BIRTHING UNDERSTANDING:

AN EXAMINATION OF THE FEMALE EXPERIENCE OF INFERTILITY

A thesis submitted to the Caspersen School of Graduate Studies

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Master of Medical Humanities

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Dedication

This is for all of the women who have had, have, or will have the experience of infertility. I hope you will keep telling your stories. For those who have found happiness, congratulations, and for those still searching, I sincerely hope you find true joy.

CONTENTS

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I want to express my sincere appreciation to my advisor, Dr. Philip Scibilia, for working with me tirelessly and supporting my vision for this project.

Second, I am grateful to my reader, Professor Linda Van Blerkom, for introducing me to the field of medical anthropology. Without her, I would not have discovered my interest in this topic. She has taught me invaluable lessons that I will carry with me always.

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Chapter 1

INTRODUCTION

From the time women are little girls, we feed, clothe, and love our dolls as though they are our children, and the mental blueprint of having babies and becoming mothers begins to form. Girls are taught that bearing children is part of womanhood, and the discovery during the childbearing years that having children might not be possible is devastating.

Infertility affects the lives of nearly seven-million women between the ages of fifteen and forty-four in stable relationships in the United States ("Infertility" at *CDC*). As of 2013, the Centers for Disease Control and Prevention reported that the prevalence of reported infertility cases in the United States has decreased in recent years. ("National"). However, research from 2010 suggests that the prevalence of infertility is increasing (Chachamovich et al. 101).

The aim of this paper is to identify the impact of reproductive problems on women's lives and help readers gain a better understanding of the female experience of infertility from the time a woman discovers difficulty with conception through the duration of the fertility-treatment process. The paper explains that adequate understanding of the experience is lacking and needs to improve. An improvement in understanding the experience of infertility among medical professionals, family, friends, and the community has the ability to ameliorate emotional and social components and diminish suffering. Stories from women and medical professionals addressing seven elements of the female infertility experience are presented to achieve this goal. Once the

stories conclude, analyses of both perspectives are made regarding the elements of the female infertility experience. The availability of resources for women is addressed, and possible solutions to improve the overall female experience of infertility are provided.

The female experience of infertility will be the focus. Despite the fact that men have a role in creating children, the goal of this paper is to understand infertility from the female perspective. Women are responsible for bearing children regardless of which partner is the cause of infertility and are often blamed by society or blame themselves if they are unable to conceive whether or not the origin of infertility is female related.

The topic of infertility has been discussed for centuries. Fertility was important in ancient Egypt. Photographs of women with children were a regular part of ancient Egyptian life. Fertility figurines were given as offerings (Silverman). In the Old Testament, Hannah,[1] Rachel,[2] Rebekah,[3] and Sarah[4] experienced problems bearing children, and in the New Testament, Elizabeth had difficulty conceiving.[5]

Today, infertility continues to be studied and discussed. While research pertaining directly to the scope of this project is lacking, various studies, books, and

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[1] See *New International Version Bible* 1 Samuel 1:10 "In her deep anguish Hannah prayed to the LORD, weeping bitterly. And she made a vow, saying, 'LORD Almighty, if you will only look on your servant's misery and remember me, and not forget your servant but give her a son, then I will give him to the LORD for all the days of his life, and no razor will ever be used on his head.'"

[2] See *New International Version Bible* Genesis 29:31 "When the LORD saw that Leah was not loved, he enabled her to conceive, but Rachel remained childless."

[3] See *New International Version Bible* Genesis 25:21 "Isaac prayed to the LORD on behalf of his wife, because she was childless. The LORD answered his prayer, and his wife Rebekah became pregnant."

[4] See *New International Version Bible* Genesis 11:30 "Now Sarah was childless because she was not able to conceive."

[5] See *New International Version Bible* Luke 1:13 "But the angel said to him: "Do not be afraid, Zechariah; your prayer has been heard. Your wife Elizabeth will bear you a son, and you are to call him John."

articles contribute to the topic of this paper. Peterson et al. conducted research on fertility understanding among male and female college students and found that a majority of students in the study plan to have children, but the respondents lack awareness of age-related reproductive limitations and believe fertility treatment is more successful than it actually is. The lack of fertility awareness found in the study contributes to the discussion on the lack of infertility understanding in this paper. Wu et al. found that fertility treatment demands that female patients are able to set time aside for treatment, and the time that is required as part of seeking reproductive services adds to the stress women with infertility feel. The time, and other demands, required when seeking fertility treatment will be mentioned again later. Souter et al. found in their study of patients' satisfaction with fertility treatment that patients are dissatisfied with the information they receive and the length of time spent waiting for results from physicians. Patients feel that adequate emotional support is not provided, and Malin et al. found that patients feel that physicians lack empathy and understanding. Souter et al. and Malin et al. support some of the main recurring themes explained in this thesis. Psaros et al. conducted a study that looked at the impact of depression on fertility treatment and concluded that women with high levels of depression have difficulty committing to treatment. Psaros' argument that levels of depression interfere with treatment adds an additional layer of complexity to the current research. Turner et al. studied changes in levels of stress and anxiety at different phases of treatment. The authors concluded that levels of stress and anxiety are elevated at all points of treatment, but women with lower levels are more likely to have reproductive success. The study supports the current research in regard to the emotions experienced when encountering reproductive difficulties. Daniluk wrote an article on the

need for specialized counseling techniques for clients experiencing infertility and suggests that counselors must modify therapy to meet the specific needs of those seeking counseling due to reproductive problems ("Strategies"). Domar researched the benefits of mind/body programs for infertility and found that the use of a mind/body program can decrease stress associated with infertility. A study by Wingert et al. found that the Internet is a method of support, but the information found online needs to be monitored to ensure women are receiving reliable information. Y. Epstein et al. concluded from their research that there are limitations of the Internet as a support service and argue that women need to seek support from other outlets in addition to the support found online. Research by Daniluk, Domar, Wingert et al., and Y. Epstein et al. support the issue raised in this paper that support services need to improve and be specially designed to decrease suffering caused by infertility. Chachamovich et al. examined quality-of-life issues associated with the infertility experience and found that quality-of-life levels are lower in women experiencing infertility but not men. The research conducted by Chachamovich et al. adds to the argument made in this thesis that infertility affects many aspects of women's lives. Greil's research illustrates the need for women with infertility to be viewed in the larger social context because the medicalization of infertility focuses on women as patients but fails to address the social component. Greil's paper supports the argument made in this thesis that infertility understanding by a woman's social network needs to improve. Wirtberg et al. concluded that the experience of infertility affects women's lives long after treatment ends. Infertility leads to long-term emotional consequences. Women tend to carry memories of the experience with them and recall tension within marital relationships many years after completing treatment. Wirtberg et

al. reinforce the impact of infertility discussed in this thesis. Williams' research is the study that aligns most closely with the topic of this paper. Williams conducted interviews with women to understand the psychological effects of the infertility experience. The author found similar themes to the research reported in this thesis. She concluded that the needs of women experiencing infertility vary greatly, but in general, women feel that outsiders do not understand the experience.

The existing literature shows that the topic of infertility is the focus of many researchers. The literature also demonstrates that more work needs to continue to gain a better understanding of the topic. Attempts are being made in many different fields within the biomedical and social sciences to improve knowledge about infertility, and this paper will expand on the existing research by viewing the topic through the lens of medical humanities. This paper fills an important void in existing research by examining both female and medical professional perspectives on the topic and assessing the experience holistically. A better understanding of the depth of human experience is possible due to the important contribution the field of medical humanities makes to various other disciplines researching aspects of the topic. To the author's knowledge, there is no existing research looking at female and medical professional perspectives on the female infertility experience within one piece of research. The selection of research pertaining to the topic mentioned here shows that infertility presents a major problem in the lives of the women it affects.

Chapter 2

THE BASICS OF INFERTILITY

Infertility is defined as the inability to conceive or carry a viable fetus to term after twelve consecutive months of unprotected sex. It is estimated that six percent of women in the United States between the ages of fifteen and forty-four experience infertility. Women who experience irregularities in their menstrual cycles on a regular basis and women older than the age of thirty-five are encouraged to seek medical attention if they are unable to successfully conceive after a period of six months. Women who do not have regular menstrual cycles may not be ovulating properly, and women older than thirty-five years of age have fewer eggs than younger women ("Infertility" at *CDC*).

Girls are born with a finite number of eggs at birth. When girls begin menstruating, the egg reserve begins depleting. As women age, the number of eggs left becomes fewer and fewer with each menstrual cycle. Women begin their lives with approximately 300,000 eggs and enter their thirties with only approximately 30,000 remaining. Therefore, the likelihood of conceiving significantly decreases as women reach the age of thirty and further decreases with each passing year. In addition, the quality of eggs deteriorates with age (Butler; Wallace and Kelsey). As people age, their skin becomes wrinkled, some lose their hair, and their bodies generally deteriorate. Women's eggs are much the same.

There are two classifications of infertility. Women are diagnosed with primary infertility if pregnancy has never been achieved or if attempts at pregnancy end in spontaneous abortion (commonly known as miscarriage). Secondary infertility is the

term used when women are unable to get or stay pregnant after carrying a healthy baby to term ("Infertility Definitions").

Risk Factors

There are a number of risk factors that contribute to infertility. Women who smoke, eat a poor diet, exercise or drink alcohol excessively, experience stress regularly, have hormonal problems or sexually-transmitted diseases, or are overweight or underweight are more likely to experience problems with fertility ("Infertility Fact Sheet").

Medical Diagnoses Contributing to Infertility

When a woman discusses her difficulty conceiving with an obstetrician/gynecologist (OB/GYN) for the first time, medical recommendations are made. The preliminary steps taken often involve laboratory tests to check for abnormalities. Basic blood, thyroid, and other hormone levels will be evaluated prior to referral to a fertility specialist.

There are a number of medical conditions that can cause infertility. However, in thirty percent of cases, a specific diagnosis is unable to be made after sufficient testing has been completed by an OB/GYN or fertility specialist (Ray 591). The table on the following page gives basic information regarding some common diagnoses.

Table 1

Potential Medical Causes of Infertility

Medical Condition	Symptoms	Causes	Treatment
Polycystic Ovary Syndrome or (PCOS) Numerous cysts on ovaries	Excessive or abnormal menses	High insulin level Inflammation due to infection Heredity	Medication Surgery
Primary Ovary Insufficiency (POI) Pre-mature menopause-like symptoms	Irregular menses Hot flashes Vaginal dryness Sleeping problems	Cancer treatment Genetics Hormone imbalances	Medication
Uterine Fibroids Noncancerous tumors of the uterus	Heavy menstrual bleeding Lower back or abdominal pain Bloating Frequent urination Pain during intercourse	Hormone imbalances Obesity Eating habits Genetics Advanced age	Medication Surgery
Spontaneous Abortion Miscarriage occurring prior to week twenty of pregnancy	Menstrual bleeding	Environmental toxins Obesity Smoking Alcohol use Age Hormone imbalances Immune conditions Diabetes Infection Previous miscarriages	Medication Surgery
Endometriosis Endometrial tissue growing outside of the uterus	Abnormal menstrual bleeding Spotting Pain during intercourse Intense cramping	Retrograde menstruation Immune system deficiencies Lymphatic system abnormalities	Medication Surgery
Pelvic Inflammatory Disease (PID) Infection of the pelvic region	Odorous vaginal discharge Fever Abdominal pain Sexual discomfort Painful urination Irregular menses	Vaginal or cervical bacteria Sexually-transmitted disease	Medication
Ectopic Pregnancy Pregnancy outside of the uterus	Absent or irregular menses Abdominal, shoulder, or low back pain Cramps Low blood pressure	Surgery to untie fallopian tubes Multiple sexual partners Previous infertility treatment Over age 35	Medication Surgery

Sources: "Ectopic" at *NLM.NIH*, "Endometriosis" at *Mayoclinic* and *Resolve*, Griebel, Craig P. et al., "Miscarriage" at *NLM.NIH*, "NCI" at *Cancer*, "Pelvic" at *Womenshealth*, "Polycystic" at *Mayoclinic*, and "Uterine" at *Womenshealth*.

In addition to the basic information given in the table on the previous page, some more in-depth information needs to be given regarding spontaneous abortion. Spontaneous abortion is most likely to occur in the first seven weeks of pregnancy. Approximately, fifteen to twenty percent of women miscarry ("Miscarriage"). The majority of cases (seventy-five percent) occur before reaching the twelfth week of pregnancy. Women are diagnosed as infertile if they experience two or more spontaneous abortions successively ("Multiple Miscarriage").

The table of explanations on the previous page shows that many causes and symptoms lead to different diagnoses. To determine an actual cause of infertility, medical professionals must thoroughly evaluate and test patients to find the origin of the problem. For the thirty percent of patients diagnosed with unexplained infertility, a conclusive diagnosis will never be made.

Chapter 3

THE FERTILITY TREATMENT PROCESS:

WITHIN THE WALLS OF THE FERTILITY CLINIC

Fertility treatment has evolved in the past thirty years. Artificial insemination, the process of inserting sperm directly into a female's cervix, was conducted for the first time by a surgeon named John Hunter around 1790 (Guttmacher 623). John Rock, a physician, and his laboratory assistant, Miriam Menkin, performed the first *in vitro* fertilization (IVF) in 1944. However, the fertilized eggs died in the lab.[6] In 1978, the first successful product of IVF was born. Her name is Louise Brown (Manganaro). Brown was created in Britain by a British scientist, Robert Edwards, and obstetrician, Patrick Steptoe (Johnson 245-62). In the United States, the first healthy baby created through IVF was born to Judy Carr in 1981. Her baby, Elizabeth, was created by Howard Jones, a physician and former colleague of Edwards (R. Epstein). Edwards, Jones, and Steptoe had a history of pushing the limits of technological advances in medicine. In 1992, intracytoplasmic sperm injection (ICSI) was successfully used for the first time by scientists in Belgium ("Intracytoplasmic" at *MYVMC*). Today, reproductive services continue to evolve. Reproductive procedures are performed on a regular basis, and it was estimated in July of 2012 that five-million babies have been created by IVF and ICSI ("World's").

[6] The 2006 PBS film *Test Tube Babies* tells the history of assisted reproductive technology. Physicians, patients, and researchers had the chance to tell their stories about reproductive technology. Louise Brown's story can be found on the *American Experience* website on pages entitled "First Human Eggs Fertilized in a Laboratory" and "The US' First Test Tube Baby."

Treatment Process

Whether or not a diagnosis has been made prior to the initial appointment at a fertility clinic, finding a cause of infertility is a preliminary step toward effective treatment.

A reproductive endocrinologist (RE) is a physician who treats patients experiencing problems with fertility ("What"). Many of the services REs provide are assisted reproductive technologies (ART). ART is defined as fertility treatments in which eggs and sperm are physically manipulated by medical professionals. A procedure requiring handling of sperm alone is not classified as ART ("Assisted" at *CDC*).
The preparation for the first visit to an RE is complex. Patients are required to complete multiple pages of paperwork (see Appendix A for examples). Patients are asked about general information, but they are also required to give details of their menstruation pattern, sexual history and practices, previous pregnancies, exercise habits, previous test results, overall understanding of reproductive services, and medical, surgical, family, and gynecological history. A new-patient packet of information is normally ten to fifteen pages in length. Additional blank pages are provided for patients to discuss their motivation for seeking reproductive services. The patient is responsible for understanding her insurance benefits prior to the first appointment with the fertility specialist (*RMANJ*).

Once the preliminary paperwork has been completed, insurance benefits have been understood and verified, and the RE has run an array of diagnostic tests, a course of treatment is chosen. Some clinics require a psychological evaluation before treatment begins. Psychological testing is used to educate couples on the emotional burdens

created by fertility treatment and to ensure patients and partners are equipped to deal with the treatment process. There are a number of procedures the RE can use once the diagnosis of infertility has been identified.

While the list of medical conditions leading to problems with conception or carrying a baby to term is extensive, the treatment options offered by fertility clinics are equally complex. Figure 1 shows the female reproductive system to help readers better understand the following information on specific treatments.

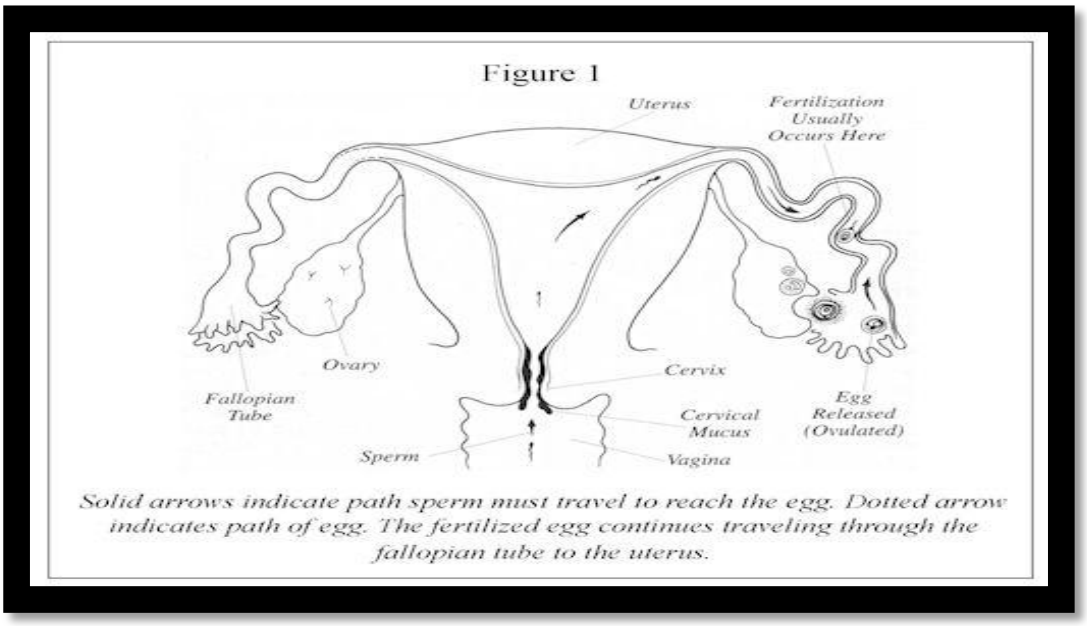

Figure 1. Female Reproductive Region

Source: *Assisted Reproductive Technologies: A Guide for Patients* 4.

On the following page, Table 2 gives information on some of the most common fertility-treatment methods. Treatments are listed in order from least to most invasive and expensive.

Table 2

Common Fertility Treatments

Medical Treatment	Indications	Explanation of Treatment	Cost	Success Rate
Medication Often used in conjunction with ART, IUI, or artificial insemination	Problems with ovulation	Medication prescribed based on diagnosis	$50 to $500 or more per cycle	Varies depending on diagnosis
Intrauterine Insemination (IUI)	Unexplained infertility Endometriosis Male-factor infertility	Sperm inserted into uterus through catheter	$350 to $885 per cycle	10 to 20 percent per cycle
Artificial Insemination	Unexplained infertility Endometriosis Male-factor infertility	Sperm inserted into cervix, fallopian tubes, or uterus	$350 to $885 per cycle	10 to 20 percent per cycle
Intracytoplasmic Sperm Injection (ICSI)	Problem with embryo attachment Male-factor infertility	Eggs retrieved from female, injected with sperm in lab, and embryos inserted into uterus	$1500 per cycle plus medication costs $3000 to $5000 per cycle	20 to 40 percent per cycle
***In Vitro* Fertilization (IVF)**	Unexplained infertility Fallopian tube abnormality Male-factor infertility	Eggs are retrieved from female, combined with male's sperm in lab, and embryos inserted into uterus	$7500 to $8200 per cycle plus medication costs $3000 to $5000 per cycle	20 to 40 percent per cycle
Gamete Intrafallopian Transfer (GIFT)	Same indications as IVF and ICSI Used rarely except for patients with certain religious beliefs	Eggs and sperm inserted into fallopian tubes separately to join naturally	$15,000 to $20,000 per try	Unavailable due to rare use
Zygote Intrafallopian Transfer (ZIFT)	Same indications as IVF and ICSI Used rarely except for patients with certain religious beliefs	Eggs and sperm joined in laboratory and embryos then inserted into fallopian tubes	$15,000 to $20,000 per try	Unavailable due to rare use

Sources: "Embryo" at *HFEA*, "Gamete" at *Cancer*, Guttmacher, "Intracytoplasmic" at *ASRM* and *MYVMC*, "Intrauterine" at *Americanpregnancy* and *COE.UCSF*, "IVF" at *NHS*, "Fertility" at *Babycenter*, "The Costs" at *Resolve*, and "Understanding" at *RMANJ*.

Due to the number of assisted reproductive technologies requiring egg retrieval, Figure 2 shows the egg-retrieval process.

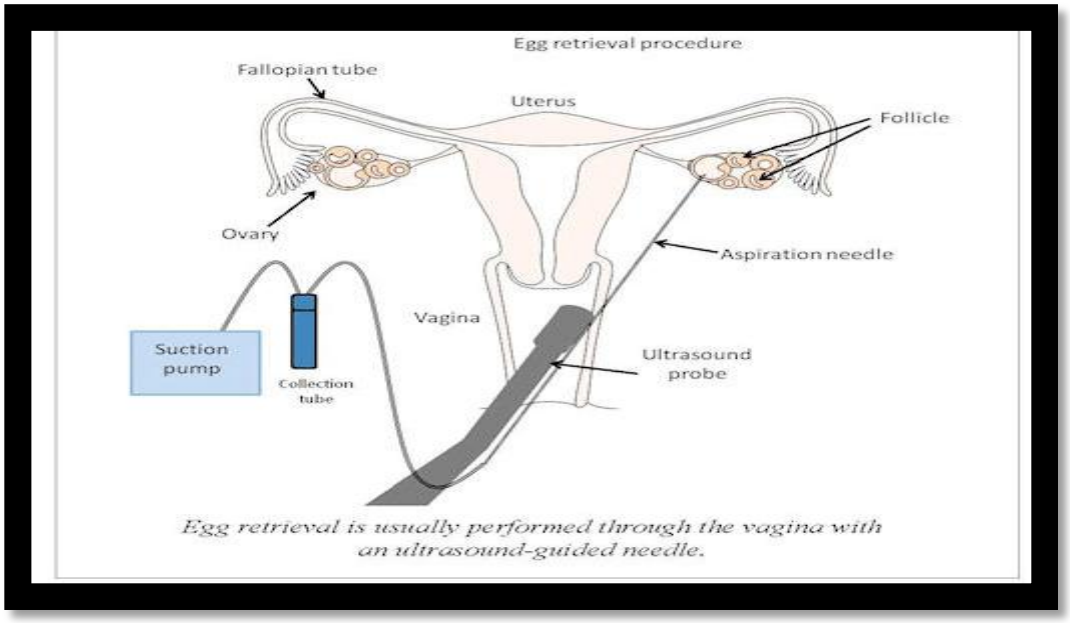

Figure 2. Egg Retrieval

Source: *Assisted Reproductive Technologies: A Guide for Patients* 7.

Donor Eggs and Sperm

Some causes of infertility require the use of donor eggs or sperm. If sperm or eggs are provided by a donor, the procedures of IUI, IVF, and ICSI are conducted in much the same way. The woman trying to conceive will make the same preparations for the recommended procedure whether the eggs and sperm being inserted belong to her and her partner or donors. If a donor is used, the treatment process becomes more complicated because prospective donors are screened vigorously before a desired candidate is selected. The cost of treatment increases when a donor is used because the

genetic material is not being provided by both of the intended parents, and preparations for the use of a donor are extensive.

Preimplantation Genetic Diagnosis

Preimplantation genetic diagnosis (PGD) is a fairly recent procedure in which the eggs retrieved from patients preparing to undergo IVF or ICSI are combined with sperm in the laboratory. After gametes have joined in the laboratory, cells are taken from newly formed embryos to check for detrimental or unwanted genetic conditions ("Pre-Implantation"). Couples undergo PGD to avoid having a baby with catastrophic or unplanned medical conditions. If testing indicates any potential problems, patients can forgo the insertion of embryos.

Safety and Ethical Considerations

Questions may be raised in regard to existing guidelines limiting the number of embryos permitted to be transferred to patients. Most clinics follow the guidelines set forth by the American Society for Reproductive Medicine (ASRM) and insert a maximum of one or two embryos per cycle. These rules have been put in place to prevent multiple births or developmental issues due to multiple fetuses. Women of older age are sometimes permitted to have more embryos transferred because of increased vulnerability and advanced age. However, fertility specialists must discuss the potential risk for multiple births with each patient. If patients do not feel comfortable having two embryos transferred, they can elect to have only one inserted ("Criteria").

Complementary and Alternative Treatments

Complementary and alternative medicine (CAM) continues to gain popularity in the American medical system. In the treatment of infertility, acupuncture, meditation, chiropractic care, mindfulness practices, yoga, prayer, and various other non-Western techniques are used in conjunction with biomedicine to increase the chances of conception.

A majority of patients use CAM of some kind during fertility treatment, but only approximately thirty percent of patients seeking alternative therapies report the usage to their physicians.

Physicians often do not mind if their patients are using CAM, and some doctors recommend CAM therapies to their patients. However, many fertility specialists are not sure if complementary and alternative approaches have any impact on the success of reproductive services (Clark et al.).

Insurance Coverage

Healthcare costs in the United States are high and fertility treatment is also expensive. Insurance companies do not always cover the cost of reproductive services. An OB/GYN office often helps patients check individual insurance coverage, but patients are ultimately responsible for knowing whether their insurance provider reimburses for fertility treatment. Most fertility clinics will not schedule a new-patient appointment until insurance coverage has been verified and treatment has been authorized. Insurance companies have specific guidelines regarding reproductive services. A few cycles of IUI are required in most cases as the first treatment before more expensive procedures are

covered unless there is a specific diagnosis deeming more invasive and expensive treatments necessary ("Understanding"). Insurance does not always cover CAM, but alternative and complementary treatments are often less expensive than other medical therapies.

In conclusion, the complexity of medical treatments available for infertility and the overall fertility-clinic experience require dedication from patients and medical professionals. Patients must make the necessary preparations before and during the treatment process and have a thorough understanding of their bodies as well as the demands associated with seeking reproductive assistance.

Chapter 4

FEMALE PERSPECTIVES ON INFERTILITY

The depth of the experience of infertility cannot be understood without learning from the women who encounter the painful reality of reproductive problems. A selection of stories told by real women who wanted to write about their journeys represents general themes encountered when experiencing infertility. The names used here have been taken directly from each published story.

Helen

Helen did not have trouble getting pregnant; she had trouble staying pregnant. Her first pregnancy happened not long after she married but it ended in spontaneous abortion (Bialosky and Schulman 15-28).

After her second miscarriage, Helen was devastated. Every attempt she made to prevent another miscarriage failed. She was deeply depressed and even thought that dying would help to escape the loss she felt. Helen felt as though she no longer had control and blamed herself for her reproductive problems. She thought miscarrying might have been a punishment for having premarital sex and her earlier choices in life. Acupuncture, doctors' appointments, and yoga classes did not help her feel any better about the current situation. Helen lacked the one thing she wanted most.

The emotional pain she experienced was made worse by people around her disregarding the importance of her unborn children. While others thought Helen should move on and try getting pregnant again, she was mourning the children she had lost. She

may have carried her babies for only a short time, but she still considered them to be part of her.

The best way Helen could deal with infertility was to become invisible. She did not want to see her baby-toting friends and tried to hide from everyone who had children. She blamed herself for her failure at childbearing. Her dysfunctional reproductive parts made Helen feel like she was letting everyone down around her.

The fact that Helen felt out of sync with her husband did not make her reproductive problems any easier. Helen's desire to have children was stronger than her husband's. He did not understand why she wanted to become a mother so badly. He was content with their life without having children. He did see the emotional and physical pain she encountered in her quest to have a child, and he realized that undergoing fertility treatment was an extremely difficult process.

Eventually, Helen became pregnant again. One day shortly after confirming the pregnancy, she had heavy bleeding and thought she must have lost the baby. Bleeding during previous pregnancies indicated the loss of her babies, and she thought this time would be the same. Helen's doctor soon delivered some unexpected news. She was still pregnant. Her doctor instructed her to stay in bed, and she was there for sixteen long weeks. Near the end of the pregnancy, Helen's doctor released her from bed rest. After Helen and her husband returned from a vacation she was initially uncomfortable taking due to her feelings of responsibility toward the life she was carrying, Helen gave birth to a healthy little girl. The unborn little girl she had so often dreamt about during previous pregnancies was alive. After not giving up, Helen was able to give birth to a living child.

Although Helen is incredibly grateful for her little girl, she will never forget what to her were the children she lost. She carries memories of their short lives with her. Helen's story ends with these words:

> Here is what it means to be a habitual aborter. You have children—not in the world inhabited by other people but in the private world of your heart—you have children you will never get to mother. They are secret children like those children you read about, confined to an attic or a closet. No one but you recognizes their existence, you yourself don't even know their form, their genders, the shape of their noses, the color of their eyes, and yet the strength of their souls flutters inside your heart like a caged bird's wings. As a mother, it is your job to get them out into the world, but you have failed them hopelessly, and so they haunt you, inhabiting a hyperreality that, in the middle of the night, feels truer and more real than any reality you have ever known. They are your children, and you are their mother. Yet you do not stop your life for them. Instead, you go on. (Bialosky and Schulman 28)

Agnes

Agnes' early attempts at conception were unsuccessful. As soon as she thought something may be wrong, she took a trip to the library to look for books about infertility and human reproduction. Agnes did everything the books told her to do. She took her temperature as directed and had sex at the times described as optimal in the books she read. "I bought one ovulation kit after another, kept incredibly detailed records of my menstrual cycle … and lay with a pillow under my rear end after sex so that gravity

might help the sperm find their way. A couple of times I even stood on my head" (Bialosky and Schulman 61).

When Agnes consulted medical help, her doctor explained that she had blocked fallopian tubes. She had surgery to repair her tubes and was told afterward that there was a lot of scarring. Agnes was starting to feel less hopeful that she was going to be able to get pregnant. The realization that she might need help was difficult. "Resorting to *in vitro* seemed an admission of failure. I didn't want to believe that I was handicapped to the extent that I needed drugs, doctors, an operating room, and a laboratory to do what I should have been able to do simply by having sex with Dan in our bed" (Bialosky and Schulman 62).

Finally, the call from the clinic came. Agnes was starting IVF and everything else that went with it. She arrived at the clinic for her first appointment in preparation for IVF.

> My blood was drawn, and I was taken to a small room for a vaginal ultrasound, a procedure that's a lot like sex, like intercourse anyway. A handsome young doctor tore open a familiar plastic packet and unrolled a Trojan rubber over a penis-shaped probe. The lights were dimmed. The doctor squeezed some lubricant from a tube, inserted the probe into my vagina, and wiggled it around. (Bialosky and Schulman 65)

Once the first appointment was over, her husband, Dan, injected the necessary hormones into her in preparation for IVF. She rode the subway to almost daily visits to the clinic. As she was riding the train with people who looked like they were going to their jobs, she thought, "You're on your way to work. I'm on my way to get pregnant" (Bialosky and

Schulman 64). Other people on the train may have wanted to accomplish certain things in their careers, but Agnes wanted a baby to be her accomplishment.

The time spent at the clinic day after day was filled with assessing other women around her. She tried to figure out their statuses. Were they pregnant yet? Were their bodies cooperating better than hers was? As Agnes thought about the forty-percent success rate for women undergoing the first IVF cycle advertised by the clinic, she wondered if she would be one of the successes. Agnes saw the same woman at almost all of her appointments. They seemed to have this connection although no words were ever exchanged. The woman was going through the same reproductive craziness as she was.

Finally, the day arrived. Agnes was taken to a procedure room and eggs were retrieved. As she lay on the table, Agnes thought about the woman that lay on the table before her and wondered if her retrieval was successful. Luckily, Agnes had more than a dozen eggs retrieved. While waiting, Dan saw the husband of the woman Agnes felt the connection with and found out her retrieval was unsuccessful. Agnes worried that something might happen to her eggs and wondered if the eggs would survive.

A few days after the retrieval, Dan and Agnes returned for the insertion of embryos. Four ideal embryos were selected to insert, and eleven of her eggs had been fertilized in all. The procedure went as planned, and the doctor told them to return in two weeks. The two-week wait felt like forever. She did not follow the fertility clinic's instructions and eventually broke down and purchased a home pregnancy test. The test was positive. Agnes was pregnant.

Agnes thinks back to her infertility experience and wonders if her children will understand her reasons for using IVF.

> I do sometimes wonder what Mary, Grace, and Alina will make of their beginnings when they're old enough to understand them. Will it matter to them that they spent a couple of nights swimming around in a petri dish? Will they, perhaps, attribute some portion of whatever degree of alienation they feel from their father and me when they're fifteen to the manner in which they were conceived? If they do, they'll be wrong. But they won't know that until and unless they have babies of their own, naturally, artificially, any way at all. (Bialosky and Schulman 68)

Phoebe

Her struggle began after she miscarried at five weeks. She had been married to Jeff for two years, and they had tried for six months to get pregnant. This was their first pregnancy. Jeff and Phoebe were traveling to see their parents for the holidays when Phoebe discovered she was spotting during a bathroom stop. They went to the nearest emergency department, and Phoebe's suspicions were confirmed. She was miscarrying. After the visit to the hospital, they continued on the trip to visit their parents, and Phoebe notified her doctor. She was advised to make another visit to the nearest hospital. She did as instructed and was told again that she was miscarrying, but no procedures were needed because her body was doing what it was supposed to do (Potts).

When Phoebe explained that she miscarried, people were not sympathetic in the way she needed. Phoebe said it made her upset when people said "'sorry for your loss.' I didn't lose anything! It makes it sound like I left it at the mall!" (Potts 32) She followed all of the pregnancy instructions, and still, her baby was taken away. Phoebe thought her

mother would be supportive and understanding, but she did not comfort Phoebe in the way she had expected. Her mother said that miscarriages happen, and she would be able to get pregnant again. Lots of women may experience miscarrying, but the fact that other people do not understand the experience does not make it easier. However, Phoebe saw women around her who had had babies taken from them and eventually became mothers, and she was optimistic she would be able to have a baby, too.

After the miscarriage, Phoebe went to the obstetrician to find out the reason. After being thoroughly examined, the doctor advised her to see a fertility specialist due to her age and history. The fertility specialist was unable to find an explanation for the miscarriage and told Jeff and Phoebe to try on their own for six months. She did everything she could think of to get pregnant. Surely, the right foods and monitoring ovulation would help her conceive.

Six months later, Phoebe was still not pregnant. Jeff accompanied her to the fertility clinic, or "fertility factory" as Phoebe referred to it, for the next step. The doctor asked a number of questions, but Phoebe had questions of her own. Could the cat's fecal matter cause infertility? What about drinking city water, eating soy, commuting, or using the microwave?

After the doctor discussed options with Jeff and Phoebe, and made sure their health insurance would cover treatment, they were on their way to having a baby. Phoebe wanted to start as soon as possible, but Jeff was more concerned about the effects and complexity of treatment. Phoebe was nervous about administering injections to prepare for intrauterine insemination (IUI), but with Jeff's help, she became comfortable.

When the time was right, Jeff and Phoebe returned to the clinic for insemination. Phoebe was nervous that the sperm would not be able to find her eggs. After the procedure, they waited. Fourteen days seemed like a long time. They returned to the clinic to find out Phoebe was not pregnant, and it was time to start the next cycle. Three more attempts at IUI were unsuccessful, but she found that Jeff was supportive through the entire process. During this time, Phoebe felt depressed and alone when close friends found out they were pregnant with twins.

After four attempts at IUI with no pregnancy, Phoebe switched to *in vitro* fertilization (IVF). She had to take more hormones and have more injections. On the day of the insertion, Phoebe was uncomfortable due to her bladder being full to allow the doctor to have a better view on ultrasound. The usual time for insertion was said to be ten minutes, but the doctor discovered her uterus was tilted making access somewhat difficult. After some discomfort, the insertion was complete, and Jeff and Phoebe went home to wait.

The return visit to the clinic showed that Phoebe was not pregnant. Two more IVF attempts were unsuccessful, and the doctor explained that the number of embryos inserted should be increased to increase the chances of conception. However, an increase in embryos also meant the possibility that the number of embryos would need to be reduced if the cycle was successful. The decision to destroy embryos was difficult, but Jeff and Phoebe decided to go ahead and increase the number to increase their chances of having a baby. At this point of treatment, the doctor was apologetic that Phoebe had not gotten pregnant, but when she asked if they should stop, her physician explained that, in his opinion, they were not to a point of needing to stop yet. The doctor gave Jeff and

Phoebe hope when they felt discouraged. Finally, after five failed IVF attempts, the doctor and insurance company put an end to fertility treatment. The doctor was sad for them. He had met with his partners often for advice on helping Jeff and Phoebe during the treatment process due to the level of complexity of Phoebe's situation. Phoebe is thankful her doctor and insurance company were the ones to make the decision to discontinue medical treatment because she does not feel she would have been able to make the decision on her own.

Throughout the infertility experience, Jeff and Phoebe experienced much sadness. She was upset when she saw or heard that other women were pregnant or had babies, and Jeff felt like fertility treatment created distance in their relationship. He wanted conception to be about being intimate with none of the other added stuff. Phoebe did not discuss their experience with others much because she felt that the need to have IVF meant she could not do what women should be able to do. She was ashamed, but Jeff gave her strength. In the end, they do not have a baby, and they decided adoption was not an option. Their family consists of Jeff, their cat Reuben, and Phoebe (Potts).

Lisa

Lisa did not have just one problem causing her infertility but four. Her husband had low-quality sperm, her blood tests showed problems with her thyroid and follicle-stimulating hormone (FSH) levels, and one of Lisa's fallopian tubes needed to be surgically corrected (Moorhawk).

During Lisa's problems with fertility, some people were kind and said the right things, but others did not understand or support the situation. "After a friend of mine

conceived, she asked me if my husband and I were doing it right. Other people said I should forget about any more treatment and just adopt but I wasn't at that place yet" (Moorhawk 1895). Encounters with friends who had children were difficult. She found that people jumped to the idea of adoption while she was still trying to figure out how to have a baby of her own. Adoption would be an option Lisa and her husband would choose if necessary, but she was not ready to give up on her attempts at having a baby. Lisa felt her doctor focused too much on his concern that pregnancy seemed unlikely due to the diagnosis of multiple contributing factors instead of being on her team of supporters.

Lisa finally reached the point of having ten failed intrauterine inseminations, and the time had come to move on to *in vitro* fertilization. She knew one cycle of IVF was all she could afford, so she felt the pressure for success on the one and only try. Fortunately for her, the cycle of IVF worked, and she is now the mother of a little boy (Moorhawk 1884-1907).

Strongwoman

Strongwoman began trying to get pregnant at the age of 33, and after six months of failed attempts at conception, she sought assistance from a fertility specialist. Strongwoman was diagnosed with multiple conditions contributing to her fertility problem. She was diagnosed with endometriosis, adenomyosis, and other factors that made conception difficult (Strongwoman).

Strongwoman was not satisfied with her first RE, so she decided to seek a second opinion. In consultation with the second RE, a decision was made to try IUI. IUI was

the most affordable option because Strongwoman did not have health insurance coverage for reproductive services. The first and only IUI attempt ended in miscarriage, and Strongwoman's treatment approach was changed. Her best chances at having a baby included IVF, but Strongwoman needed a surrogate to make her dream possible.

Although Strongwoman was not going to be carrying a baby personally, her eggs would be carried by a surrogate. Despite using a surrogate, Strongwoman was required to make the normal preparations for the egg-retrieval process. Preparations included frequent visits to the fertility clinic, ultrasounds, and medication. Changes in diet and exercise were made to increase the chances of success.

In addition to the normal demands of fertility treatment, Strongwoman encountered the additional stress associated with using a surrogate. A costly attorney created the necessary paperwork for surrogacy, and Strongwoman was financially responsible for her surrogate's fertility care at a different clinic in a different town in addition to her own personal fertility treatment. Treatment required more than money. Strongwoman had to set time aside for treatment and to make sure the needs of the surrogate were met. Holidays had to be spent at home to remain in close proximity to the clinic, and vacations were postponed due to treatment.

After spending months preparing for an optimal attempt at IVF, Strongwoman had eggs retrieved and two embryos were transferred to her surrogate. The embryos did not survive, and Strongwoman was devastated. A decision was made to try another round of IVF, and all of the demanding preparations began again. The number of eggs retrieved for the second cycle doubled from the first attempt, and Strongwoman was optimistic. Routine visits to the clinic led to news that the surrogate was pregnant, and

she was pregnant with twins. At first, Strongwoman was shocked because she had planned on one baby, but she quickly accepted the reality that she was going to have two.

The pregnancy presented new challenges. Strongwoman's surrogate called one evening worried because she was bleeding. She was twelve weeks pregnant at the time. She went to the emergency room, and Strongwoman waited at home for news because she was too far from her surrogate's town to travel to the hospital. The news came that both babies were alive, and the surrogate was sent home with instructions to follow up in the morning with her obstetrician. Other pregnancy complications included the babies growing at a slower than normal pace, and at thirty-two weeks, Strongwoman's surrogate gave birth via an emergency caesarean section. The babies were healthy but remained in the neonatal intensive care unit for three weeks.

Strongwoman is grateful for her son, daughter, and the woman who so kindly made her dream possible, but the experience of infertility devastated her in a number of ways. She felt as if her family and physicians did not understand the pain she was going through. Her mother was supportive only some of the time, her sister did not understand the desperation to have a child despite having children of her own, the doctors did not always provide the information, support, compassion, and understanding desired, and Strongwoman's husband did not always view fertility treatment at the same level of importance as she did. The lack of understanding from her family and physicians made her feel as though she was alone. She wrote, "It is an isolating feeling to realize that the people you love are incapable of being what you need them to be. But, that is the truth that infertility has revealed to me" (Strongwoman).

Strongwoman not only felt as if her family and doctors did not support or understand the experience, she was also devastated by the feelings of lack of control, guilt, blame, worry, and dread. She did not feel as though she had control over her own fertility and felt guilty because her body was not doing what normal bodies should do. Strongwoman blamed herself for her inability to achieve what so many other women accomplish easily and worried constantly that her and her surrogate's attempts at reproduction would end tragically. She dreaded the financial costs, time commitment, physical demands, and possibility of failure that accompanied fertility treatment.

Although Strongwoman's life changed drastically when she discovered her reproductive problems, she is grateful that her journey did not end in devastation. Shortly after Strongwoman brought her babies home, she wrote,

> I know how lucky I am to have reached my happy ending. Infertility does not always end happily. But I hope everyone reading this will find the strength to conquer the challenges that their personal infertility struggle bring[s] and reach their own happy ending, even if it looks different than you thought it would in the beginning. (Strongwoman)

Beckie

Beckie's concerns about reproduction began early in adulthood when she was diagnosed with polycystic ovary syndrome (PCOS), but her worries increased after her and her husband's active attempts at conception did not end in pregnancy (Beckie).

Beckie's story differs from the other stories told here in an important way. She lives in Canada where reproductive services are strictly monitored, and the wait for an

initial appointment with an RE is often months or a year in duration. Additionally, fertility clinics are not as prevalent in Canada making treatment more difficult for patients who live far away. In Beckie's case, she waited for her first appointment with an RE for one year because the waitlist was long. She lived far from the clinic which necessitated hotel stays when she was undergoing treatment.

During Beckie's one-year wait for treatment, and even before she requested a referral to a fertility clinic, she tried diets, supplements, home monitoring, and acupuncture. At the time of her notification from the clinic of her first appointment, she had not yet conceived on her own.

Finally, after one year of waiting, she stepped into the clinic for the first time. After a battery of tests, in-depth discussion with her RE, consultation with a psychologist, and an information session, Beckie and her husband were permitted to start treatment. She used oral and injectable medication in preparation for IVF. Once she reached a point in her cycle that required close clinic monitoring, Beckie began staying in a hotel close to her RE's office. Her cycle progressed as desired, and eggs were retrieved. One embryo was transferred, and she returned home to wait. After two weeks, she followed up at the clinic and was told that she was not pregnant. Beckie tried one more cycle of IVF at the same clinic. The second attempt at IVF did not result in pregnancy, and Beckie decided to consult an RE in Las Vegas. Although her new RE had a history of great success and changed Beckie's treatment plan due to additional diagnoses, she did not get pregnant with a third cycle of IVF.

Beckie endured many struggles during her infertility experience. The cost of treatment and distance from the clinic contributed to the stress of infertility.

Another element that contributed to her negative experience was that she did not feel that others understood the pain she was going through. Her pregnant friends were experiencing great happiness as they prepared for the births of their babies, and they could not understand the deep sadness Beckie was feeling.

> One thing I have come to accept about people is that they cannot understand. They will never get it because it is so far from the realm of something that they can relate to and relatability is what it all boils down to. On the outside everything appears normal but they don't see the longing, loss and constant disappointment infertility brings. (Beckie)

Beckie's friends were not the only people she felt did not understand her situation. She encountered a pharmacist that was less than understanding and customers at the store she owned who did not understand the difficulty of getting pregnant. The clinic staff did not seem to understand the stress of treatment because Beckie never saw the same physician at her appointments, and she was referred to office nurses by her physicians to answer any questions. The clinic failed to understand the needs of patients traveling far from home for treatment despite advertising that it made special accommodations for them. The only person who understood the experience was her husband.

Beckie tried to remain positive about her experience by blogging and talking to people about her situation, but she found that her nearly six-year struggle with infertility changed her life. She found that she was envious of women who had children easily, felt she did not have a choice that so many other women have, wanted her life to be normal again, and felt that all joy was stripped away from a part of life that should be enjoyable.

She said,

> Life is not guaranteed to be easy and definitely not kind. I just want to feel normal again; I want to have hopes and dreams. I want to be able to accomplish something that I put my mind to. All I ever planned on was having kids and that dream at the moment is nothing but a long and disappointing ride to a seemingly never ending pit of failure. (Beckie)

Maya

Maya had the husband and career but not the family she so desperately wanted. In 2010, Maya and her husband started the journey of infertility. Part of the life they envisioned included children, and they were going to find a way to find the missing piece of their life and the plans they had made (Maya).

The cause of Maya's inability to get pregnant was diminished ovarian reserve. Although she was only in her early 30s, her eggs were depleting faster than normal. Her RE recommended IVF as the best treatment option for the diagnosis, and Maya prepared for her first IVF cycle. Routine visits to clinic showed that fewer than the desired number of follicles were developing, but the RE remained optimistic and the cycle continued. On the day of retrieval, a small number of eggs were retrieved, and Maya and her husband went home for the two-week wait. As the wait continued, the clinic called almost daily to deliver the latest report on the embryos. Some of the embryos did not survive but hope remained. The news eventually came that none of the embryos had survived, and Maya and her husband were devastated.

After the first failed cycle of IVF, Maya tried IUI, but the result was the same. She was not pregnant. Her RE explained that the quality of her eggs was a problem, and Maya needed to think about using an egg donor. Maya's younger sister was willing to donate her eggs. Maya and her sister began preparing for their cycle of IVF. Preparations went well, and many more follicles were detected than the number seen during Maya's first cycle. Everyone was hopeful. On retrieval day, numerous eggs were retrieved. Maya, her husband, and her sister went home to wait. During the wait, reports came that some of the embryos were developing. The day of the transfer arrived, and three embryos were inserted. Maya and her husband were hopeful that this time would work. The results were delivered and Maya was not pregnant. A final IVF attempt with a frozen embryo from the previous cycle was made, but the result was the same. Maya was not pregnant. Maya had to decide the route she wanted to try next. She decided to use a donated embryo. After preparations for the cycle of IVF were made, the donated frozen embryo was inserted, and once again, Maya and her husband waited. For the first time, good news was delivered. Maya was pregnant.

In addition to the craziness of treatment, Maya found her experience with infertility to be financially, physically, and emotionally taxing. She is a psychotherapist and tried to follow the same advice that she would give her clients, but infertility was different from anything she had ever experienced. Treatment required that money was available for doctors and medications. Additionally, Maya used CAM therapies such as acupuncturists, a curandera, and reiki that she thought would help her conceive, which added to the financial burden. Work had to be missed to make treatment possible. Trips could not be taken because funds needed to be saved for treatment.

The infertility experience was also physically demanding. Maya had to stay in bed longer than usually advised after the embryo transfer due to complications. She wanted to move around, and she was not even permitted to be in the comfort of her own bed because sleeping in her bedroom required her to climb stairs. Maya stayed on the couch, missed work, and worried about the embryos she was responsible for carrying. The confinement to the couch was incredibly difficult, and Maya was also prohibited from having sexual intercourse for three months and from taking baths. She gained weight and did not feel normal due to the hormones, and she was sore and bruised from daily injections.

In addition to the financial and physical burdens created by infertility, Maya experienced many emotions. She felt that she did not have control of her life and that she did not have time to process information from her RE because decisions had to be made quickly. During her experience with infertility, she never felt fully mentally prepared. She felt guilty for disappointing her parents and for dragging her husband on the miserable journey of infertility. Maya felt jealous of her friends who had or were having babies and found that avoidance was the best method to deal with her feelings of jealousy. She was angry that she could not have children on her own and felt the expensive costs of fertility treatment made a normal part of the female experience seem like a luxury. Maya and her husband's quality of life had been stripped away. The days prior to infertility were difficult to remember because the pain of the infertility experience dominated their life together.

The next element of Maya's infertility experience is the issue of identity. She identified as an infertile woman, and the new identity consumed her life. Maya said,

> The identity of an infertile woman is one that is forced upon you. No matter how much it's rejected, it doesn't go away. It has to be integrated into that person's self in some form—be it anger, denial, depression, isolation, acceptance. Like the role of motherhood, the role of infertility has no escape. Unlike the role of motherhood, the infertile woman gets no party. There are no gifts, formal set up of support or classes that help you transition and come to terms with this new identity. Not even your own mother knows what to say or do for you. (Maya)

Maya no longer identified as a woman enjoying her 30s with a good job and great husband. Instead, she was an infertile woman incapable of accomplishing the normal accomplishments of womanhood.

The final element of the infertility experience she encountered was the lack of understanding. Maya's husband was supportive and tried his best to understand. They tried to minimize the strain on their relationship but found they were out of sync in a few areas. Maya was ready to consider adoption, but her husband wanted to step back and evaluate the situation. Friends with children could be unsympathetic. They were so far from the pain Maya was experiencing that they could not understand her situation.

> Even though people and friends try to understand, they just can't, and there is an isolation that comes with not being understood that is both unavoidable and understandable. I can't blame people for not knowing what to say or saying things I think seem stupid and trite. I can't imagine being terminally ill, or watching a loved one through a terminal illness. (Maya)

Although Maya understood the reasons other people had difficulty understanding her situation, the inability to have compassion made Maya's experience more stressful and created distance in her friendships.

Maya's infertility experience is still ongoing. The last update on her blog was from the twentieth week of her pregnancy. At that point, she was worrying daily and found that trusting her body was nearly impossible. After everything she went through, she had trouble believing her body would do what it needed to do. If all is going according to the best possible plan, she is still pregnant, but regardless of where she is in her infertility journey, Maya's and her husband's lives have been forever changed by the experience of infertility (Maya).

Analysis

The stories included here illustrate the magnitude of the infertility experience. When these stories are considered all together, several themes emerge. Seven elements of the infertility experience that emerge from these accounts are: the demands of treatment, isolation, lack of support and understanding, the issue of identity, and the related issues of guilt, blame, and shame.

First, the demands of treatment are evident. The stories explain that there are many financial, time, and physical demands of treatment. Finances lead to the inability to receive adequate treatment. Lisa could not afford more than one round of IVF. Beckie and Maya chose to forgo vacations to ensure that the necessary funds were available for their treatment needs. If a woman does not have the financial resources necessary, reproductive options are limited. Time is another factor. The stories illustrate the time

commitment required by fertility treatment. Agnes spent her days traveling on the subway to and from her appointments, Beckie had no option but to stay in a hotel in an unfamiliar town far from home in the time leading up to her retrievals and transfers, and Helen and Maya had to take time off from other obligations due to complications that required bed rest for extended periods of time. Treatment requires making a lot of time for it. Physically, women seeking treatment must endure the unwanted effects of medication and hormones. Maya found she gained weight, and daily injections were painful. Treatment demands that patients limit activities to avoid any complications. In Berger's study,

> Several participants recounted that the struggle with infertility negatively affects relationships with their husbands, friends and family. The effects on spousal relationships were related to the woman being irritated, the demands the treatment put on the time and financial resources of the couple and in one case, the disagreement between husband and wife regarding the use of treatment. (Berger et al. 61)

These financial, time, and physical demands of treatment are unavoidable and have a negative impact on the experience of infertility.

Second, these stories each contain an element of isolation at some level. All of the women in these stories experienced some level of frustration in their relationships with friends or loved ones that resulted in seclusion. Some of the women chose to isolate themselves because the pain of seeing other women with children or the burden of explaining their infertility was difficult. Other women felt they were segregated involuntarily due to the inability of others to relate to the experience. In a study of

psychological effects, Williams found, "Oftentimes the infertile women stopped calling their friends and made excuses as to why they could not get together. They felt alone, misunderstood; they were angry, resentful, and thought that no one could offer them the empathy they needed" (Williams 20). Women's tendencies to be selective in whom they share the details of their experience with (Berger et al. 63), and an overreliance on online resources (Y. Epstein) add to the feelings of loneliness. Whether women with infertility are separated from others voluntarily or involuntarily, some form of isolation often becomes a reality. As these stories indicate, the emotional pain of the infertility experience is intense and feeling connected to other people who have not experienced reproductive problems is difficult. Maya captures the element of isolation in a powerful way by referring to the infertility experience as "IF Island" (Maya).

The third element is the lack of support and understanding. Each woman's story illustrates this to some degree. Helen felt her husband did not fully understand her desire to have children, Phoebe and Strongwoman felt misunderstood and unsupported by family and friends, Lisa did not think her doctor understood the impact of the situation, and all of the women felt that outsiders did not understand the gravity of the infertility experience. Williams found "friendships became strained, and sometimes even dissolved; unsympathetic bosses added guilt and fear of reprisals to their stress; unthinking co-workers and mere acquaintances asked stress-provoking questions and offered unwelcome advice which reflected ignorance of the phenomenon" (Williams 16). The failure to communicate effectively, insensitive comments, and lack of support are common themes of infertility, and as the women's stories show, adequate understanding and support are essential for women experiencing infertility.

Fourth, the issue of identity is a major component of infertility. Letherby makes the argument in her paper that "it is necessary to recognize that 'infertility'/'involuntary childlessness' is a profound shock to some individuals' sense of self which often involves distress and represents a challenge to an individual's identity" (Letherby 279). Maya explained in her story that she began to identify as an infertile woman. She did not choose the identity, but rather, the identity began to consume her life. As one can learn from the stories here, the experience of infertility affects many aspects of life, and the inability to conceive has the ability to make women evaluate the question of identity. Strongwoman's, Beckie's, and Maya's blogs illustrate that the change in identity can be a slow process, but as issues of infertility deepen and the inability to conceive stretches over time, the identity of infertility outweighs any identities present before the experience of infertility began.

Although all of the elements have some relation to one another, the final three issues tend to be connected directly. Guilt, blame, and shame are unavoidable aspects of the infertility experience. Maya felt guilty that she could not produce the grandchildren her parents wanted, and she felt bad that she needed to burden her sister with donating eggs. Helen blamed herself for her previous life choices. She felt that her inability to conceive was some type of punishment for events of her earlier life. In the other women's stories, the element of blame is also present. A failure to achieve what is deemed normal for the female body leads women to blame themselves for the inability to achieve a normal part of womanhood. Berger found, "Some women felt that the failure to conceive or carry a pregnancy to term speaks to their inadequacy. While struggling to

view it as a medical issue, a few perceived infertility as a personal fault" (Berger et al. 60). Agnes and the women in the other stories felt they were at fault for their inability to reproduce. Finally, shame is a common element of the infertility experience. Phoebe chose not to discuss her reproductive issues with anyone. After her mother reacted to Phoebe's situation poorly, she chose to keep her feelings to herself. She felt ashamed, as did the other women in these stories, that she could not have the same chance to reproduce that so many other women have.

The stories of Helen, Agnes, Phoebe, Lisa, Strongwoman, Beckie, and Maya give readers a glimpse into the female experience of infertility. The same themes are found in all of their stories and serve as a representation of the seven-million women who find themselves stranded on "IF Island" (Maya). The experience is unlike any other, and the impact of infertility, depending on the individual experience, often changes a woman's life forever whether or not conception is achieved.

Chapter 5

MEDICAL PROFESSIONAL PERSPECTIVES

The perceptions of medical professionals give a different perspective on the female experience of infertility. The stories that follow were told by nurse practitioners, physician assistants, and physicians specializing in reproductive medicine from various U.S. locations. Each medical professional (MP) was interviewed and asked the same list of questions. The complete list can be found in Appendix B. The questions were designed to elicit information from medical professionals about their perceptions and awareness of the female infertility experience. Numbers have been assigned to each MP to protect her or his identity because interviews were conducted on the condition of anonymity.

MP #1

MP #1 works at a large fertility clinic. She had an interest in women's health prior to working in the area of reproductive medicine but explained that her current position happened by chance. In the time she has spent working in the specialty, she said she has learned that "infertility impacts women. Not only women in their 30s, but it can impact women who are much younger depending on their situation or depending on their disease." MP #1's work prior to working at the fertility clinic focused on pregnant women but not young women who wanted to get pregnant.

At the clinic MP #1 works at, a normal day begins with patients in the middle of cycles coming in prior to 9:30 a.m. to be monitored through laboratory tests and ultrasounds. The testing for each patient varies depending on her diagnosis.

A patient then waits a day to a few weeks for her test results to be delivered. The time it takes for results to be available is determined by the type of test ordered. Many members of the clinic staff participate in the patient-monitoring portion of the morning before focusing on other tasks.

Once 9:30 a.m. passes, medical professionals at the clinic may see patients, perform artificial inseminations, call to check in on patients, or conduct egg retrievals on women undergoing IVF. Physicians have a set daily schedule for egg retrievals, and a patient's regular doctor may not be the physician performing the retrieval if the procedure does not fall on the doctor's regularly scheduled retrieval day. As MP #1 explained, the possibility that a physician other than the woman's regular doctor might conduct the procedure can cause some anxiety for patients.

Once the normal tasks of the morning are complete, physicians or staff members make phone calls to patients to discuss concerns or test results, and they send prescriptions to pharmacies. Physicians perform embryo transfers during afternoon hours. The clinic uses the same physician rotation for egg retrievals and embryo transfers.

A regular day at the clinic includes physicians seeing twenty to forty patients. Physicians respond to their own patients during regular office hours, but the clinic follows a call schedule in which doctors rotate on nights and weekends.

MP #1 mentioned that cost is a barrier to treatment. While health insurance covers some fertility services, she said insurance "is not where it needs to be" because health insurance companies do not fully understand the complexity of fertility treatment.

The lack of consistency in treatment coverage among patients' medical insurance carriers makes providing appropriate reproductive services difficult.

MP #1 went on to explain the difficulties of treating women with infertility. She said that age limits treatment options for women. A forty-three year old woman's only treatment option involves the use of a donor's eggs, but MP #1 explained that a thirty-two year old woman may require donor eggs if she has a low egg reserve. While age creates problems when treating infertility, it is only one problem on a list of many.

Women face another difficulty when seeking reproductive assistance. MP #1 said that there are women who do not have reproductive problems, but the cause of infertility might be due to the male partner. In those cases, the woman often feels the burden of infertility in the same way she would if she received the diagnosis and not her male partner. The woman might take responsibility for the problem because she must undergo the same preparations whether the diagnosis belongs to her or her partner. The female patient is required to visit the clinic on an almost daily basis if undergoing IVF, and each visit may take an hour or more.

Aside from the specific difficulties faced, MP #1 explained that going through fertility treatment takes dedication. She said, "It's hard for patients because their lives don't go on hold. A lot of them work. A lot of them have families and commitments." The shame and secrecy often involved with seeking reproductive assistance also make explaining absences to an employer difficult, and women being treated no longer have the freedom to take spur-of-the-moment vacations.

The interview concluded by MP #1 saying that she wishes she could help women understand that "there's no clear-cut answer as to whether their cycle will be successful,

and we may not know that answer. There's a fix for a lot of women but not everyone. Some people leave here without a success." Despite the difficulties faced when treating women who have reproductive problems, MP #1 said working in this area is "rewarding. In most cases, it's rewarding." She hopes that her specialty is making a difference in women's lives (MP #1).

MP #2

MP #2 has been working in the areas of women's health and reproduction for many years. At this stage of his career, he continues to see patients on a limited basis due to other work responsibilities. He chose this specialty because he finds reproduction interesting and "intellectually stimulating."

MP #2 has his own philosophy regarding his patients. He believes patients must have the ability to participate in their care. He helps his patients understand the nature of their specific diagnosis and treatment options, and he believes that treatment is made easier when patients and partners are knowledgeable about the process and the people who play a role in it.

MP #2 explained that many patients seeking reproductive assistance experience an "element of disbelief." For much of life, people try to be careful and prevent pregnancy, but when the time comes to get pregnant, patients find it may not happen quickly. The avoidance of pregnancy and control of reproduction lead to patients feeling surprised when they are unable to conceive.

MP #2 went on to discuss that a patient may recall past life experiences or choices she may have made when problems with conception are encountered. Women who chose

to terminate pregnancies in earlier years or those who have miscarried question whether the inability to get pregnant is some kind of punishment. In some religious traditions, MP #2 said, "Fertility is a sign of God's power," and infertility may be viewed by some patients as a superior being's disfavor with previous choices. MP #2 is grateful that his patients share information about emotional struggles they might be having because feelings of guilt and blame need to be worked through in order for patients to have effective medical treatment. MP #2 invites his patients to be open about any concerns. He commonly gives patients information regarding support services at the initial visit.

MP #2 explained his perceptions of the burdens women with infertility experience. He explained that holidays can be difficult because holidays are times of the year when the focus is often on the family. The absence of a pregnancy or child may lead to patients feeling unwanted emotions. Women with infertility also experience a sense of loss when expectant mothers or women with children are seen in the waiting room of the clinic because they are considered to be "successful" by patients undergoing treatment.

The next burden a patient might experience is tension with her partner because both members of the couple are not equally committed to the process. MP #2 said he can "sense that one partner wants this more than the other" through body language and overall participation in medical care. He has seen couples separate after having a baby and wishes he could help patients understand that a baby is not the solution to marital problems.

A third burden in the area of reproduction is cost. Medications can cost more than one-hundred dollars per day, and blood tests range from $200 to $250 each. Patients do not always have the money needed for reproductive services, and health insurance does

not always cover necessary treatments for patients. MP #2 said that treatments allowed by insurance companies may not be appropriate, which leads to the misuse of healthcare spending. He understands that infertility may not be viewed as a debilitating disease by the public, and there are limited financial resources available, but the financial piece of reproductive services is a burden to many patients seeking treatment.

MP #2 believes his branch of medicine is truly unique because he is able to be part of the creation of life. The patients he sees open their lives to him and trust him with information no one else among their family and friends may know. The practice of reproductive medicine allows him to see "two people having the same medical problem simultaneously" because couples encounter the same experience and suffering when encountering problems with infertility. He finds the specialty to be "emotionally, spiritually, and intellectually satisfying." To summarize his experience in reproductive medicine, he said,

> There's an emotional aspect of it that's pretty amazing, and that helps to feed my soul and helps me to feel like I've made some kind of a contribution on the planet. I didn't discover a cure for cancer. I'm not on my way to Stockholm to pick up my Nobel Prize, but there are people on the planet whose lives I influenced in some way. (MP #2)

While MP #2 continues to try to make a difference in the lives of his patients, he carries their stories with him (MP #2).

MP #3

MP #3 has spent many years treating patients with infertility. The reason he chose medicine as a career goes back to his childhood. Doctors were important to his family when he was little, which led to his choosing a career as a medical professional. MP #3 believes the important role his mother played in his life may have led to working in the area of women's health.

MP #3 explained that a feeling of surprise often accompanies a patient's inability to get pregnant. Having children is a normal process of life for many. People grow up, get an education, and get married. There is an expectation that having children naturally will be achieved easily. However, MP #3 said only approximately eighty to eighty-five percent of couples get pregnant in the first year of trying and getting pregnant is not an easy task. He said the experience of infertility is "very emotional and difficult." There is "a lot of pressure on the couple, especially the woman."

The interview concluded with MP #3 explaining that education can help the treatment process and the overall infertility experience. Treatment outcomes improve when women are knowledgeable about their bodies and general information regarding infertility (MP #3).

MP #4

MP #4 has spent his career working in the area of reproductive medicine. He found he was drawn to the specialty because it is interesting and important.

MP #4 perceives the female infertility experience to be complex. He has learned that women with certain religious beliefs who encounter reproductive problems feel more

of a responsibility to have children due to their beliefs. Women of certain faiths view their reproductive problems as a supreme being's punishment. The importance of religion has an impact on the overall infertility experience. His faith is important in his life and has contributed to his desire to work with women with fertility problems.

MP #4 acknowledges that seeking fertility treatment is an undertaking with many demands. The demands of treatment make the experience more difficult, and he is glad he is part of a specialty that has the ability to change lives (MP #4).

Analysis

The question may be raised why this chapter is part of a paper on the female experience of infertility, and this analysis addresses that question.

First, there are many demands of fertility treatment. The women's stories illustrate the burdens of treatment, but the medical professional perspective shows that the clinic structure lacks flexibility which makes the infertility experience more complex. While clinics need to operate efficiently, strict schedules and demands add stress to a situation that is already extremely difficult for women. Fertility treatment demands that their lives are scheduled around clinic appointments, phone calls from physicians and clinic staff, and inflexible procedure scheduling. The demands of treatment further complicate the female infertility experience.

Second, medical professionals' perceptions of the experience vary greatly. The perceptions differ depending on the level of engagement with patients and the medical professional's willingness to understand. Perceptions vary because some medical

professionals understand the complexity of the experience while others minimize infertility to a medical problem that needs to be cured.

Third, some of the same elements present in the women's stories have been mentioned by the MPs. The medical professionals interviewed explained that time and financial costs are a burden, women feel they do not have control of their bodies and reproduction, and relationships with family and friends are strained. The experience of infertility causes women to blame themselves for their reproductive problems and past choices, feel shame because their bodies are not working properly, experience guilt because they feel their inability to conceive is a burden to their partners and families, and feel isolated because outsiders do not fully understand the difficult experience.

Finally, the area of reproductive medicine is demanding of both the medical professionals who choose to work in it and the women who find they have no choice but to seek it. Medical professionals must realize that fertility treatment is one piece of a complicated puzzle. While medical professionals may think educating women about the complexity of the fertility-treatment process is important, a willingness to understand their patients' overall experience of infertility assists medical professionals in providing effective treatment (Roter). Education is merely one component of the infertility experience, and as the women's stories show, they seem to be educated about their reproductive problems. A thorough understanding of the fertility-treatment process does not appear to be lacking. Education about the life-consuming nature of infertility is as important for medical professionals as women's education regarding fertility treatment.

Chapter 6

SOLUTIONS TO IMPROVE THE FEMALE EXPERIENCE OF INFERTILITY

Due to the nature and impact of the infertility experience, encountering reproductive problems is never going to be easy for women. However, through better awareness, understanding, and support, it is possible to improve the overall experience. The elements identified in this paper illustrate that improvements need to be made in a number of ways to diminish the suffering associated with infertility.

The elements of identity, isolation, blame, guilt, shame, the lack of understanding, and the demands of treatment indicate a need for support services. The women's stories in this paper suggest that the level of support desired is often absent. There are many types of support that could be implemented more effectively. Existing support services include online and faith-based resources, support groups, and counseling.

Online Resources

Many websites such as *Resolve*, *Fertilityauthority*, and *Dailystrength* offer general information, online forums to discuss certain topics, support group listings, and numerous other resources. The Internet is a place where answers to questions are easy to find, and women can communicate with others about the experience.

A forum is an online discussion board divided into specific topics. Some forums require users to register, and others can be accessed by anyone. Each forum is monitored by a volunteer or organization employee who has extensive knowledge of or personal experience with infertility. The topics range from general discussions about infertility

and treatment information to specific forums on certain diagnoses or stages of treatment. Forums are also available for specific family members of women to provide support for various treatment participants close to the patient. The Internet provides a place where women can feel safe and ask questions without being exposed or uncomfortable. The forums found on these sites serve as a form of regular communication about all questions related to infertility and provide support to women who may lack other methods of assistance and encouragement.

Blogs created by women who have experienced infertility are another important online resource. Some women such as Strongwoman, Beckie, and Maya document their journeys through the use of blogs, and others write after treatment terminates. Blogs follow a similar format as forums. Some focus on specific aspects of infertility while others serve as an account of the overall experience. Many bloggers write regularly to share each step of the reproductive journey with other people. Blogs and forums provide a way for women with reproductive problems to connect despite geographical separation. Various blogs can be found online, and websites such as *Creatingafamily* provide links to blogs based on specific interests.

While online resources prove to be important for women with infertility, research has been conducted on the limitations of information on the Internet and explains that online resources must not be the only method of support consulted (Y. Epstein et al.). The authors of a study on infertility-related online information suggest,

> We believe that it is important for mental health professionals to seek ways to encourage patients using Internet infertility forums to avoid withdrawing from real-world interactions. Moreover, patients turning to the Internet as their sole

> source of support might choose welcoming face-to-face venues if those venues were part of the daily and weekly groups and organizations that they encounter. (Y. Epstein et al. 513)

Faith-Based Support Services

There are many faith-based resources for infertility. If couples hold religious beliefs, their pastors, rabbis, or priests can help during the process. Although a religious leader may not have specific knowledge of infertility, comfort may be found in discussing the experience with someone women trust.

If women do not find the comfort they desire by talking to a religious leader, many faith-based tools are available online. There are specific sites that provide infertility information for religions such as Catholicism, Judaism, and non-denominational Christianity. The websites offer additional resources, videos, and general information. A faith-based book offering assistance to couples is available online and is entitled *A Time to Be Born: A Faith-Based Guide to Assisted Reproductive Technologies* (Ott 2009).

Support Groups

Support groups are often the most common resource listed on fertility-clinic websites. Clinics give information on finding support groups, and many online resources offer listings as well. However, most groups only meet monthly or every other month.

Counseling Services

The psychological component of infertility is a major factor in the process. Most of the elements discussed in this paper are related to emotions. As readers saw in the two chapters of women's and medical professionals' stories, emotions are unavoidable when experiencing infertility. Women feel isolated, feel a part of life is missing, have trouble communicating with other people, experience problems with self-esteem, and encounter emotions they have never experienced before. This is due to the stress that accompanies the inability to conceive and the hormonal changes caused by fertility medication.

Psychological services are an essential part of treatment as high levels of stress make the experience of infertility more difficult. Through counseling, patients learn how to express their feelings with friends and loved ones. Counselors specially trained in treating patients with infertility can help address the elements of isolation, identity, blame, guilt, and shame, and they can provide women with ways to cope with the demands of the experience.

Recommendations

While a number of support services are available, women need to have access to better services to ease the burdens of the infertility experience. As the women's stories illustrate, women feel isolated and misunderstood. Programs in which women can come together with others going through the same experience may improve the elements of infertility.

One proposal is the implementation of a narrative program. Storytelling programs provide a setting where women can openly communicate with other females who

understand the experience. The ability to spend time in a creative environment with those who understand the burdens of infertility diminishes feelings of loneliness.

The program will be structured to occur for two hours once a week for five weeks. While this may seem to be another commitment that requires more time than that already demanded by treatment, some women may be interested in a unique method of support. Ten to twelve participants currently experiencing infertility may attend. A person with narrative training leads the program in consultation with a counselor.

In the first meeting, women have a chance to introduce themselves to others in an icebreaking activity. After the icebreaking activity concludes, participants hear a song relating to their experience. The participants jot down any emotions they have while listening to the song. The song repeats one time to ensure everyone hears the lyrics. When the song finishes for the second time, lyrics appear on a projection screen. Participants begin following a writing prompt focused on emotions evoked by the song. After completing the writing prompt, women share their work with other participants.

The facilitation of subsequent sessions implements different mediums and writing prompts. Sessions two, three, and four use videos, poems, and photos. Session five is a chance for participants to express themselves in the artistic method of their choice. Members receive information on session five at the conclusion of session three to allow for preparation. Methods to use in preparation for session five include music, photos, prose, poetry, painting, drawing, and sculpting.

The narrative-program design encourages the discussion of each creation by each participant at each session. However, members' levels of comfort are important, and there is no requirement to participate if having feelings of discomfort. If any participants

appear to be uncomfortable, the group transitions to sharing creations anonymously to prevent any unease.

The purpose of this program is to give women experiencing infertility a safe place to discuss the process openly with other women. While some people may not feel comfortable talking with counselors or relatives, the program gives participants an opportunity to express their emotions through creative outlets. The use of narrative makes it possible for women experiencing infertility to connect with others around them. Through interactions with other women, stress levels may decrease. The program has the ability to help participants feel that other women understand the experience, diminish feelings of isolation, and address infertility elements such as the demands of treatment, blame, guilt, and shame.

Storytelling programs exist for women with post-partum depression and other medical diagnoses, but currently, narrative programs that focus on the female experience of infertility are not identifiable.

The Need for Improved Understanding

While the implementation of a narrative program is one possible solution, there is one final piece necessary to improve the overall experience.

A major element of the experience of infertility is the lack of understanding. All of the women's stories identify that this element is a common theme. The presence of this element in every woman's account of infertility shows that an outsider's inability or unwillingness to understand the situation contributes negatively to the overall experience. Understanding needs to improve in three major ways.

First, medical professionals play an important role in making reproduction possible, and they are important in the lives of their patients. A patient may feel she is not adequately understood by her medical provider, but the medical professional may believe he or she is providing quality treatment. Malin et al. found,

> [T]he way care was given was amongst the most common satisfactory aspects of infertility care, and the most common reason for dissatisfaction. And the most positive treatment experience meant a good relationship with the infertility doctor, in which the doctor was humane, a good person, had time to listen, communicated well and was seriously committed to the woman's problem. (Malin et al. 131)

In order for understanding to improve, physicians and other medical professionals must make an effort to understand the woman's experience of infertility beyond the treatment that is provided within the walls of the clinic. As the chapters on female and medical professional perspectives illustrate, medical professionals have some awareness of the demands of treatment but often lack adequate knowledge of the overall experience. Patients need to feel that the professionals providing treatment are educated about the burdens created by infertility. Improved understanding will provide necessary information for medical professionals to treat patients effectively, and it will make patients feel more understood and strengthen the connection women feel with medical professionals.

Second, the general public needs to be better informed about the burdens created by infertility to improve the process for women who are experiencing it. To improve overall awareness, better education is required. The process can begin with people who are passionate about the topic, but wider community participation is required to help

women traveling on the infertility journey. Creating public awareness requires that people start the conversation, and a supportive, nonjudgmental environment must be created within communities to help women feel comfortable telling their stories.

Third, friends and family must gain a better understanding of the impact the experience of infertility has on women's lives. Understanding can be improved by friends and family consulting online resources, listening, and acknowledging the delicate nature of the situation. While the women in the stories mentioned that people who are not familiar with the experience have difficulty understanding the complexity of the situation, family and friends seeking better understanding can alleviate elements of the infertility experience.

In conclusion, the idea that the elements of infertility identified in this paper can be eliminated entirely is unrealistic. However, through increased awareness, improved implementation of support services, and medical professionals, the larger community, family, and friends gaining a better understanding of the experience, some of the suffering associated with infertility can be ameliorated.

Conclusion

The experience of infertility is unlike any other situation women encounter. Women are faced with a system that is difficult to navigate when they are unable to conceive. Life must change drastically to make committing to the demands of fertility treatment possible. Women are forced to place trust in medical professionals because their bodies fail to operate normally, and they feel as though they have lost control.

Medical professionals, friends, and families do not understand the depth of suffering. Medical professionals are looking through the lens of biomedicine and have a formula to make the infertile body fertile again. However, the inability or unwillingness to understand the complexity of the experience of infertility makes the situation more difficult for women. Treatment needs to focus on more than the physical body. The whole patient needs to be considered. An increased understanding of the experience of infertility has the ability to improve the process by making women feel comfortable about discussing their problems.

Support services are beneficial for women to address the elements of isolation, identity, demands of treatment, blame, guilt, and shame, but current offerings are not as extensive as needed. More resources need to be available to the seven-million infertile women in the United States.

Through improving understanding, implementing new programs, and enhancing support services, the seven elements of the experience of infertility can be alleviated. The ability to express concerns openly with other people builds community, and sufferers need a network of people who understand.

Our society does not understand the impact infertility has on the lives of its sufferers, but the recommendations identified in this paper have the ability to improve the overall experience of infertility and diminish the suffering women experience when trying to create life.

Appendix

Appendix A

NEW-PATIENT PAPERWORK FOR FERTILITY TREATMENT

NYU Langone | FERTILITY CENTER

Package for New Patients

Thank you for choosing the NYU Fertility Center, a leader in the field of reproductive medicine. We are pleased to offer our patients a full range of treatments for both male and female infertility, as well as fertility preservation services and gynecologic care.

We ask that all patients please bring the following with you to your initial consultation:

- ☐ A copy of your medical records that related to prior gynecologic treatment, infertility care or surgeries. The medical record information can be faxed to us from your referring physician prior to your appointment, or you can mail your medical records to us at the following address:

  NYU Fertility Center
  c/o <insert the name of your NYUFC physician>
  660 First Avenue, 5th Floor
  New York, NY 10016

  or fax to (212) 263-7853

  If coming for fertility services and you have already had an hysterosalpingogram (HSG), please include the actual films and not just the report.

- ☐ Your insurance card and, if necessary, insurance referral and authorization.
- ☐ Photo ID
- ☐ Medical records that relate to fertility for your partner, if appropriate. The medical record information can be faxed or mailed to us prior to your appointment using the same information above.

Fertility and Oocyte Cropreservation (Egg Freezing) Patients should complete:

- ☐ All documents in this package, which includes a *Notice of Privacy Practices Acknowledgement.* We ask that you please sign this only after reviewing the Notice of Privacy Practices, which will be provided to you in print when you sign in for your appointment and is also available online at: http://www.nyufertilitycenter.org/patients/forms

General Gynecologic and Surgery Patients should complete:

- ☐ All documents in this package, **except the Preconception Genetic Questionnaire.** We ask that you please sign the *Notice of Privacy Practices Acknowledgement* only after reviewing the Notice of Privacy Practices, which will be provided to you in print when you sign in for your appointment and is also available online at: http://www.nyufertilitycenter.org/patients/forms

Thank you again and welcome!

The NYU Fertility Center Team

NYU Langone MEDICAL CENTER

□ J. Grifo □ N. Noyes □ A. Berkeley □ F. Licciardi □ D. Keefe □ M.E. Fino □ B. Hodes-Wertz

Patient Information

Name (Last, First, MI)			Maiden Name	Today's Date
Street Address				NYULMC Medical Record Number
City	State	Zip	Gender ☐ Male ☐ Female	SSN
Cell Phone ( ) Preferred ☐	Work Phone ( ) Preferred ☐		Home Phone ( ) Preferred ☐	
Occupation	Employer / Address		Email Address	
Date of Birth	Preferred Language	Marital Status □ Single □ Married □ Divorced □ Widowed □ Separated □ Domestic Partner □ Other		
Race	Ethnicity		Religion	

Guarantor Information

Is patient also guarantor? □Yes □No (If no please provide information below)

Name	Address	City/State/Zip	Telephone	Relationship to Patient

Partner Informati

Name	Gender ☐ Male ☐ Female	Date of Birth
For Emergency Contact ( )	Occupation	Employer

Medical /Referral Information

Who referred you to NYU Fertility Center?
□ Physician (please complete information below) □ Patient □ Friend/Family □ Website □ Other: _____

Referring Physician	Physician Phone/Fax (if known) ( ) /
Physician Address (if known)	
Required Laboratory □ Quest □ Enzo □ LabCorp □ Other: _____	Required Pharmacy

Insurance Information

Primary Insurance Company	Policy #			Group #
Claims Address	City	State	Zip	Phone
Patient's Relationship to Insured ☐ Self ☐ Spouse ☐ Child ☐ Other _____	Name of Subscriber (if other than patient)			
Subscriber's Social Security #	Gender ☐ Male ☐ Female	Date of Birth		
Secondary Insurance Company	Policy #			Group #
Claims Address	City	State	Zip	Phone
Patient's Relationship to Insured ☐ Self ☐ Spouse ☐ Child ☐ Other _____	Name of Subscriber (if Other Than Patient)			
Subscriber's Social Security #	Gender ☐ Male ☐ Female	Date of Birth		

Please provide your medical and pharmacy benefits cards, for both primary and secondary insurance even if we do not participate with your carrier. You must advise NYULFC of any change in address or insurance carrier. As a service to our patients, we provide a courtesy bill pay reminder call and possibly other important calls that may be placed using a prerecorded message. By providing your cell phone number, you consent to receiving such calls at this number. By signing below, I acknowledge that the information I have provided is correct.

Patient Signature: _____ Date: _____/_____/_____

Guarantor Signature (if other than patient): _____ Date: _____/_____/_____

NYU Langone | FERTILITY MEDICAL CENTER | CENTER

Review of Systems

Patient Name: _____ ***Date of Birth:*** _____ ***Today's Date:*** _____

Please complete the following and return with your registration form. Answer yes to any current condition or condition that you have had in the past.

CONSTITUTIONAL	Yes	No
Weight Change > 10lbs.		
Fever		
Sweats		
Fatigue		
EYES		
Glaucoma		
Cataracts		
Vision Surgery		
EARS, NOSE, THROAT		
Loss of Hearing		
Dizziness		
Nose Bleeding		
Gum Bleeding		
RESPIRATORY		
Chronic Cough		
Bronchitis		
Shortness of Breath		
Asthma		
Pneumonia		
CARDIOVASCULAR		
Heart Attack		
Chest Pain/Angina		
Heart Murmur		
Anemia		
Transfusions		
Phlebitis or Blood Clots		
Rheumatic Fever		
Heart Surgery		
GASTROINTESTINAL		
Reflux		
Hepatitis A		
Blood in Stools		
Diarrhea/Constipation		
Hernia/Repair		
Gall Bladder		
ENDOCRINE		
Diabetes		
Thyroid Problem		
Hormone Treatment		

BREAST	Yes	No
Masses		
Breast Surgery		
URINARY SYSTEM		
Urinary Tract/Bladder Infection		
Kidney stone(s)		
Incontinence		
Trouble urinating		
GENITAL		
Pelvic Infection		
Pelvic Surgery		
Pelvic Pain		
Endometriosis		
SKIN		
Cancer(s)		
Rashes		
NEUROLOGIC		
Stroke		
Seizures		
Head Injury		
Nerve Damage		
PSYCHIATRIC		
Depression		
Anxiety		
Substance Abuse		
MUSCULOSKELETAL		
Osteoarthritis		
Rheumatoid Arthritis		
Gout		

COMMENTS:

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NYU Langone MEDICAL CENTER | FERTILITY CENTER

Notice of Privacy Practices Acknowledgement

By signing below, I acknowledge that I have been provided with an online or print copy of the Notice of Privacy Practices.

_____

Signature of Patient or Personal Representative

_____

Print Name of Patient or Personal Representative

_____

Date

_____

Description of Personal Representative's Authority

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Preconception Genetic Questionnaire

Patient Name: _____ Date of Birth: _____

Partner Name: _____ Date of Birth: _____

1. Do you, your partner, or anyone in your families have any of these disorders? If yes, please indicate the relationship of the affected person to you or your partner.

Duchennes-Muscular Dystrophy	No	Yes	_____
Hemophilia	No	Yes	_____
Neural Tube Defect (Open Spine)	No	Yes	_____
Neurofibromatosis	No	Yes	_____
Marfan's Syndrome	No	Yes	_____
Polycystic Kidney Disease	No	Yes	_____
Myotonic Dystrophy	No	Yes	_____
Huntington's Disease	No	Yes	_____
Cystic Fibrosis	No	Yes	_____

2. Do you or your partner have a birth defect or familial disorder not listed above? No Yes
   If yes, please specify the disorder and indicate the relationship of the affected person to you or your partner:

3. Do you or your partner have a close relative with an intellectual or developmental disability, autism, a birth defect, Fragile X, familial disorder or a chromosome disorder such as Down Syndrome? If yes, please specify the disorder and indicate the relationship of the affected person to you or your partner: No Yes

4. In any previous marriage(s) or relationship(s), have you or your partner had a child born with a birth defect or had a pregnancy or child diagnosed with Down Syndrome? If yes, please specify the defect and indicate the relationship of the affected person to you or your partner: No Yes

5. Have you or your partner in this or any previous relationship had a stillborn child or more than two (2) first-trimester miscarriages? If yes, please provide further information: No Yes

6. Did you or your partner have carrier testing for cystic fibrosis? If yes, please indicate who was tested, the results and include a copy of report if possible: No Yes

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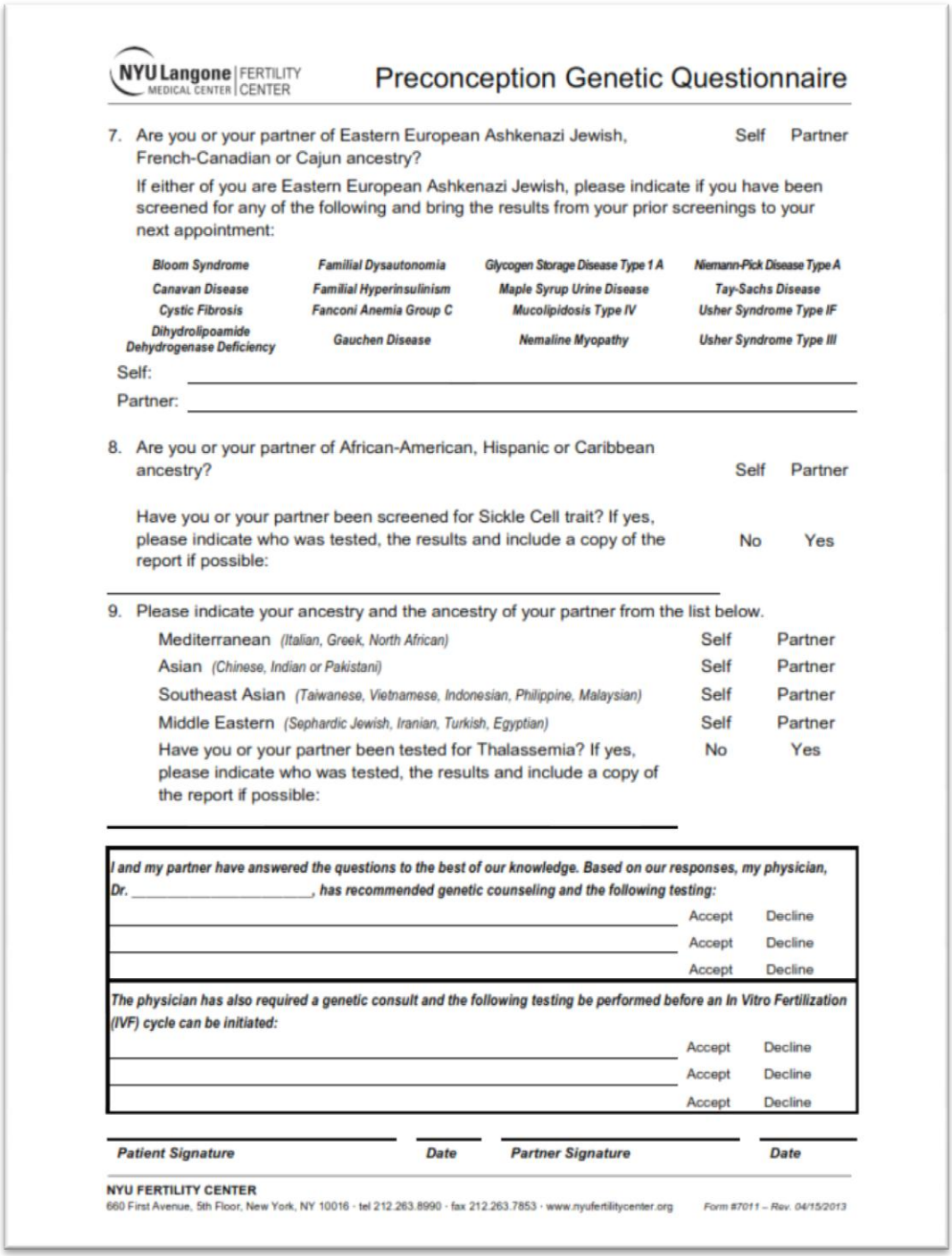
Form #7011 – Rev. 04/15/2013



NYU Langone | FERTILITY MEDICAL CENTER | CENTER

Preconception Genetic Questionnaire

7. Are you or your partner of Eastern European Ashkenazi Jewish, French-Canadian or Cajun ancestry? Self Partner

   If either of you are Eastern European Ashkenazi Jewish, please indicate if you have been screened for any of the following and bring the results from your prior screenings to your next appointment:

Bloom Syndrome	*Familial Dysautonomia*	*Glycogen Storage Disease Type 1 A*	*Niemann-Pick Disease Type A*
Canavan Disease	*Familial Hyperinsulinism*	*Maple Syrup Urine Disease*	*Tay-Sachs Disease*
Cystic Fibrosis	*Fanconi Anemia Group C*	*Mucolipidosis Type IV*	*Usher Syndrome Type IF*
Dihydrolipoamide Dehydrogenase Deficiency	*Gauchen Disease*	*Nemaline Myopathy*	*Usher Syndrome Type III*

Self: _____

Partner: _____

8. Are you or your partner of African-American, Hispanic or Caribbean ancestry? Self Partner

   Have you or your partner been screened for Sickle Cell trait? If yes, please indicate who was tested, the results and include a copy of the report if possible: No Yes

_____

9. Please indicate your ancestry and the ancestry of your partner from the list below.

   Mediterranean *(Italian, Greek, North African)* Self Partner

   Asian *(Chinese, Indian or Pakistani)* Self Partner

   Southeast Asian *(Taiwanese, Vietnamese, Indonesian, Philippine, Malaysian)* Self Partner

   Middle Eastern *(Sephardic Jewish, Iranian, Turkish, Egyptian)* Self Partner

   Have you or your partner been tested for Thalassemia? If yes, please indicate who was tested, the results and include a copy of the report if possible: No Yes

_____

I and my partner have answered the questions to the best of our knowledge. Based on our responses, my physician, Dr. _____, has recommended genetic counseling and the following testing:

_____ Accept Decline

_____ Accept Decline

_____ Accept Decline

The physician has also required a genetic consult and the following testing be performed before an In Vitro Fertilization (IVF) cycle can be initiated:

_____ Accept Decline

_____ Accept Decline

_____ Accept Decline

Patient Signature ***Date*** ***Partner Signature*** ***Date***

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Source: *Nyufertilitycenter*

Appendix B

MEDICAL PROFESSIONAL INTERVIEW QUESTIONS

1. Why did you agree to be part of this research?
2. What led you to choosing this medical specialty?
3. What have you discovered about working in this specialty that you wish you knew long ago?
4. Describe a normal day of work.
5. Please explain your call schedule.
6. How many patients do you see in a normal day?
7. What is your philosophy on treating patients with infertility?
8. When preparing to see a new patient, how much of the chart do you review prior to the initial visit?
9. Can most initial treatments be identified by reviewing the patient's chart prior to the first visit?
10. Walk me through a new patient visit.
11. What general observations do you make when you are seeing a patient for the first time?
12. To what degree do patients want to discuss the infertility experience during treatment?
13. What do you find is the most difficult part of treating infertile women?
14. What do you wish you could help patients better understand?
15. What patient barriers have you encountered when treating patients with infertility?
16. What support services, aside from offerings at your clinic, are requested?
17. Briefly, sum up your perception of the infertility experience.
18. Would you be willing to participate in future research?
19. What additional comments would you like to add?

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