infertility: men and women respond differently. *Fertility and Sterility*, 55(1), 100-108.
- Wu, A. K., Elliott, P., Katz, P. P., & Smith, J. F. (2013). Time costs of fertility care: the hidden hardship of building a family. *Fertility And Sterility*, 99(7), 2025-2030. doi:10.1016/j.fertnstert.2013.01.145
- Wu, A. K., Odisho, A. Y., Washington, S. 3., Katz, P. P., & Smith, J. F. (2014). Out-of-pocket fertility patient expense: data from a multicenter prospective infertility cohort. *The Journal Of Urology*, 191(2), 427-432. doi:10.1016/j.juro.2013.08.083

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