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Misproduction as Body: Examining the Psychological and Medicalized Experience of Female Factor Infertility

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MISPRODUCTION AS BODY:
EXAMINING THE PSYCHOLOGICAL AND MEDICALIZED EXPERIENCE OF
FEMALE FACTOR INFERTILITY

Tiffany Star Behringer

A THESIS

in

Anthropology

Presented to the Faculties of the University of Pennsylvania in Partial Fulfillment of the
Requirements for the Degree of Master of Science

2005

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Supervisor of Thesis

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Dedications

I would like to dedicate this work to my grandparents, Jeannie and Jim Wehrman, who have continuously supported me through the struggles and triumphs of life; to Emilie Anderson, whose compassion and intellectual curiosity have inspired me and to Dan Asen, whose unwavering support has meant the world to me.

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I would like to thank Dr. Fran Barg, whose guidance and support allowed me to complete this work and expand my horizons. As a professor and friend, she is truly an inspiration who has positively impacted my life, work, and future. I would also like to thank Dr. Rebecca Huss-Ashmore, given her dedication to medical anthropology and her students. Finally, I would like to acknowledge the respondents in this study, who graciously allowed me into their thoughts and lives.
ABSTRACT

MISPRODUCTION AS BODY:
EXAMINING THE PSYCHOLOGICAL AND MEDICALIZED EXPERIENCE OF
FEMALE FACTOR INFERTILITY

-Tiffany Behringer-

Objective:
To examine the cultural model of infertility of women in a large urban setting in
order to better understand the emotional and social experience of women who have
sought medical attention for infertility.

Rationale:
According to the Centers for Disease Control, approximately 15 percent of
women of childbearing age in the United States have received medical attention for
infertility. With this attention, perceptions of femininity and masculinity are challenged,
as a seemingly basic component of identity and sexuality is challenged by the inability to
conceive. This process creates a host of psychological, logistical, and relational
difficulties for couples wishing to have children when they cannot.

Cognitive anthropology, defined by D’Andrade as the study of the ways in which
individuals and populations make sense of their world, is an excellent theoretical
framework for examining culture and the decisions and values people place on particular
issues. By interviewing 11 women who are currently experiencing or have experienced

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infertility in a large urban setting, this study defined the cultural schema of infertility, examined beliefs surrounding the importance of reproduction, the experience of medical treatment related to infertility, and the emotional and relational strain that infertility places on the lives of women. This exploration is important given the changing demographics of childbirth in the United States and our increasing ability to treat infertility. Because cultural models tend to be shared among relatively homogenous populations, the general themes articulated in this study can be extrapolated to the experience of women seeking medical attention for infertility.

Methodology:
Research Aims:

In this study, I pursued the following three areas of inquiry:

1. What is the experience of medical treatment for infertility like and how does this experience shape women's perceptions of their bodies?
2. How does infertility itself affect women's perceptions of themselves and their relationships with their partners?
3. How is infertility discussed and what can this discussion tell us about its position within the nexus of sexuality, morality, and reproduction?

Recruitment of Respondents:

In order to reach a broad sample of women experiencing infertility, I placed an advertisement in the Philadelphia Metro, a free daily newspaper found throughout the
Philadelphia area. The advertisement asked women, aged 18 to 50, to call or email me if they had received medical attention for infertility.

The women interviewed were at varying stages of infertility treatment, with some just beginning the process, some “successful” women who had been able to conceive, and a few women who were never able to conceive despite receiving infertility treatment. Based on their responses to questions surrounding the logistics of infertility treatment including the financing necessary for more invasive treatments, these women are also at varying levels of socioeconomic status. Thus, these women represent a broad-based sample of individuals experiencing infertility in an urban setting.

**Procedures:**
Each subject was asked to consent to one semi-structured qualitative interview to be completed over the phone. Interviews were voluntary and verbal consent was obtained before the interviews took place. Approval from the Institutional Review Board at the University of Pennsylvania was obtained before interviews began. All components of the interviews were recorded and then transcribed. Once information was received, I coded it in order to isolate important themes. Because individuals with relatively homogenous backgrounds tend to hold similar cultural schemas, a set of 11 qualitative interviews allowed me to analyze the individual reality of infertility and its treatment for women in an urban setting. This is not to say that each individual woman interviewed in this study would have an identical narrative of infertility. Instead, common themes are expected to
be shared throughout their more nuanced experience, given the fact that cultural models are shared, but individual schemas are not.

Data Analysis:
Once themes were identified, I then went back and coded again line by line in order to explore subcategories and decisions within each topic. This analytical method has been explored and utilized by several researchers and is most appropriately called the constant comparative method, given its insistence on continuously creating and evaluating theories based on “patterns, themes, and common categories discovered in the observational data.” 3 Finally, I reviewed the outline created by the second coding process in order to make comparisons across the respondents. 4 This final step allows for elaboration on important issues, which eventually leads to themes and examples given in the final report. This process also allows for the introduction of demographic information, which in turn allows for the evaluation of theme salience based on respondent characteristics.

Results:
Aim #1:
I found that women described the experience of infertility treatment as painful, embarrassing, and “like a roller coaster.” The experience of consistently receiving treatment that focuses on one’s shortcomings reinforced women’s feelings of inadequacy.

In addition, the experience of infertility care often proved difficult for women attempting to balance both their careers and their desire to become pregnant. Finally, medical treatment for infertility was often humiliating for the husbands of respondents.

Aim #2:
Given the importance placed on reproduction in the cultural model of successful womanhood in the United States, the cultural model for infertility included the notion that infertility pointed to a great inadequacy for the respondents. Respondents felt that they had failed one of their basic functions in life and this sense of failure had profoundly negative implications for their confidence, ability to navigate the medical community, and their relationships with their significant others.

Aim #3:
Infertility was simultaneously discussed as a failure of basic production, a denial of the basic biological right of procreation, a frustrating experience, and an experience that tested their perception of life, relationships, and the future. Each of these constructions point to the central role that infertility plays in our societal perception of successful womanhood. In addition, the secrecy surrounding infertility further illustrates its position as a stigmatizing condition and also society’s unwillingness to discuss the problems inherent in sexuality and reproduction.
Conclusions:

Infertility is a devastating condition that requires men and women to question their identity, ability to be successful individuals, and futures. For those individuals who are able to afford infertility treatment, the experience further develops their sense of inadequacy and anxiety surrounding the condition. However, actions can be taken to make the experience easier. For one, counseling should be built into the system in order to allow couples experiencing infertility an avenue to discuss their fears and doubts. In addition, additional research should be undertaken to understand the public’s knowledge of infertility and correct oversights and inaccurate information. Finally, we must work to reconstruct our perception of successful womanhood and masculinity. Until we do so, couples diagnosed with infertility will continue to suffer, at the hands of a pronatalist society where reproduction and the ability to utilize assisted reproductive technologies are valued, yet couples cannot discuss their experiences for fear of being ostracized.
Misproduction as Body: 
Examining the Psychological and Medicalized Experience of Female Factor Infertility

Chapter 1: Introduction

Around the world, fertility, childbirth, and infertility conjure up social and cultural meanings and images based on local and national perceptions of femininity and masculinity. In some areas, fertility is seen as a great natural gift, something that defines womanhood and allows men to gain additional worth in the patriarchal system. In others, fertility is seen both as a gift and a curse, as countries begin to understand the true significance of the debt crisis and the perceived detriment of population growth. Still, in other areas of the world, fertility transcends negative and positive boundaries, as it ebbs and flows between career plans, the women’s rights movement, the medicalization of childbirth and reproduction, and political discourses on teenage pregnancy, abortion, and poverty. This last arena is where many American men and women find themselves today, caught between their desires for successful careers and their ‘natural’ compulsion towards desiring natural and swift genetic reproduction. Yet, for approximately 6.1 million American women and their partners, thus about ten percent of the reproductive age population, a future diagnosis of infertility looms on the horizon.¹ With this diagnosis comes the possibility of shattering traditional gendered identities and the creation of questions surrounding the exact meaning of gender in a society so obsessed with the immortality of youth and metaphors of reproduction and consumerism, that it fails to recognize the futility of sexual reproduction.

In this study, I will first provide a framework for understanding infertility in the United States by examining literature surrounding infertility as a disease, notions of biological versus social identity, and the emotional experience as infertility as shown through qualitative studies. I then go on to describe the theory and methodology of cognitive anthropology, the framework I utilized in this study. Finally, I describe the experience of infertility as seen through my respondents, in order to comment on the psychological and social experience of infertility, its treatment within the United States, and its connection to greater notions of sexuality, reproduction, and identity.
Chapter II: Review of the Literature

Infertility exists as a multi-faceted entity comprised of societal perceptions, gender roles, medical expertise, power dynamics, and psychological experience. Thus, in order to consider the experience of infertility for women in a large urban area in the United States, it is necessary to examine both the construction of infertility and its experience from a variety of vantage points including that of the medical community and the individual patient.

With this in mind, I begin this literature review with a discussion of the construction of infertility within the medical community and the way in which this construction is shaped by societal perceptions of infertility. I then go on to discussing the experience of infertility from the vantage points of women receiving medical attention for infertility. This discussion allows for a greater understanding of the cultural norms surrounding reproduction in the United States and the consideration of the “misproducing” body. Finally, I provide a framework for understanding the way in which people make sense of these meanings and experiences, by discussing the underpinnings of cognitive anthropology and cultural models.

Defining Infertility: Disease versus Illness

In order to understand infertility in the United States, we must first differentiate infertility as a disease with infertility as an illness. Disease can be defined as the biological and objective experience of sickness. As a disease, infertility itself is defined as “the inability to conceive after a year of unprotected intercourse in women under 35, or
after six months in women 35 or over, or the inability to carry a pregnancy to term.³ As Charles Rosenberg argues, in order to be recognized as a disease that allows individuals to receive sympathy, care, and compassion, a disease must be named. And, in order for this naming to occur (and for social legitimacy to be bestowed on individuals with a condition), “any disease must turn on the existence of some characteristic mechanism. This reductionist tendency has been logically and historically tied to another characteristic of our thinking about disease – its specificity."³ Illness, on the other hand, is the individualistic reality of sickness. In order to be effective and complete, discourses on illness must address the social, political, and psychological ramifications of a particular ailment for the individual. Thus, in order for a disease to be classified (which subsequently provides social legitimacy for the experience of individuals with the condition), the condition must be specific, diagnosable, and also impair vital functioning. In addition, constructing infertility as an illness requires us to consider gender, the value placed on parenthood in the United States, social inequality, and other outside influences. However, as we will see, given infertility’s connection to cultural perceptions of reproduction, medical treatment gate-keeping, and maternal factors including aging (a process that, in itself, cannot be considered pathogenic), it is difficult to fully articulate whether or not infertility is a disease or simply an illness without examining both

infertility's clinical makeup and its position within a cultural system that values youth and reproduction. It is here that I begin.

Infertility as a Disease: Etiology

As a condition within the medical framework, infertility is not technically present until reproduction has somewhere failed to occur. Thus, in order to understand infertility as a byproduct of failed reproduction, we must first understand the basic components of the reproductive sequence. Beginning with the male, we see that this process is extremely complex. In order for a male to ejaculate, the following actions must take place:

Sperm leave the testicles bathed in testicular fluid, enter a cluster of microscopic tubules at the top of each testicle, and then move into a tightly coiled, fifteen-foot long tube called the epididymis. From the epididymis, sperm enter the vas deferens, a fifteen-inch-long tube about as thick as a Venetian blind cord, that rises into the abdomen. From the vas, sperm and testicular fluid enter the ejaculatory duct, formed by the end of the vas and the exit duct of the seminal vesicle, a gland that produces approximately 65 percent of the semen. The ejaculatory duct empties into the bulb of the urethra. Here, sperm from each testicle combine with a mixture of fluid produced in the prostate gland, which empties into the bulb of the urethra through a separate duct. Muscles surrounding the urethra contract rhythmically to cause ejaculation, the sudden spurt of semen from the penis.4

If these steps occur properly during sexual intercourse, semen enters the vagina of a female. However, before this process, the female reproductive system has already been preparing for the arrival of sperm. "Under the supervision of the gonadotropin hormones

FSH [follicle stimulating hormone] and LH [luteinizing hormone], one of the two ovaries normally produces a mature egg each month. Once released from the ovary the egg must be gathered into the fallopian tube for its journey through the tube to reach the uterus. Then, if the egg is fertilized by a sperm after sexual intercourse, the egg must implant itself into the uterine wall in order for pregnancy to even begin. However, even if pregnancy occurs, a variety of physiological processes can cause women to lose the developing embryo through miscarriage. In some cases, women experiencing infertility do not have difficulty becoming pregnant, but instead, it becomes impossible to carry the developing embryo (and later fetus) to term.

According to the Centers for Disease Control, approximately ten percent of the reproductive population in the United States will experience infertility upon trying to conceive. This reduced fertility can have several physiological causes: For women, scarring (as a result of infection, surgery, or injury) may occur in the fallopian tubes that blocks or damages them, “making it difficult for an egg to be fertilized or for an embryo to travel to the uterus.” In addition, ovarian dysfunction can occur when eggs are not released normally. This can be caused by aging (given the fact that one’s eggs are produced before birth), cysts in the ovaries, or through iatrogenic procedures. Finally,

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infertility in women can be caused by “immunological problems, chromosomal abnormalities, cancer chemotherapy, and serious illnesses.”

In addition to female infertility, male infertility can also occur. It is estimated that “in approximately 40% of infertile couples, the male partner is either the sole cause or a contributing cause of infertility,” usually due to “a low sperm count or problems with sperm function that makes it difficult for a sperm to fertilize an egg under normal conditions.” However, for approximately twenty percent of couples, idiopathic infertility is diagnosed. This means that, after exhausting all of their diagnostic capabilities, the physicians involved with infertility diagnosis and treatment were unable to determine the cause of a couple’s decreased reproductive capacity. While this lack of explanation may sound burdensome and detrimental to the individuals attempting pregnancy, the Centers for Disease Control report that couples experiencing unexplained infertility actually have above-average success rates when treated with artificial reproductive technologies using their own sperm and ova. “In general, couples diagnosed with tubal factor, ovulatory dysfunction, endometriosis, male factor, or unexplained infertility had above-average success rates. The lowest success rate was observed for those with diminished ovarian reserve. Additionally, couples with uterine factor, ‘other’ causes, or multiple infertility factors had below-average success rates.”

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10 ibid.
Infertility as a Disease: Diagnosis

In order for couples to potentially overcome their infertility, it is important for both men and women to undergo a proper diagnostic workup. For women, this may include an evaluation of their medical history, “physical examination, tests of blood hormone levels, ovulatory function, and hysterosalpingogram (HSG) (an x-ray of uterus and fallopian tubes.) Laparoscopy, which involves the insertion of a thin, lighted telescope-like instrument into the abdomen to look at the uterus, ovaries, and fallopian tubes, may be necessary to exclude factors such as endometriosis and adhesions (scar tissue) which may not be apparent by HSG.”¹¹ For men, infertility screening will usually include “a history and two properly performed semen analyses.”¹² Once infertility is diagnosed, either causally or through exhausting all diagnostic capabilities (as in the case of unexplained infertility), couples must decide if they wish to pursue treatment for their disease. In this way, infertility is like any other condition. Of course, receiving this diagnostic work-up, is contingent on having either the economic resources available for medical attention or health insurance that will cover infertility diagnosis and/or treatment. In many cases, this coverage is not available unless the underlying causes of infertility are related to other detrimental conditions that could cause additional complications, such as endometriosis or polycystic ovarian syndrome.

Infertility as a Disease: “Treatment” Options

If couples decide to pursue infertility treatment (and have the resources available to do so), they are shuffled into a world of vast technological innovation and innumerable potential opportunities for “success”, defined as conceiving and carrying the pregnancy to term, but not necessarily treating the underlying cause of the “problem.” (It is here that discussions of infertility as a disease are questioned, given the fact that many medical treatment exists to treat and rid the body of the condition, not to provide palliative care.) Most couples choose to pursue assisted reproductive technology treatment (ART), before turning to other options such as surrogacy or adoption. “Nationwide, more than 107,000 assisted reproductive technology (ART) procedures were performed in the United States in 2001. ART refers to infertility treatments in which an egg and sperm are handled in the laboratory (i.e. in vitro fertilization and related procedures.)”¹³ In 2001 (the most recent year that data are available for), “approximately one percent of the United States infants born were conceived through ART.”¹⁴ Thus, these techniques are readily available for United States couples with the financial resources to use them. As we will see in the interviews, however, this is often not the case, and in many circumstances, even when couples have the financial resources necessary to complete infertility treatment, they may not be prepared for its heavy emotional and social toll.

As we have seen, within the category of assisted reproductive technologies, we find several medical techniques for achieving pregnancy. The first, artificial

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¹⁴ ibid
insemination, involves obtaining a sperm sample and then injecting the sperm into the woman's vagina. Another (and more invasive) technique, in vitro fertilization (IVF) consists of combining sperm and egg in a laboratory dish, waiting for fertilization to occur, and then re-implanting the resulting embryo(s) into the woman’s uterus. In addition, in a procedure known as zygote intra-fallopian transfer (ZIFT), the resulting embryo(s) can also be injected directly into a woman’s fallopian tubes. Furthermore, a mixture of egg and sperm (unfertilized), can be transferred directly into a woman’s fallopian tubes in a procedure known as gamete intra-fallopian transfer (GIFT.) These latter two procedures are more invasive because they involve inserting a laparoscope into a woman’s abdomen to transfer the embryos or gametes into the fallopian tubes. In contrast, IVF involves transferring embryos or gametes into a woman’s uterus through the cervix without surgery.\(^{16}\)

According to national data from the Centers for Disease Control, approximately forty-nine percent of ART procedures are completed using standard IVF. An additional forty-nine percent utilize a procedure known as intracytoplasmic sperm injection or ICSI. In this procedure, instead of waiting for egg and sperm to combine in a laboratory dish, a sperm is injected directly into the egg. Once combined, the resulting embryo is transferred into a woman’s uterus through the cervix. ICSI is usually utilized in order to circumvent male factor infertility. Finally, a small percentage of ART procedures utilize


\(^{16}\) Centers for Disease Control’s Reproductive Health Information Source. “Section 2b: ART Cycles Using Fresh, Nondonor Eggs or Embryos.” [http://www.cdc.gov/reproductivehealth/ART01/section2b.htm](http://www.cdc.gov/reproductivehealth/ART01/section2b.htm)
GIFT or ZIFT. Overall, utilizing non-donor eggs or embryos, "35% of cycles started in 2001 among women younger than 35 resulted in live births. This percentage decreased to 28% among women 35-37 years of age, 20% among women 38-40, 10% among women 41-41, and 4% among women older than 42." Thus, there is a definite correlation between increased maternal age and reduced success when utilizing ART. For many older women (and individuals with particular physiological conditions that make success with non-donor gametes or embryos difficult) the question of treatment turns towards donor options, either through donor insemination of egg or sperm, or through the utilization of donor embryos.

For heterosexual couples who are unable to bear children using their own eggs and/or sperm and for homosexual couples, embryo donation or donor insemination of egg or sperm provide a viable chance of pregnancy. According to Resolve, a national support group dedicated to helping individuals cope and overcome infertility, there are several steps that couples pursuing ART with donor gametes or embryos must be willing to take. These include "undergo[ing] standard prenatal medical screening and testing for infectious diseases; agree[ing] to a psychosocial consultation; talk[ing] to a lawyer about setting up a legal contract that clearly defines all parties' rights and obligations regarding any future children" and releasing the donor(s) from any future liability. While egg or

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18 ibid
sperm donation allows one partner to have a genetic tie to the child created, embryo donation completely eliminates genetic parentage for the couple who desire a child of their own. This issue of biological parentage needs to be carefully considered before embryo donation is used. Finally, the last ART option involves using a “gestational carrier” or a surrogate mother. In one scenario, the surrogate carries an embryo created by a couple who cannot carry a child to full term and then relinquishes any parental rights to the child after his/her birth. With this procedure, the couple retains their genetic connection to the child being created, but does not physically experience pregnancy. According to the Centers for Disease Control, 0.7 percent of ART cycles utilizing non-donor embryos in 2001 chose gestational carriage. Another possibility, particularly for women who cannot provide their own ova or carry a donor embryo to term, involves a surrogate mother who will allow her own eggs to be fertilized by the male partner’s sperm in the laboratory before carrying the created embryo to term. This procedure still allows one partner to be connected biologically to the child. Ironically, given the desire of couples involved in surrogacy to have this connection, many couples refuse to have subsequent paternity testing of the resulting infant to guarantee that s/he is related to the male partner. According to Ragone, allowing this paternal uncertainty “represents an attempt to redress symbolically the imbalance created between wife and husband through the surrogate arrangement.”

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20 Centers for Disease Control’s Reproductive Health Information Source. “Section 2c: ART Cycles Using Fresh, Nondonor Eggs or Embryos.” [http://www.cdc.gov/reproductivehealth/ART01/section2c.htm](http://www.cdc.gov/reproductivehealth/ART01/section2c.htm).

In addition to challenging notions of paternity and biological closeness to one’s children, surrogacy also calls into question appropriate sexual and marital relations. In Ragone’s study on surrogacy, fathers seemed especially bewildered about the process. One respondent, Tom, spoke about his perception of sexuality and the biological mother of his child, the surrogate. According to Ragone, by stating “Isn’t she supposed to be my wife?”, Tom was demonstrating the concern and confusion experienced by husbands, “their ambivalence underscoring the continued symbolic centrality of sexual intercourse and procreation in American kinship. The father’s relationship to the surrogate, although strictly noncoital, is altered by the fact that it produces what was always, until the recent past, the product of a sexual union – namely, a child.”

Ultimately, each of these ART procedures may be rewriting American notions of sexuality, childbirth, and appropriate parenthood. Ragone continues:

Historically there have been three profound shifts in the Western conceptualization of the categories of conception, reproduction, and parenthood. The first occurred in response to the separation of intercourse from reproduction through birth control methods, a precedent that may have paved the way for surrogate motherhood in the 1980s. A second shift occurred in response to the emergence of assisted reproductive technologies and to the subsequent fragmentation of the unity of reproduction, when it became possible for pregnancy to occur without necessarily having been ‘preceded by sexual intercourse.’ The third shift occurred in response to further advanced in reproductive medicine that called into question the ‘organic unity of foetus and mother.”

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23 ibid.
As procedures become more invasive and the reality of designer babies comes into view, this third shift surrounding the unity of fetus and mother will have direct ramifications throughout the medical industry, the political arena, and in living rooms throughout the Western world. In addition, these treatments provide an interesting vantage point for discussion concerning infertility’s legitimacy as a disease, given the fact that each treatment directly conjures up discussion of social notions of motherhood, fatherhood, and acceptable reproduction. However, one might argue that even this avenue of inquiry can be mapped onto other diseases, including those involving stem cell treatment and transplants, where the physiological reality of the condition is juxtaposed with a treatment that demands sociological consideration.

Yet, as we will now see, infertility ultimately further questions the objectivity and specificity of disease, given the fact that the last two options of “treatment”, adoption and deciding to be childless, circumvent both the medical arena and the value placed on the patient’s will to get better and seek medical intervention within the traditional view of disease. For those who turn to ART unsuccessfully, for those who do not want to grapple through the ethical and cultural issues surrounding donor insemination or surrogacy, or for those who do not want to undergo invasive treatment for infertility, two additional options exist. The first, adoption, allows couples to have a child without involving the medical community. This “treatment” is thought-provoking given the fact that, by definition, most diseases are given significance and validation through their ability to be diagnosed and treated, either palliatively or curatively, within the medical community. In
addition, like donor insemination and embryo donation, adoption calls into question our societal notions of gender and parenthood. Should adopted children’s relationship to their parents be considered the same as biological children within the vantage point of society? In a qualitative study completed in India, Bharadwaj found that “when reproduction goes awry, couples would rather secretly resort to accepting donated sperm than choose the option of adoption, an option that evokes widespread fears of making infertility permanently ‘visible’ and irreparably upsetting the sacred social and biological triad of mother (womb), father (semen), and child (foetus).”\(^{24}\) Unfortunately, this conceptualization of adoption is also seen in the United States. According to Miall, “a kinship system defines who is related to whom and, in North American culture, has traditionally been based on blood or biological relationships among individuals.”\(^{25}\) This focus on biology can cause great turmoil in couples who have already experienced the violations of selfhood associated with infertility. Furthermore, for couples experiencing infertility, the question of how one’s identity is shaped by parental origins or inclusion in a “nontraditional” family structure needs to be considered before beginning the adoption process.

If couples have chosen adoption, several steps are needed in order to fulfill their desire for an adopted child. First, according to the American Society for Reproductive


Medicine, couples should consider the type of child they desire, based on age, ethnicity, and other considerations including special needs. Next, they should contact an adoption agency in order to learn more about the process and what is expected of them. Then, the couple wishing to adopt should prepare for a home study, a visit that allows the adoption agency to evaluate the couple’s home situation and ability to properly care for a child. If this visit and other evaluations go well, the couple should prepare for the placement of the child in their home. Follow-up and legal consultations will also be needed in order to guarantee the rights of the adoptive couple to their adopted child.26 Yet, even when this entire process is complete, additional considerations will arise, especially concerning the issue of identity and adoption disclosure. While disclosure is a personal choice within the adoptive couple, most researchers and counselors recommend telling the child of his/her origins in cases of both adoption and embryo donation, in order to guarantee adjustment and preserve trust within the family structure.27 “Evidence suggests that accidental or delayed disclosure can cause children to feel shocked, confused, betrayed, and impairs their sense of trust.”28

The final option for infertile couples is to decide that not having a child is okay. However, this decision directly violates the assumptions of our pronatalist society. As Whiteford and Gonzalez state:

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To be childless in a pronatalist society is to run against the norm with all its concomitant sanctions. According to Veevers and Miall, two primary procreative norms predominate in North American society. One is that all married couples should reproduce; the other is that all married couples should want to reproduce. These norms (extensively documented in the literature), in conjunction with ‘probirth’ governmental policies (i.e. income tax deductions) that encourage reproduction and reward the image of parenthood, form the basis of a pronatalist society.29

Thus, when having children becomes a necessary milestone in pronatalist societies, deciding not to become a parent calls into question one’s identity and ability to satisfy societal requirements as a developing individual committed to a partnership over time. As previously mentioned, this final option also calls into question the legitimacy of infertility as a disease given the fact that the decision is made outside of the medical arena and also is a decision either to give up on medical treatment or to never pursue medical treatment for a condition even when one has the means to do so. Thus, if infertility is to be considered a disease, then this direct “assault” against medical authority over the body could be constructed as nonadherence, which would subsequently invoke a variety of psychological consequences for individuals who have already endured the pain that infertility brings given its construction in the United States as a reproductive failing for both men and women. This notion of failure and the psychological consequences of infertility, resulting in part due to cultural norms and reproductive values, is where I now turn.

Infertility as Illness: Cultural Norms and Reproductive Values

As we have seen, infertility can devastate individuals’ perceptions of themselves as members of relationships, families, and larger society. According to Whiteford and Gonzalez\textsuperscript{30}, infertility causes great shame for women as they navigate their gendered identity, an identity that is negotiated in a society that views “motherhood [as] the ultimate expression of being a woman.”\textsuperscript{31} However, women are not alone. According to Dr. William Petok, a consultant physician for Resolve, “the failure of their procreative body functions is often devastating for men, especially since they are so closely linked with sexuality. Men may consider it an assault on their masculinity if they are the cause for the failure to conceive.”\textsuperscript{32} Not surprisingly, this line of thinking finds great support in popular culture. In their study on newspaper depictions of infertility and sperm counts, Gannon, et al. documented instances where men’s sperm counts were constructed as directly proportionate to their masculinity, including a claim comparing a man with a low sperm count to a hamster. As the researchers state “this conflation of fertility, potency, and masculinity has consequences for infertile men. Fathering a child is seen as proof of masculinity and, in consequence, not fathering one is seen as a failure of masculinity.”\textsuperscript{33} Thus, infertile men are forced to question their own sexuality as a consequence of unfair and uncompassionate depictions of masculinity in popular culture. And this injustice can


seriously impair men's ability to cope with infertility or discuss it effectively with their partners.

According to Petok, “although forty percent of infertility is attributed to male factors, it appears that men are not as willing or as able as their female partners to talk about their experience.” As we have seen, this lack of communication can be attributed to the likely shame experienced after a diagnosis of infertility is given and can also be linked to the narrowness of infertility conceptualizations seen in popular culture. “One consequence of this repertoire [of sperm count corresponding to levels of masculinity] is that men are provided with a limited range of linguistic resources from which to construct accounts both of what it is to be a man and of health-related issues and concerns.” In addition, men's unwillingness to discuss infertility with their partners may also stem from the before seen notion of reproduction and childbirth as ‘women's business.’ “Unlike women, men are not reminded on a monthly basis of their fertility or lack thereof, thus exacerbating the feelings that men may appear less sensitive and distressed by childlessness. Monitoring ovulation is a woman's task, and contraception is often a female's responsibility.” Thus, men are often unequipped to handle the reality of infertility. Unfortunately, the fact that our culture values the strong male and given the devastation that females experience as a result of their own battles with infertility, couples may be unable to handle their anxiety and depression as a consequence of

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infertility diagnosis. In addition, as we will see in the responses provided in this study, perceptions of fertility as a component of womanhood may create serious anxiety surrounding performance, acceptable femininity, and one’s status as a functioning and successful woman.

**Infertility as Illness: Psychological Consequences**

Narratives constructed in a study by Whiteford and Gonzalez directly highlight the difficulties presented by infertility. For example, when discussing her experience with the medical community, one respondent stated:

> The secretaries...I feel inadequate. I mean I feel embarrassed in front of these women. They take the semen sample, and I am ashamed that they know what my husband had to do that morning, that I have to be inseminated, and that everyone knows. There’s a big feeling of having no privacy, and you feel you have to expose yourself. Now they have a vaginal ultrasound that they use on me every day. It’s humiliating. It’s gotten to the point where I’ve lost a lot of my self-respect. It comes to the point where you don’t care anymore. You just want them to go ahead and do what they must. I have to; I want this, and this is the price I have to pay for it.\(^{36}\)

In this account, we see that being an infertility patient can be an emotionally painful and humiliating event, as reproduction and sexuality, two intertwined concepts that are traditionally thought of as private and outside of the realm of biomedicine, are exposed in the sterile medical environment. Thus, it is not surprising that “research has shown that women undergoing treatment for infertility have a similar, and often higher, level of ‘stress’ as women dealing with life-threatening illnesses such as cancer and heart disease.

Infertile couples experience chronic stress each month, first hoping that they will conceive and then dealing with the disappointment if they do not. Infertility consists of a monthly revictimization which is not dissimilar to the experience of cancer treatment and remission. This stress can also, in itself, further impair couples ability to conceive, given popular notions of stress, reproduction, and menstruation, as inter-connected. In addition, given the fact that “treatments such as in vitro fertilization do not cure infertility even when they were successful; rather, they alleviate the condition of involuntary childlessness,” infertility can be especially painful. Given this pain, it is imperative that couples seek help in order to deal with the emotional suffering associated with infertility. “Books can offer information and understanding about the emotional aspects of infertility. Support groups and meetings can reduce the feeling of isolation and provide an opportunity to learn from others who are experiencing infertility. Individual and couple counseling offer the chance to talk with an experienced professional who will help you sort out your feelings, identify coping mechanisms, and help you choose solutions to your problems. Discussions with family members and friends are also options.”

Unfortunately, regardless of couple’s support systems and ability to gather information, the experience of infertility will continue to be one of turmoil, particularly for couples who do not succeed in becoming pregnant, as long as American culture

values biological reproduction over socially constructed parenthood. "Until U.S. dominant culture norms value women equally for their productive and reproductive roles, flawed social identities for infertile women will remain. The uncontrolled growth of the medical industry, however, transforms that identity by communicating to infertile women that they have an obligation to expose themselves to medical intervention, regardless of the financial, emotional, and physical costs. That transformation prolongs and publicizes the hidden burden of infertility." While this account fails to recognize some agency in the lives of infertile couples and their decision to pursue reproductive technologies, it does point to the inherent conflicts in a pronatalist society that thrives on technological innovation, medicalizes reproduction and sexuality, and then scorns those who utilize this innovation and the medical institution in order to satisfy the culturally constructed requirement of parenthood.

Infertility as a Disease: What's in a Label?

Having examined the nature of infertility as a disease (etiology, diagnosis, and treatment within a biomedical framework) and the lived experience of infertility as an illness, I now turn to the question that began this journey. Is infertility appropriately classified as a disease? As Whiteford and Gonzalez argue, infertility actually points to a theme of greater medicalization of reproduction and not necessarily a specific disease entity.

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Until the 1950s infertility was often thought of as emotional, rather than medical in origin. Not until the 1960s and 1970s, when the development of synthetic drugs allowed physicians to control ovulatory cycles and the technology of laparoscopy allowed them to see women’s internal reproductive biology, did infertility become medicalized. Some research suggests that while new drugs and technology were significant developments in the medicalization of infertility, the treatment of infertility became a large-scale industry partially in response to socioeconomic factors. Between the 1950s and the 1970s, U.S. fertility rates fell. At the same time, there was an increased supply of physicians trained in obstetrics. Three other factors further set the stage for the transformation of infertility into a medical industry: the decreased availability of healthy white infants for adoption, the sexual revolution and the increased incidence of sexually transmitted diseases, and the increased frequency with which women entered the job market and delayed the onset of childbearing.  

Thus, the medicalization of infertility and the creation of technologies to treat it have actually led to its reconstruction as a disease for the medical gaze. Thus, given the fact that infertility has received recognition as a disease in the medical community and within the economic system, with the development of third party payer systems for treatment in states such as Massachusetts and Rhode Island, we may now recognize infertility as a disease, not from its specificity or adherence to the Parsonian concepts of patient role and provider, but instead due to its legitimization as a condition treatable within the economic system. Thus, the question of infertility as a disease necessarily turns to a question of signification, not absolute classification.

While not arguing for infertility to be excluded within the confines of a disease category, Sande'owski and deLacey do question the “proliferation of meanings of

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infertility.”43 While these researchers do not wish to belittle the profound suffering of women and men who experience infertility, they do, nonetheless, question the cultural biases behind defining the inability to reproduce of older, successful white couples as pathogenic, while labeling successful reproduction outside of professional heterosexual couplings as abnormal. Infertility diagnoses “are largely guises for white, married, and socioeconomically advantaged persons, as members of poor and minority groups are seen to be hyperfertile and single persons and gay and lesbian couples to be ‘dysfertile’, that is, as unsuitable for parenthood no matter what their fertility status.”44 Thus for Sandelowski and deLacey, it is imperative for discourses on infertility to take into account its social context, within the confines of the distinctive political economy of the United States, where the ability to receive medical attention for the condition legitimizes it and ultimately allows one to be considered infertile in the first place. Ultimately, until the cultural constructions of sexuality, reproduction, and parenthood are questioned within popular culture, reproduction may continue to be seen as a necessity. Furthermore, as technology becomes more pervasive for the “treatment” of infertility, those who do not partake in it, may be perceived as further deviant, with couples who choose not to have children being constructed as lacking normative values.

In order to explore the cultural model of infertility within a broad-based sample, I have qualitatively interviewed women from a variety of economic, professional, and


44 Ibid
familial backgrounds within a large urban setting. These interviews touch on the value placed on fertility, the emotions associated with infertility, and the greater social context of reproduction in the United States. In order to analyze these data, I have utilized cognitive anthropology.

**Cognitive Anthropology as a Research Framework**

Cognitive anthropology, defined by D’Andrade as the study of the ways in which individuals and populations make sense of their world, is an excellent theoretical framework for examining culture and the decisions and values that people place on particular issues. By investigating cultural knowledge and the way it is transmitted, D’Andrade argues that cognitive anthropology allows researchers to study “how people in social groups conceive of and think about the objects and events in their world.” Numerous studies have shown that cognitive anthropology is especially helpful for examining health issues due to its cultural sensitivity and the complex nature of health decisions. Furthermore, cognitive anthropology contains several methods that allow researchers to construct cultural schemas for a variety of health concerns and issues.

Ward Goodenough, an Emeritus professor at the University of Pennsylvania, defined culture as “what you need to know to get along in a group of people.” Thus,

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culture shapes our perception of the world and analyzing the influence of culture on decisions and understandings of reality helps researchers create more effective programs that have real impacts on the health of communities. D’Andrade\textsuperscript{48} goes further and shows that culture is shared through social rules and shared mental constructs. These constructs, known as schemas, have powerful effects on rationality, emotions, motivation, and perception.

D’Andrade states that humans construct reality by filling in slots within a cognitive model known as a cultural schema. According to Strauss and Quinn\textsuperscript{49}, cultural schemas organize knowledge into meaningful structures which allow individuals to process knowledge in a culturally appropriate manner, mostly unconsciously. These cultural schemas, in turn, help reinforce the meaning of objects in reality. Cultural schemas reconstruct reality by “alter[ing] our memories of past events, determin[ing] the meanings we impart on ongoing experience, and giv[ing] us expectations for the future.”\textsuperscript{50} When these schemas become more complete and complex, they are known as cultural models.

Cultural models influence memory, perception, and reasoning. D’Andrade\textsuperscript{51} argues that cultural models influence these factors of human-existence to a point that makes it difficult for individuals to interact with their world in a nonbiased manner. Thus,

\textsuperscript{50} \textit{ibid}
studying the cultural model of infertility is extremely valuable given cognitive anthropology's ability to understand underlying influences on perceptions of infertility for women in an urban setting given these perceptions' ties to greater views on reproduction, sexuality, and the gender roles of men and women. Naomi Quinn\(^2\), in an influential article about marriage, shows that individuals make decisions based on the level of their goals. Quinn shows that married women want to satisfy upper level goals of equality and womanhood, but also hope to satisfy lower level goals that allow them to appeal to their husbands and avoid marital conflict. For infertile women, I postulate that women have upper level goals surrounding the cultural imperative to reproduce and lower level goals about their desires to make individual decisions related to their sexuality and relationships with their significant other. By examining upper-level and lower-level goals, researchers can understand motivational factors and also analyze why individuals make the decisions they do, since, as Quinn argues, schemas propel individuals into action.

D'Andrade\(^3\) furthers the notion of hierarchies of cultural schemas and discusses master motives, which he believes affect all action and perception and trickle down to middle level and lower level schemas that influence decisions and perceptions. In addition, D'Andrade\(^4\) adds a fourth component, emotional schemas. Emotional schemas,
according to D’Andrade, influence behavior by motivating the recall of certain schemas, shaping those schemas according to experience, and making cultural models much stronger. Worthman\textsuperscript{55} also finds that emotional schemas influence decisions and perceptions of the world and states that emotions affect the way we learn about the world around us, the way we categorize memories, and the way we think and react. Thus, Worthman believes that culture influences emotions and thus influences all of the thinking processes that rely on emotions for information. Given the importance of emotions, using methods that would allow respondents to discuss their emotional responses to certain situations would enhance the construction of a cultural model and allow for better understanding surrounding respondents’ perceptions and motivations. Thus, examining the emotions surrounding the experience of infertility allows us to understand women’s perception of infertility as a failure on their part to be successful women and gives us a framework for understanding why so many women undergo invasive, costly, and time-consuming procedures in order to potentially achieve pregnancy.

In addition to impacting cultural schemas, emotions also serve as a means of social control. They allow someone to feel guilty, for instance, in order to prevent them from stealing. However, other influences allow for social control over decision making.

According to Mellers\textsuperscript{56}, et al. these include the social context (the idea that the mere presence of others influences decisions), social networks, social learning, and group decision-making. Thus, women’s perceptions of infertility and their position as infertility patients are connected with their desires to fulfill social constructions of appropriate femininity and satisfy the perceived desire of their physicians and family members to be witness to a successful pregnancy. Overall, it appears that cultural schemas influence action through “linkages with emotion and motivation.”\textsuperscript{57} In addition, appraisals that allow for decision-making and understanding of the world are modified by early experiences and culturally prescribed moral and ethical judgments that are internalized\textsuperscript{58}.

In conclusion, cultural models are, according to D’Andrade, “important motivational forces that allow individuals to strive for the attainment of goals,”\textsuperscript{59} goals that lean on actual reality according to Lakoff and Kovecses\textsuperscript{60}.

In order to understand the ways that people understand their world, “anthropologists had to create tools to further comprehension of seemingly abstract ideas and foreign cultural models.”\textsuperscript{61} For example, Elisa Gordon\textsuperscript{62} shows that cognitive


\textsuperscript{58} Ibid


anthropologists can also use semi-structured interviews to examine cultural domains. Because individuals with relatively homogenous backgrounds tend to hold similar cultural schemas, a set of 11 qualitative interviews allowed me to analyze the individual reality of infertility and its treatment for women in an urban setting. This is not to say that each subgroup of women present in this study, including women from varying socioeconomic backgrounds with different levels of medical access, women of different ethnicity, and women in different positions within their careers have identical experiences. Instead, common themes are expected to be shared throughout their more formal models are shared, but individual

that allow researchers to analyze the potential to improve lives. Cognitive

ally sensitive and examine overarching a variety of methods that accommodate cultural model of infertility (and thus the social interactions of infertile women), I
Chapter III: Methods

Cognitive anthropology is an excellent theoretical framework for examining culture and the decisions and values people place on particular issues. By interviewing 11 women experiencing infertility in the United States, this study examined perceptions of infertility in relation to the female body, women's navigation of the medical community in response to their infertility, and the greater implications for infertility within their relationships and futures. Because cultural models tend to be shared among relatively homogenous populations, the data received from this study gives us a basis for understanding the experience of infertility in an urban setting.

Research Aims:

In this study, I pursued the following three areas of inquiry:

1. What is the experience of medical treatment for infertility like and how does this experience shape women's perceptions of their bodies?
2. How does infertility itself affect women's perceptions of themselves and their relationships with others, including their partners?
3. How is infertility discussed and what can this discussion tell us about its position within the nexus of sexuality, morality, and reproduction?
Hypotheses:

Based on the information presented in my literature review, I hypothesized the following results based on the research aims presented above:

1. The medical treatment of infertility will be seen as particularly promising for women experiencing infertility, but the service provided will consist solely of treatment for the body (within the Cartesian duality of mind and body as separate entities) and this may lead to women's hyperawareness of their bodies.

2. The experience of infertility will cause women to question their success as women and will create relational strain for women who have steady partners.

3. Infertility will be discussed as a failure to succeed and a failure of the reproductive body, which will allow us to point to the importance placed on reproduction and the stigmatizing nature of impaired sexuality.

Subjects:

Eleven women in an urban setting were interviewed in this study. The women were of differing socioeconomic and education status, with five women in professional positions who had earned graduate degrees, two women with bachelor degrees in professional positions, three women who have completed high school, and 1 woman who was currently in college. The respondents ranged in age from 26 to 47. In addition, ten respondents were married and one was single with a steady partner. Furthermore, five respondents were black and the remaining six respondents were white. Four women had
one biological child, two women had two biological children, and one woman had both an adopted and a biological child. The women ranged in age at diagnosis, from 19 for one woman suffering from polycystic ovarian syndrome to 40 years of age. Finally, five women had succeeded in getting pregnant as a result of infertility treatment, with one woman seeking an additional child through IVF who has yet to be successful. Four women are still undergoing infertility treatment and the final two women have stopped treatment, one after experiencing numerous miscarriages and the other after deciding that her and her husband did not have the financial resources necessary for more invasive medical treatments. Please see Appendix B for a graphical presentation of these demographic data.

Setting:

All interviews were performed over the telephone utilizing a recording device and each lasted approximately 45 minutes.

Procedures:

Recruitment of Respondents:

In order to reach a broad sample of women experiencing infertility, I placed an advertisement in the Philadelphia Metro, a free daily newspaper found throughout the Philadelphia area. The advertisement asked women, aged 18 to 50, to call or email if they
had received medical attention for infertility. The advertisement ran on Tuesday, February 1\textsuperscript{st}, Thursday, February 3\textsuperscript{rd}, and Wednesday, February 9\textsuperscript{th}.

Consent:

Each respondent was asked to consent to one semi-structured qualitative interview after calling or emailing to schedule an appointment. Interviews were scheduled at a later date from initial contact and respondents were told both at initial contact and at the beginning of the interview that they were allowed to decline at any point, that they had a right to refuse to answer any questions, and that the interviews would be tape-recorded. Furthermore, respondents were told that they would be asked to discuss their medical treatment for infertility, the emotions they experienced during infertility treatment, who they turned to for support in coping with the experience, and what the coping relationship was like during the interview. Thus they were aware of the interview topics prior to agreeing to be interviewed and were reminded of the topics right before the interview began. This study received ethical evaluation and approval from the Institutional Review Board at the University of Pennsylvania on January 18, 2005. Interviews commenced the following week, with most being performed in February.

Confidentiality:

Interview responses are confidential and are not linked to particular respondent in any manner. Subjects are referred to only by their initials.
Semi-Structured Interviews: A Rationale

I decided to construct a semi-structured interview in order to explore the respondents' cultural model of infertility. Each semi-structured interview was recorded using a digital voice recorder and then subsequently transcribed shortly after the interview was completed. By using a semi-structured model and completing a transcript for each interview, I was able to explore individual components of women's lives more carefully utilizing a constant comparative framework, while also collecting basic information in a semi-systematic way that allowed me to make comparisons across respondents during the data analysis stage of research.63

In constructing questions for the interviews, I attempted to avoid common pitfalls of researchers that are highlighted in Weller's64 discussion of interviewing and questionnaire construction and were further discussed by Dr. Frances Barg on December 1, 2003 during her cognitive anthropology course at the University of Pennsylvania.65 I attempted to avoid ambiguous, long, hypothetical, and leading questions that show a particular agenda. I also avoided questions that contained overlapping intervals or ambiguous accuracy requests. Finally, I tried to create questions that would not embarrass the respondents and I attempted to save sensitive questions until the latter part of the interview.

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64 ibid
Each question attempted to explore the three research aims of this study (The questions are included in Appendix A.) The interview began with basic questions surrounding respondents’ diagnosis of infertility. The interview then continued with more detailed questions relating to their responses surrounding diagnosis, including questions examining their experience in the medical environment, questions surrounding their emotional state and ability to receive support from others, and questions about their hopes for the future. The next section of questions explored greater perceptions of gender roles in the United States, by examining the respondents aspirations for the future when they were younger, their perception of themselves after being diagnosed with infertility, their relationship with their significant other, and their perception of the construction of success in the United States for both men and women. The third section of questions aimed to further flesh out the most salient aspects of their experience with infertility, as well as their disclosure of infertility to others. The fourth set of questions was related to demographics including their age, ethnicity, job position, education level, and number of children. I chose to place this section towards the end because I did not want to set a tone for the interview at the beginning that would consist of numerous short answers. Finally, the last section allowed respondents to elaborate on any previous responses and also gave them a chance to touch on any themes that were especially salient for them that may not have been left out by the interview questions. After the interview, general comments were written down discussing the respondent and any problems that may have arisen during the interview process.
Data Analysis:

All interviews were transcribed by myself and then coded in order to elicit the main themes found in the data. Twelve main subject areas were identified by reading through the transcripts before coding began:

1. Male experience with infertility
2. Psychological experience of infertility for women
3. Medical treatment, experience, and staff
4. Coping with the diagnosis
5. Secrecy: Sharing of diagnosis
6. Infertility as “woman’s issue”
7. Female gender role
8. Function of children
9. What can be done to make the experience better
10. Pregnancy
11. Knowledge of infertility when younger
12. Considering other options; Life expectations for the future

These themes were selected based on the questions asked in the semi-structured interviews as well as respondent’s answers. Themes 5, 6, 10, and 11 were less explicitly explored in the questions of the interviews, but were deeply intertwined with the responses given for questions about the medical treatment and psychological experience of infertility.

Once the interviews were coded based on these twelve general themes, I then went back and coded again line by line in order to explore subcategories within each topic. For instance, in the category of “Male Experience of Infertility”, the subcategories were “the construction of masculinity”, “the reconstruction of sexual intercourse as a duty”, and “emotional support provided by husband.” This analytical method has been
explored and utilized by several researchers and is most appropriately called the constant comparative method, given its insistence on continuously creating and evaluating theories based on "patterns, themes, and common categories discovered in the observational data."66 In this method, "categories [coded for] may be in vivo [emphasis in original] codes that you take directly from your respondents’ discourse or they may represent your theoretical or substantive definition of what is happening in the data."67 Thus, this method allows for detailed analysis of the actual data while also allowing researchers to begin developing theories based on the responses in a systematic manner. Finally, I reviewed the outline created by the second coding process in order to make comparisons across the respondents. Neuman refers to this step as selective coding in that, at this point, "researchers look selectively for cases that illustrate themes and make comparisons and contrasts after most or all data collection is complete."68 Thus, this final step allows for elaboration that eventually leads to themes and examples given in the final report. This process also allows for the introduction of demographic information, which in turn allows for the evaluation of theme salience based on respondent characteristics. While cognitive anthropology argues that cultural schemas are comparable across relatively homogenous groups, individual differences will still be present. Coding by demographics allows for a greater understanding of variables that decrease sample cohesion. Variables

such as age, education level, ethnicity, and previous childbearing have effects on the perceptions and values attested to in the responses given during interviews.
Chapter IV: Results

My position:

I am an American white female with three and a half years of college education. I am currently working on a B.A. in anthropology and health & societies and an M.Sc. in medical anthropology. I have thus studied numerous issues in women’s health and medical anthropology more generally. I believe that women are not merely reproductive machines and that it is acceptable for women to be childless. However, in my future, in addition to pursuing a career in public health, I do wish to become married and in many years from now, have two children. In this way, I was able to relate to the desires of my respondents to conceive. However, regardless of this, I attempted to remain value neutral and constructed questions in a manner that did not automatically assume that reproduction was a vital part of identity or an individual’s life, a condition that is attested to in the interview questions shown in Appendix A. However, given my status as a well educated and relatively young white woman, some of my respondents may have felt uneasy discussing such a sensitive topic with me, particularly respondents that may view reproduction as a private matter and especially for respondents who view their own difficulty achieving pregnancy as a failing on their part and have not come to terms with these feelings. However, given the many candid responses I received from women of all backgrounds represented in my study, I believe that objectivity was achieved to the best of any researcher’s ability.
Main themes:

High Expectations

When describing their roles as women, the respondents stressed the importance of becoming a mother and their perception that other women experience similar desires. For instance, when asked what her expectations for the future were when she was younger, AF stated that "I figured I would be married and possibly have a couple of kids." Furthermore, when asked "do you think your expectations were similar to other women’s?" AF continued by stating that "I would think so. I would think that around this age, most women would like to, if not settle down, to at least start trying to settle down...and start a family." In addition, when asked the same question, SM responded "Um, I thought that I would be, um, just about where I am right now except for having two children. I think, working with a family and a house in the suburbs. Able to balance it all." Here, SM affirms the need to have children and also brings in the notion that successful women have both careers and children. While this idea was not shared by all respondents, the idea of balance and a need to accomplish within the duality of motherhood and the workforce ran strongly through several interviews. For instance, when asked about the definition for success as a woman, JS stated:

I think it's really all over. A woman, the expectations of women are just insanely high and um, that's why so many women are so depressed and unhappy because they're just expected to fulfill. To be a wonderful mother, a wonderful wife, and a career woman, you know? And if you're not, then something's wrong with you or you're less of a woman and um, you know, there's there's, it's all over the place I think.
Here, JS is not only invoking the importance of children, but is also testifying to the extreme difficulty women experience as a result of society's perceived expectations. As we will see, these expectations dramatically shape the experience of women who are infertile, by affecting the way they see themselves and reconstruct their identity as "malfuctioning" members of society.

*Function of Children*

Given the fact that infertility only originates from a desire to have children, it was surprising that women tended to mention their current or potential children only when prompted to do so by the question "Why is it important or not important to have children?" However, once respondents began to discuss children and their role, a number of functionalities for children began to emerge. For instance, some women felt that having children would allow them to satisfy the expectations of others and fulfill their desires. Thus, as AF stated:

> Everyone's anticipating him or her...my mom, she's so ready to be a grandma again. And my husband of course because, you know, we don't have any kids together. Well, we don't have any kids period, what am I saying together! Well, I've been pregnant but I had a miscarriage and that's another reason, I lost a baby at 18, you know, it's, it's just everybody's waiting. All my cousins. All my uncles and my mom.

Here, we see that children act as a life-changing entity that satisfy core components of a traditional narrative of adulthood that is expected by the family and friends of the infertile woman. In addition, other respondents pointed to the functionality of children in terms of
providing a future for their lineage and to help create a future of successful adults. For instance, YK stated:

It’s [having children] the continuity of life and caring for children and expecting children caring for you and the relationship for the child different stage of life and everything’s important. Because children, they grow up and then they become parents and grandparents and life itself and it’s important to bring up a child that is caring, loving, and responsible.

In addition, RW stated:

Um, why is it important [to have a child]? I just, to have children, I believe first of all, they’re a gift from God and the, it’s to have an offspring that you can love and grow and show things and teach things to and who knows, you may be raising the next president of the United States...So, I think it’s beautiful to have offspring to, to grow and love and show them things in life. To teach them, yea.

Thus, for these respondents, having children is important in order to ensure a future both for them, to help create a new future for society, and to provide an avenue for introducing the beauty of life to someone else.

Respondents also stated that having a child was necessary because of some maternal urge created both naturally and through the childcare of younger family members. Thus, according to MD, “I just always wanted to have a family, you know. I took care of my nephew when he was young...and I did a lot of babysitting for cousins and it seemed like I was always taking care of everyone else’s kid, I always wanted to have my own. In addition, DD stated “For me, I would say it’s important for me to have children because, I guess I’ve always been told and I know that I do have a maternal instinct and I know that I could be a good mother.” Here, we see that motherhood is
something that is potentially biologically ingrained within the individual. One could imagine that this construction reinforces feelings of biological and social failure, given its direct violation of a natural instinct. Finally, respondents like PR felt that having a child allowed one to truly experience the world and therefore was a necessary part of being not only a woman, but also a human being.

I think that having children makes you a more complete person. That’s, that’s just my opinion. In that you, um, you become whole. I don’t, I can’t really explain. You’re, you’re so much more vulnerable. You’re just more vulnerable and open to the experience of life, I think, when you’re a parent.

Thus, for these women, having a child allows one to fulfill social and societal expectations and also allows them to live a life that they view as more fulfilling and complete. This functionality of children and women’s perception that being a successful woman requires them to obtain success in their careers and be married with children work in tandem to create the notion that women must reproduce. Subsequently, when their attempts fail, women who have the means to do so turn to the medical community for an answer. In doing so, they enter a new arena, with rules and expectations that shape women’s perceptions of their bodies, value as individuals, and future.

*Medical Treatment: The Body in Clinical Space*

My own shadowing experience with a reproductive endocrinologist introduced me to the movement through space of patients undergoing treatment for infertility, which
in turn allowed for an understanding of the self and body as separate entities within infertility care. Like most doctors' offices, patients first move into a vast waiting area and are required to fill out forms, including those relating to insurance coverage they may or may not possess. In addition, patients are required to hand in any prior diagnostic or treatment materials including cat-scan results from other physicians, former blood work, and a history of medications. After this procedure, they are required to move to one of two places. If it is their first visit, they (and their partner, if present) are led to a cozy room with two chairs, a desk, a computer, a special light to examine diagnostic film, and a chair for the physician, behind the desk and next to all of the technological equipment. Here, the physician appears to dominate the conversation, steering it to topics that are directly relevant and key to the woman's reproductive health, and for the most part, away from topics about the psychological experience of infertility or additional social factors. Questions asked are all related to the history of menstruation, former pregnancies, experience with fertility difficulties, and any previous diagnostic and treatment procedures a woman has undergone. After this questioning period, there is a brief pause to allow the woman (or couple) to ask questions of the physician and then a plan is enacted, usually consisting of some preliminary diagnostic examinations of the man and woman.

For couples who have been to the clinic before for diagnostic examinations, the movement through space is different. Here, the woman (or couple) is led to a clinical examining room with all of the typical instruments found in a doctor's office, as well as a
gynecological examination table. On the wall are posters of the female reproductive system and the menstruation cycle, visual representations of the core ‘problem.’ Once in this room, the woman is given a gown to change in to and is required to remove everything except her bra. This experience parallels Katherine Young’s description of the internal medicine examination. In her discussion on disembodiment, Young states “over the course of the medical examination, certain of these [personal] boundaries are peeled away to permit a close inspection of parts of the body. At the same time, other boundaries are introduced. Thus persons to be examined are put into a closed room so that its walls substitute as evidential boundaries for the clothes they take off, the difference being that the physician is inside the boundaries along with the person.”

Thus, within the infertility encounter, clothing is taken off and the walls of the clinical room, complete with posters of the healthy reproductive system and the developing fetus, suddenly stand for the social and personalized body of the infertility patient. And, in some ways, this metaphor can be extended to the plush room, where discussions of infertility begin, as people describe the intimate and personal details of their inability to conceive, giving part of their selves away by taking down that boundary and, in return, receiving comfort and shelter by the walls of the room, barren of posters and a physician who seeks the physiological explanation for their difficulties of reproduction, an explanation that is rooted in their newly accessible bodies.

These two spaces also directly correlate with the description by Katherine Young of the medical examination. According to Young, “medical examinations are divided into

two parts: the history-taking and the physical examination. These internal constituents of the realm of medicine are bounded by greetings and farewells that mark the transition between the realm of the ordinary and the realm of medicine. The shift from greetings, in which the physician emerges from his professional role to speak to his patient as a social person, to history-taking in which the physician elicits information from the patient about his body, is the first move towards dislodging the self from the body.\textsuperscript{70} However, within infertility treatment, instead of engaging in social greetings (which appear to be more within the realm of the nurses within the busy infertility treatment center I witnessed) within both the intake interview and the medical examination encounter, space is instead utilized to delinate the type of interaction a patient should expect. By utilizing one space for the discussion of infertility and the patient’s actions and role as an individual and another space for the unveiling of the patient’s body and manipulation of technology and physiological entities to treat infertility, medical personnel indicate whether or not a patient is supposed to be a (somewhat) active participant in the dialogue surrounding their bodies and history, or a detached body waiting to be examined and “treated.” This work of distinct spaces (the separation of body and self) parallels Emily Martin’s discussion of childbirth when she states that “for such a woman, the separation between the body and self needs no further explanation. She is literally divided into her ‘self’ and her ‘body’; people are doing things to her body, but paying no attention to her self.”\textsuperscript{71} While Martin is discussing the separation inherent in cesarean sections through the use of


a drape between the mother’s head and pelvic region, this separation is nonetheless also seen in infertility treatment, where a blanket is positioned over the woman’s chest and abdomen while the physician stands at the end of the examining table, and the woman is placed in the position typical of gynecological examinations with her partner, if present, positioned at her head.

This separation has important implications for both the patient and the physician. For one, this separation allows for the objectification of the body that may be necessary in order to cope with the invasive nature of gynecological examinations, examinations that would violate notions of appropriate social behavior if not positioned within the confines of the medical institution. As Katherine Young states “The dislodgment of the self from the body is designed to preserve the social persona from the trespasses of the examination. But the self is so deeply worked into the body that physicians must also be concerned to preserve the dignity of the self, the social person whose lodgment happens to be the body. This dual attention to the body as incarnate and discarnate, self and object, is handled by a delicate manipulation of frames and boundaries that might be called an etiquette of touch. In response, patients can cede their bodies to the realm of medicine by abstracting themselves for the nonce. But they can also, equally delicately, compose themselves outside of their bodies, for instance, within the realm of narrative.” Thus, the self and body are necessarily distinct in order to preserve social integrity and, at the same time, open the body up for examination. However, this separation of the body and self nonetheless creates difficulties for women, as they attempt to negotiate infertility
treatment and reorient infertility treatment back into the narratives of their complete selves.

*She Who Has No Voice*

The separation of the self and body within the clinical encounter may impair women’s abilities to speak up to their physicians, given the fact that the separation, as a repositioning of the patient by the physician, ultimately points to the physician’s increased power. As SM, who began working as a therapist after her experience with infertility, stated:

> And the thing too is most, I don’t think that there are too many women that go into reproductive endocrinology and um, I think that there’s a missing link between um, the way that the process is directed by um, a male doctor and that ends up reinforcing some paternalistic attitude with their female patients. Women are afraid to speak up when they have to wait too long. They’re afraid to make noise if, you know, something hurts.

In addition, this separation also causes women to receive care that they feel is unsatisfactory. As AW stated:

> Well, I guess I should have switched gynecologists to begin with because I wasn’t really happy with the one I had because he wasn’t very, very, um, he didn’t really explain a lot of things to me and he constantly forgot every time I had my visits, ‘Oh you already have two kids, don’t you?’ And I’m like ‘No, I don’t. Can you read my file before you come into the office?’

This inadequacy of knowledge about basic components of AW’s chart and social history points both to the busy nature of the average infertility office and to the compartmentalization of the patient, where additional details become secondary to basic
physiological care. Thus, while this separation functions to allow patients and physicians to side-step normal rules of social interaction, it also sets patients up to experience extreme frustration, discomfort, and general dissatisfaction with their care. As M stated:

I still remember, it was around the holidays and I guess everyone wants to get pregnant around the holidays and I just that we were being, like it was, like we were all cattle. Like you’re just kind of being led from one room to another and I felt that the nurse was not really giving me enough attention and I felt that they didn’t do the harvesting at the right time. But, of course, duh, I still went to a third one [in-vitro fertilization] with him. I mean, I dunno, figure that one out. But it was because I believed in him!

Here, through the use of the word *harvesting* and the detached description of movement through the clinical visit, we see the reconstruction of the female body as a receptacle for reproduction and the dehumanization of the process, a dehumanization that is ironic given the focus of the clinical visit, creating a new life. Furthermore, in this description we also see that the medical experience potentially reinforces feelings of self-doubt and anxiety due to the lack of perceived support and attention given to the logistical and psychological strain of treatment. Thus, medical treatment for infertility ultimately acts to reinforce the negative consequences of the very condition it wishes to alleviate, by objectifying the biological structures and manifestations connected to the condition at the expense of the complete woman who must endure them.

*Logistics of Infertility Treatment*

In addition to the difficulties incurred as a result of the bifurcated patient role women must fulfill (that of body and complete self), the logistics of infertility treatment
can, in themselves, cause frustration. Given the expense of infertility treatment, many respondents spoke about the role finances placed in their decisions about the treatment and the frustration that inadequate healthcare benefits and worries about money created. As DD stated:

I guess when it’s a physician that you feel comfortable with and you begin to form a bond and then for whatever reason, like in my case, my health insurance is the number one thing that I feel as though has kept me from finding out [the reason behind her infertility], that it’s taking this long to find out, but um, that’s that probably the worst part about it. Having to change and having to start over again and tell your story all over again and then in the end still not know why [infertility is occurring.]

Here, DD is invoking her need for a definitive diagnosis and pointing to the inadequacies and frustration that can result from being shuffled around in the managed care system.

However, even when women have the means to pursue infertility treatment, they may continue to experience difficulties with the treatment regimen itself. According to RW, the treatment regimen was extremely painful.

Um, uh, I remember for me it [referring to being injected with infertility treatment hormones] was real painful. I had to get one of the, progesterone, injections in my butt and it had to go to the muscle. And I remember one time I would just, this is how much I wanted a baby, but I would hold to the bedding and cry while my husband gave me the injection, cry and um, one time, he couldn’t stop the bleeding. He had to keep putting pressure.

Here, RW shows that she suffered during treatment and also seems to imply that her deep desire for a child propelled her through treatment.

Finally, women also experienced difficulty with infertility treatment due to the time constraints placed on them by physicians confined by basic components of biology
and the survival of gametes. As JS stated when asked if there was anything else that was important about the experience that had not been brought up:

And, just possibly the logistical problems and some of the issues that lead to more stress and, you know, for instance with the artificial insemination, you need a fresh sample, okay? And that’s very difficult to do because, and these appointments are in the middle of the day, so if you’re working, both me and my husband are working and I guess, this is a funny story, but it’s, it’s reality you know, they need a fresh sample within like ten to fifteen minutes and what are you gonna do? We met in the parking lot of the doctor’s office and the doctor was 45 minutes from me and over an hour from my husband’s work. We had to meet there and get the sample in the car and then bring it on into the office. This is in the middle of the day. <Laugh.> Those types of things almost, you know, let my husband to just say, just wanna quit after, you know, sooner than we did because he was just like ‘This is ridiculous,’ you know? ‘This is insanity what you have to do logistically speaking...he didn’t feel comfortable going, you know, into the doctor’s office. He was like ‘No!’

Thus, the experience of infertility and its treatment is not only tied into the anxiety surrounding being a patient and the power differential between physician and patient. Instead, the experience also ties into notions about acceptable sexuality, embarrassment. In addition, as this account shows, the experience supersedes the medical space, as patients are expected to excuse themselves from life’s obligations to pursue treatment. Given the stigmatization of infertility (which will be examined later), and infertility’s shaky definition as a disease, this excusal from social roles may be all the more difficult for patients to obtain.
Infertility as Surprise

As we have seen, the experience of medical diagnosis and treatment for infertility can have negative psychological consequences for women and their significant others. In many cases, this may be exacerbated by the limited knowledge available to women about infertility at the time they are learning about sexuality and reproductive health, and subsequently planning their futures and reproductive lives. Every respondent mentioned their lack of knowledge surrounding infertility when they were thinking about their futures and blamed this lack of information on several factors, including the shift of women into the workforce and the taboo nature of sexuality more generally in this country. Thus, when asked if there was something she wished she knew about being a woman when she was younger, RW stated “Yes, I wish I knew your fertility clock ran out at an early age! ...That’s something that I do wish I knew more about, infertility, when I was younger.” In addition, other respondents felt that infertility wasn’t discussed because it did not need to be in the past. As MD stated “I guess it wasn’t covered before previously because there wasn’t a need t because women always had kids so young, but nowadays it’s totally different. People are getting their careers underway and working and that comes last and so now, people are realizing ‘Oh, wait a minute! This might not work!’ Finally, a few respondents commented on the taboo nature of sexuality more generally, with YK stating that “when I was 18 I think I was still a virgin and I didn’t think that, um, um, I don’t know. I don’t think that I even knew what infertility meant at the time cause I was, in the society at that time, discussions of sex, infertility, or fertility,
or whatever was not, uh, um, a proper subject to discuss.” Thus, the experience of infertility may come as an extreme shock, as these women grapple with a condition that they never expected and certainly did not plan to endure.

**Psychological Experience of Infertility**

Out of all of the interview topics, the psychological experience of infertility seemed to be the most salient for respondents. To generally describe the experience, JS stated:

> Oh yea, it consumed me. It completely consumed me. I couldn’t get enough books. I would just read the same books over and over again. Like the same books plus I would go out and get other books that virtually said the same thing. I was just hoping and praying to find one little tidbit of something — what was it, you know, and a number of people told me to just relax and the funny thing is is I really do think their advice was right, but when you’re at that stage you can’t relax. You just can’t. And it wasn’t until I adopted my son that, six months later, I got pregnant on my own.

Here, we see infertility as an entity that completely overpowers the woman affected by it. In addition, the experience is also seen as a roller coaster, due to the demands that are placed on women during the process of infertility treatment. According to SM:

> Well, and and, because of the nature of what you have to do in a month. You know, you have to, um, get yourself excited and have a positive mental attitude until the time you ovulate and then the two weeks between the time you ovulate and when you find out the results of the test...you know, every little thing that you feel in your body, you ask yourself, oh is this it, is this what that means, or how I know I’m going to get my period....and you know, little by little your hopes and your positive excitement get chipped away until you either get your period or you get the blood test back. And then it starts all over again. So you have like a day to feel sad and
then you know, it’s back to the doctor’s office for your day one
blood test and an ultrasound.

Thus, the experience of infertility is a volatile and demanding entity that challenges
women emotionally, socially, and logistically in a number of ways. As we will see next,
ininfertility also inscribes many meanings on the experience of being a woman and
reproductive being.

Denial of a Basic Right

Many respondents spoke of the cruel nature of infertility given the fact that
reproduction and childbirth are constructed as natural and uninhibited processes from
birth. In addition, as previously seen, respondents felt that having children was a
necessary accomplishment in order to be labeled a successful women in the United
States. As M stated:

Having kids, it’s, it’s what society expects. So, um, and you know
the experience of pregnancy and childbirth is very emotional and
it’s almost like it’s denied from you. Something that people,
something that’s supposed to come naturally – it’s denied from
you!...You know, I think it’s human nature – once something’s
denied from you that’s supposed to be, that everyone else seems to
be just enjoying, you become desperate about it. And I think yea,
it’s frustration. It’s desperation. It’s all those things.

Thus, infertility is seen as an unfair sentence, a condition that is not deserved and instead
represents the denial of a basic rite of passage.
Desire for Social Legitimacy: Infertility as Disease

As we have already seen, respondents testified to the destructive nature of infertility and its effects on their lives. As we will see later, the respondents again invoked this theme when discussing the coping mechanisms they utilized to handle the experience of infertility and the fact that, often, the experience of infertility was not understood by others. Here, we see the respondents striving for social legitimacy for their disease and their experience. As M states:

And a lot of people are ignorant about infertility and they give you the most obnoxious comments. Even though there’s a lot of information right now and the issue is more open, a lot of people are still uneducated about it. It’s a disease just like heart disease. It’s a physical thing and until people see it that way, it’s very hard to comprehend why people undergo these treatments when they’re going through infertility…and it’s a disease, but people don’t die from it. It’s not a, or even diabetes, it’s not, it’s doesn’t, it’s emotionally debilitating, but it’s not physically debilitating.

Thus, for the respondents, the legitimization of their experience, through the definition of infertility as a clinical and physiological process was extremely important. As one might imagine, this construction of infertility is also important for women struggling to have their infertility treatment paid for by insurance providers who do not currently classify the condition as a necessary coverage area.

Why Me?

The next theme that ran throughout the interviews consists of the question “Why me?” In tandem with the notion that infertility was a process that denied a basic right that
other individuals experienced without thought, that of motherhood, the question of “why me” became extremely salient for the respondents. As JS stated:

So many of my girlfriends got pregnant during that two year time period. You know, the year we tried on our own and then the year of treatment. So many and, I mean, I hate to say it, but it was devastating to hear another one got pregnant. It was horrible and then going down to family functions and all the cousins and everyone has their little babies. Uh! I would have done anything to just stay at home and go to bed and not go to any of the holidays, anything.

In addition, when asked how she would explain her experience with infertility to someone who hadn’t undergone the process, RW stated:

How would I explain it? I would tell them that infertility is very hard. It’s very time consuming. It’s very patient. It will test the relationship. It will test your religion...um, like asking God ‘Why me? Why me?’ and here you want one but here’s someone next to you that has five or six kids or by five or six baby daddy’s – ha-ha. So, it will test you as a woman.

Thus, here we see that infertility causes some women to question God’s plan for them and also to question, more generally, how they were so unfortunate. In addition, the experience also causes some women to question their relationship with their significant other. JS continued:

Why, why can’t, something like about me and my husband, maybe there’s something wrong with our relationship and maybe our whole marriage wasn’t meant to be because, you know, we can’t produce children and that was like, a really strange thought but I had those thoughts too. I never shared that with my husband. That would have hurt him, but you try to figure out why why why. Your mind goes all over the place.
Because having children is seen as a basic component of marriage and any serious relationship, the experience of infertility tested some respondents’ faith in their own relationships, as a member of a couple experiencing infertility. However, perhaps most profoundly, the experience of infertility caused women to doubt themselves and question their position and adequacy in life and the world more generally.

The Stigma of Infertility: “I’m Inadequate.”

As discussed in Arthur Frank’s book entitled The Wounded Storyteller, work by Erving Goffman on stigma “shows that society demands a considerable level of body control from its members; loss of this control is stigmatizing, and special work is required to manage the lack of control. Stigma, Goffman points out, is embarrassing, not just for the stigmatized person, but for those who are confronted with the stigma and have to react to it.”72 While Goffman is concerned more with conditions that are more readily visible on the human body than infertility, this notion of stigma and its association with a lack of control over the body can nonetheless be mapped back on to infertility. As PR stated:

Oh yes, it was horrible. It was very traumatic. We did a lot of things that people told us, you know, would help us to get pregnant so we tried for, I guess on our own we tried having sex everyday while I thought it was an ovulatory time. Actually, we did an entire month and that and we were exhausted because that wasn’t our style. And then the doctors had said every other, well no, I guess the docs and I’m [in the healthcare field] so I did get some information because they said do every other day cause it would

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help his sperm counts and things. So, we did that. We did, it was very very draining, very degrading time in our lives to be honest.

When asked to elaborate on why the experience was degrading, PR stated:

You feel, I felt that I was a failure. That, um, you know, that this is a natural thing and that it should just occur and it was not, it wasn’t in my psyche to try to work so hard at something that, um, should be natural and it’s, it’s a private failure I guess in terms of being a couple. It’s, dehh [sic], just the experience of having to go in and talk about your failure to achieve a pregnancy is, um, you have to reveal a lot of your personal self and go in for the testing, like being in a, a radiology suit, having to be in the lithotomy position, having all of these professionals around you injecting dye up into your vagina. It’s very, it’s kinda degrading. It makes you feel really, kind of yucky.

Furthermore, according to SM, the experience “almost gets internalized. You know, ‘If I can’t get pregnant, then it must be because something’s wrong with me [me as the self, not as the body]. Thus, infertility causes suffering, as a condition mapped on a body whose functioning is dictated by a societal schedule. Then, when the reproductive body cannot meet the schedule and difficulties become apparent, the body then becomes stigmatized, in turn sending a message to the woman experiencing infertility that she, as an individual self, is deficient and impaired.

**Diagnosis as Secret**

The difficulties experienced by women and their sense of stigmatization are also noticeable in their decisions to provide only certain people with information about their diagnosis. As JS stated:

It’s a very personal thing. I dunno. It was really, I’m kinda... I talk about feelings and things with my friends, but this was just very
hard. It just wasn’t the same as talking about some other problem. You know, I felt more... I don’t know what the word is. Maybe just like a failure or something and it was hard to verbalize even to my husband.

Thus, their perceived stigmatization prevented respondents from discussing their difficulties with others. In addition, respondents also worried about becoming “pity-cases” for those who were told about their diagnosis. As MD stated when asked about who she received support from during this time, “Um, no, I really didn’t tell. The only people who knew were my husband and I think one coworker. I really didn’t share it with a lot of people.” When asked about her reluctance to discuss her difficulties conceiving with others, MD stated “I learned from the first time [The first cycle of treatment she pursued.] I had told a couple of people and then when it didn’t happen it was like, you always felt that they felt so sorry for you when you were around so when I went to the second office I didn’t tell anyone.” Thus, MD did not want to be perceived or treated as a “broken body” and instead kept her diagnosis to herself. Finally, a few respondents felt that their experience would not be understood and therefore, they decided not to disclose their diagnosis. “Have I turned to anyone for support? No, not really. Because there isn’t really anyone around me that can relate” (DD.)

However, even with the secrecy surrounding a diagnosis of infertility, most respondents were able to seek comfort from others and disclose their diagnosis. In doing so, they received a great deal of support and advice. “Um, like comfort and you know, ‘It’ll happen. Just don’t think about it and don’t give up hope because you did get pregnant before, so if you pregnant before you know, it may not be anything wrong with
you. You could', I could more or less be stressin' over it so much that that's why it couldn't be workin'” (YJ.) In addition, “My husband my mother [provided] emotional [support.] Just, you know, keeping me focused. Keeping me balanced and just telling me everything's going to be okay. ‘Don't worry about it. Everything's gonna be fine. Things are gonna work out.’ And my mom's standard answer is ‘Honey, I have seven children. There's no way that you can't have any!’” This focus on maintaining a positive attitude and the belief that “everything’s gonna be fine” point to a folk model of infertility that constructs the experience as a temporary state brought on by stress and disorder and not physiological constraints. Thus, in this folk model, if an infertile woman is given a chance to relax and maintains a positive attitude, then she should be able to get pregnant. However, this simplistic assumption, of course, has the potential to backfire, by constructing the problem as one that can be overcome by the woman experiencing the condition if she chooses to relax. For women who do not get pregnant, this construction may increase feelings of failure and may also increase the frustration felt by those around the individual experiencing infertility by becoming an issue of “nonadherence.”

This construction, which has the potential to reduce the social legitimacy of the infertility experience, may decrease women’s satisfaction with the advice and support they receive by reinforcing their feelings of isolation and frustration. According to PR “Family and friends didn’t really understand the experience and we heard a lot of things, um, ‘Oh, if you just stop worrying about it, you’ll get pregnant.’ So that, a lot of misconception with family and friends that was very very frustrating.” When asked to explain where the misconceptions came from, PR continued:
Um, I think people mean well. Um, and they want to be encouraging in a way to say, ‘Oh, don’t worry about it. You worry too much’, but I think, I think they don’t really understand it. I don’t think they’re doing it to be cruel, but it actually, it ends up being quite a cruel thing to say ‘You know, it’s you, you’re just worrying. You’re fussing.’ So, I guess, I don’t think a lot of people understand the mechanics of infertility and having children and conceiving is such a basic part of, of life, people feel that they have a lot of ideas about it even though they really don’t.

Thus, for women like PR, being able to reach out and discuss their experiences, instead of being a legitimizing action, may actually become a frustrating and upsetting experience given the construction of infertility as a temporary phenomenon caused not by physiological conditions, but instead solely by stress that can be controlled.

*Male Experience with Infertility*

Although the discussion so far has focused on the female experience with infertility and the frustration, anxiety, and pain that women encounter as a result of being diagnosed with infertility, men also endure profound frustration, concern, and humiliation as a result of infertility diagnosis and treatment.

*Supportive Concern*

One of the most important themes in women’s discussions of their significant others’ experience with infertility was that of supportive concern. That is, men wanted to be there to help their partners’ deal with the rigors of infertility treatment and were also concerned about the emotional well-being of their partners. As AW stated “Um, he’s [her husband] very supportive. I mean he wants to have a child as much as I do and you know,
whatever test he has to take or whatever he’s got to do, he, he’s willing to do it. Um, you know, whatever help I need, he’ll be there.” In addition, MD stated “He was the one who would give injections every morning. I mean he was very supportive in that and you know, he didn’t have to get up as early as I did so he would give my injections before I went to work because he was very supportive.” However, although men provide a supportive face to their partners on most private occasions, their own experiences with the medical community and their peers points to the humiliation inherent in the infertility experience of men, given the importance placed on masculinity, potency, and sexual strength.

**Masculinity and Humiliation**

When discussing the experiences of their significant others, respondents testified to their husband’s feelings of humiliation and demasculinization as a result of undergoing infertility treatment with their wives.

Not to get too deep, but one time, we had a conversation and I said to him because he’s a couple of years younger, I said ‘You know, you’re really going to hate me for this. And just cause it was so that hard on the relationship and one day he said, ‘When you look at everybody and they’re pregnant and they’re like ‘Man! I don’t want any more kids’ and here you are a male looking at you, like, and people are actually like ‘When you gonna have your first?’ So, um, that I yea, it does get hard (RW.)

In addition, JS described a time when her husband’s friends seemed to be exceptionally cruel.

Um, my husband is pretty secure in himself, but I think we did have that conversation before and he does, he did at the time, feel that
he wasn’t able to impregnate me and that’s you know, it goes against his masculinity and he even had a friend who said, ‘What’s wrong with you [husband’s name]? When are you gonna get the job done, when you gonna get the job done?’

After discussing the devastation she would have experienced as a result of a friend saying that to her and discussing her husband’s reaction, JS continued by discussing the relationships her husband (and men in general) have for themselves. “So the expectations are, for him, at least if not to be in a fifty-fifty relationship, then more, then more in control, more of the provider and the doer. And that just trickles down to, you know, the need to impregnate your wife – You’re the man, the he-man.” Thus, the respondents recognized the effect that infertility had on their husbands and its ability to cause them to question their masculinity and place in society, even if they were not the ones directly undergoing infertility treatment.

In addition to the questioning of masculinity created by infertility treatment, respondents also discussed the changing nature of sexuality in their relationships with their significant others.

And of course it created some tension between me and my husband. You know, we had to have sex on demand and it was one particular time that he just said, ‘I’m just so tired. I can’t.’ And I was furious with him and was like ‘And now is the perfect time’ and I was just begging him and he just said ‘No.’ He was just tired of everything you know (JS.)

Here, we see that sex, instead of being a spontaneous, romantic, and exciting action within the marriage has become a demanded chore that is dreaded by the husband. One can imagine that this kind of a shift would cause tremendous conflict and difficulties for
the couple. Furthermore, respondents also discussed the depersonalization of sexuality and its removal from the household and into the medical office.

First of all, your sexual relationship is turned on its ear and it's not anything you would have ever wanted and um, the demands of it, the demands of it and it's not a loving act, it's a job! And you know, especially, I felt especially for my husband, he was just expected to do this and it wasn't a loving, spontaneous act by any means at that point. It was definitely a hard science and there are other people who are really into, well, 'When did you last have sex and where?' and I mean, they even ask what position you're in" (PR.)

Given the connection of infertility to insecurity for both men and women and our previous discussion of the stigmatization associated with making infertility "public" knowledge, this shift of sexuality to the public spectrum has important implications for the couple's well-being and ability to cope with the experience.

Finally, the frustrations and insecurities of their significant others created feelings and doubt and incompetence for the respondents. When asked if the experience of infertility affected her relationship with her significant other, DD stated. “I believe so. I think that, if he and I would have had children then, that, some of the things in our relationship might not have happened.” When pressed further, DD admitted that her significant other had cheated on her. While it is impossible to tell exactly what his motivations were, this action of infidelity was reinterpreted by DD as something wrong with her, given her inability to reproduce. In addition, other women like SM noted the inequality created in their relationships by the experience of infertility, an inequality that, in turn, reinforced their feelings of inadequacy and failure.
I think at the time, he, he [her husband] recognized, well, he went and you know, it's kind of twofold. He went back to work. Well, he was in charge and had to manage when I was in the hospital for that month with my two year old um, so that alone was very stressful and taxing for him and um, and I think after the loss, um, he he disappeared into work, um, and kind of, cause I think, you know, I think men like to be able to do something and he couldn't do anything. He couldn't do anything to make it better, cause he would have done anything. Um, and it, it kind of um, set the stage for a pattern that ended up being reinforced over the next couple of years, of me being the sick one and him being the competent one because I was constantly floating between stimulating, ovulating, or miscarrying.

When asked to elaborate on how that experience made her feel, SM stated "Um, it kind of reinforced my feelings of like, of you know, being ineffective and worthless and you know, I couldn't even have a baby with all this help and he would have done anything."

Thus, the experience of infertility ultimately has dramatic effects on both the woman's perception of herself and also her interactions with her significant other, who may also be undergoing the process of questioning his identity, masculinity, and ability to 'perform.'

*Experience of Pregnancy*

Given pregnancy's central role in the narrative of infertility, it was surprising that women did not bring up their expectations of pregnancy without being prompted to do so. However, once they did, their responses ranged from that of great excitement and joy surrounding the experience, to fear, anxiety, and guilt. Thus, for the first possibility, respondents like AF stated "I think that's [pregnancy] going to be the most wonderful experience in my life. I'm nervous and scared and happy all at the same time about it, but I think it's actually going to be very, just wonderful because this child is really going to
be loved. Everybody’s anticipating him.” In addition, respondents further along in the experience of infertility who had already conceived and delivered their children also felt joy and excitement.

Oh, it was unbelievable and especially since when the, um, when I had to place the call, they gave you a date and time to call for the results and I called and it felt like I was on hold forever, but it was probably just five minutes but and um, the lady got on the phone and it was one of the nurses I knew and it was just such a wonderful thing to hear!” (MD.)

RW, another respondent who had already given birth to her child at the time of the interview stated:

I had gotten pregnant also naturally at a young age, but to me the experience with infertility, because I appreciated every day, every moment, every moment, every minute and I was very careful, every day, every moment, every minute so, to me, to me it was a love at the first time they put the egg back in me, but it was different. Since it was an embryo.

Here, we see that, while AF is looking forward to pregnancy and RW cherished the experience, they nonetheless both expressed apprehension about the process, perhaps because of the precious nature of their “treatment outcome.”

Finally, as previously mentioned, a few respondents discussed the difficulties of raising a child after conceiving through assisted reproductive technologies. According to PR:

Um, I know it’s not part of that research that you’re doing, but I felt after I got pregnant and after I had my child, I wanted to do research because I felt like, the experience of an infertile woman who then becomes pregnant and has a baby is very unique from the woman who did not go through infertility so I think there needs to be more work done on the feelings of guilt that you have once you
have your baby and just the things that you go through as someone who has gone through infertility. I think it’s a very different experience and again, it’s very isolating because not that many people go through that. I felt because, my baby was a very difficult baby, and um, and I had a major role adjustment so that it was very difficult for me and I think I felt guilty because I, unlike other women, I actively pursued this, having a child and that I didn’t have the right to complain if my child was a difficult child and that I has having a hard time adjusting to motherhood so I felt that I didn’t have any right to, to seek help or support for that...because people think, you know, oh, you won, you achieved, you’re done, and it’s really just the beginning

This discussion points both to the isolating nature of infertility and the high expectations women have for themselves, as flawless mothers, wives, and career women. Thus, ultimately, the experience of infertility is not completely resolved even for women who carry pregnancy to term and do not desire an additional child after their first post-infertility treatment pregnancy success.

**Considering Other Options**

While one respondent chose to adopt due to religious beliefs surrounding selective reduction after in-vitro fertilization and another respondent stated that “the experience [tha: of infertility treatment] has been a difficult road, but in the end it’s definitely going to be worth it because I’ll have that child. Regardless of if I have to adopt, you know, foster a child, in-vitro, you know, whatever the road leads me down, it’s definitely going to lead me to motherhood” (AF), many respondents showed general uneasiness when discussing options other than biological parenthood. M explained “Yea, you know, no because, I don’t really know how I’d handle egg donor because I don’t my
capacity to fully accept having your child be, I don’t know, half genetically linked to us and half not, but I think, um, I don’t know.” In addition, SM explained “I mean one thing we both agreed on was, um, we agreed not to do IVF and he didn’t want to adopt….My husband wasn’t sure he would be able to love a child that wasn’t our biological child.” These responses point to the intricate constructions of biological parenthood versus social parenting in the United States and our perceptions of identity, parenting, and the use of technology. As we will see, discussions of technology went beyond its ability to alter our genetic landscape.

*The Expense of Technological Innovation*

Given the fact that health insurance, even if one is able to obtain it does not often cover in-vitro fertilization and more invasive assisted reproductive technologies and given their great expense, some respondents were unable to receive the care they desired as a result of limited or no health insurance and other financial difficulties. YK, whose only option seemed to be egg donation after some basic diagnostic examinations stated, “Well, I have to be realistic. You know, nobody can do anything. You know, I need money to buy eggs and to have, you know, to have this in-vitro fertilization.” In addition, other respondents talked about the poor medical care they received due to changing health care insurance and limited options. Yet, in addition to the financial costs of infertility treatment, one respondent, SM, chose to discontinue treatment because of the emotional costs involved with the infertility treatment and her subsequent miscarriages.
“And, um, it never really changed anything because I kept getting pregnant and
miscarrying and I dunno, I guess when my son was around four and I had my last
miscarriage I decided um, you know, that emotionally I didn’t, I couldn’t do that
anymore.” Thus, as advanced as infertility treatment has become, for some respondents,
the financial and emotional costs of care were simply too great.
Concluding Remarks on the Results of this Study:

In this study, I sought to explore the following three areas of inquiry:

1. What is the experience of medical treatment for infertility like and how does this experience shape women’s perceptions of their bodies?

2. How does infertility itself affect women’s perceptions of themselves and their relationships with others, including their partners?

3. How is infertility discussed and what can this discussion tell us about its position within the nexus of sexuality, morality, and reproduction?

Based on the information presented in my literature review, I hypothesized the following results based on the research aims presented above:

1. The medical treatment of infertility will be seen as particularly promising for women experiencing infertility, but the service provided will consist solely of treatment for the body (within the Cartesian duality of mind and body as separate entities) and this may lead to women’s hyperawareness of their bodies.

2. The experience of infertility will cause women to question their success as women and will create relational strain for women who have steady partners.

3. Infertility will be discussed as a failure to succeed and a failure of the reproductive body, which will allow us to point to the importance placed on reproduction and the stigmatizing nature of impaired sexuality.
Summary of Results:

Research Aim #1:
Women described the experience of infertility treatment as painful, embarrassing, and "like a roller coaster." The experience of consistently receiving treatment that focuses on one's shortcomings reinforced women's feelings of inadequacy. In addition, the experience of infertility care often proved difficult for women attempting to balance their careers, relationships, and their desire to become pregnant. Finally, medical treatment for infertility was often humiliating for the husbands of respondents, given the fact that cultural model of masculinity includes notions of potency, aggressive sexuality, and strength.

Research Aim #2:
Given the importance placed on reproduction in the cultural model of successful womanhood in the United States, the cultural model for infertility included the notion that infertility pointed to a great inadequacy for the individual diagnosed with infertility. Respondents felt that they had failed to achieve the most basic functioning of life, reproduction. This sense of failure had profound implications for their level of confidence, ability to negotiate treatment within the medical community, and their relationships with their significant others. Finally, the cultural model of infertility points to its deep connection to notions of "natural" reproduction, spontaneous sexuality, as well as the secrecy surrounding failed reproduction and other stigmatizing sexual conditions.
Research Aim #3:

Infertility was simultaneously discussed as a failure of basic production, a denial of the basic biological right of procreation, a frustrating experience, and an experience that tested their perception of life, relationships, and the future. Each of these constructions point to the central role that infertility plays in our societal perception of successful womanhood. In addition, as previously mentioned, the secrecy surrounding infertility further illustrates its position as a stigmatizing condition and also society’s unwillingness to discuss the problems inherent in sexuality and reproduction.
Chapter V: Discussion

Infertility, defined as the inability to achieve a successful pregnancy after one year of trying for women under 35 and after six months of trying for women 35 and older, is a potentially devastating condition for individuals attempting to become pregnant. As seen in this study, infertility may cause women to question their success as individuals given the value placed on parenthood in the United States. In addition, the experience also cause some women to question their sexuality and relationships with their significant others (if applicable) given infertility's unique location within the nexus of couplehood, sexuality, and reproduction. Furthermore, as seen in the literature review presented for this study and the responses themselves, the experience of infertility is positioned within the very core of the medical institution. Based on the responses for this study and the literature review, this strong connection between infertility and the medical community can be said to exist for several reasons: the very necessity of medical attention in order for an individual or couple to be considered infertile; the gatekeeping and treatment function of the physician when providing access to assisted reproductive technologies; the social legitimacy currently gained from seeking medical attention and therefore “adhering” to the requirements of the sick role (even though, in the case of infertility there remains a lack of social legitimacy for the suffering of those experiencing infertility); and the ultimate hope for a solution outside of the individual sufferer and her/his relationship. However, while this medical attention functions in several necessary ways, it may ultimately compound the anxiety and frustration experienced while
struggling with infertility, as the individual and private body opens up to the inquisitive hands of the medical institution.

Thus, the cultural model of infertility can be seen to have several key components for the respondents in this study. This multi-faceted nature is not uncommon given the fact that, according to D'Andrade, cultural models can have several layers with differing goals and master motives. Thus, the cultural model of infertility for women who have received medical attention for infertility includes the notion that infertility is a symbol of some inadequacy within the individual who experiences the condition. The cultural model also points to our societal perception of successful womanhood, which continues to value motherhood to a great degree. In addition, infertility is labeled as a failure to achieve basic life goals and to fulfill a key biological imperative to reproduce. This sense of failure had profound implications for the respondent's levels of confidence, ability to negotiate treatment within the medical community, and their relationships with their significant others. In addition, the cultural model of infertility also holds the notion that reproduction should be a natural and automatic event. However, failing that, within the cultural model of infertility there is a value placed on receiving outside help for infertility from the medical community. This outside help, in turn, attempts to provide social legitimacy for the experience. While one might expect that receiving medical attention for infertility would reconstruct the experience by placing control in the hands of the medical community and therefore alleviating any potential feelings of fault or

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failure experienced by the patient, this does not appear to be the case. Instead, medical attention for infertility appears to tap into the cultural model components previously mentioned, those of self-doubt, frustration, and anxiety. This appears to occur given the focus placed on the physiological malfunctioning of the reproductive system and the lack of attention (and therefore support and legitimacy) given to the psychological implications and experience after diagnosis.

Finally, the cultural model of infertility, by existing within the nexus of reproduction, sexuality, and gender, also allows us to comment on the treatment of sexuality in the United States more generally. In many instances, infertility, by being defined as a failure culturally given the fact that natural and “automatic” reproduction are valued, in turn becomes a secretive and potentially stigmatizing diagnosis. This secrecy, in turn, impairs the individual’s ability to successfully cope with the diagnosis and subsequent treatment outcomes. In addition, the positioning of infertility within societal notions of appropriate sexuality and parenthood affects whose narrative is told. While much research has been done on the infertility experience of heterosexual couples including this study, very few research studies have focused on the experience of infertility for LGBT couples and single women. This may be due to the difficulty in recruiting respondents for these studies (as in the case of this study, with 10 out of 11 respondents being married to a male partner and with the remaining respondent a single heterosexual woman) or this may point to a lack of acknowledgement of this experience as distinct. This lack of acknowledgement, however, ignores certain key differences that
one might expect to find in the experience of infertility for the LGBT community and single women. For one, the treatment experience of individuals in the LGBT community and single women would be different given the necessity of donor options to achieve pregnancy. In addition, the very definition of infertility, which assumes continued conception attempts for heterosexual couples within a given time window, may impair the ability to define the true experience of nonheterosexual couples and individuals seeking medical attention to become pregnant. Furthermore, the psychological experience of infertility may be more challenging, as individuals and LGBT couples seeking medical attention to achieve pregnancy are required to confront not only their inability to become pregnant without medical assistance, but also societal notions of appropriate motherhood, fatherhood, marriage, and the use of advanced assisted reproductive technologies including donor egg, sperm, and embryo fertilization.

In conclusion, while one’s experience and individual characteristics work to create an individualized schema of infertility, the cultural model that ultimately shapes these schemas contains several key commonalities: notions of inadequacy; perceptions of acceptable reproduction from the vantage point of society; a great importance placed on the medical community; and the function of the medical community in creating social legitimacy for malfunctioning of the body (and subsequently the culturally proscribed self.)
Chapter VI: Conclusions

Like many other society's, our society deeply values natural reproduction and biological parenthood. In addition, we have constructed sexual intercourse as a natural and spontaneous action that is most appropriately utilized within a loving relationship for enjoyment and procreation. However, this latter function is extremely difficult for approximately ten percent of the reproductive population. Instead, these individuals must find the means to utilize expensive and invasive assisted reproductive technologies, if they hope to fulfill their procreative duties as mature adults. This demanding treatment requires women and men to question their identity and respective sexuality. Many individuals feel devastated by their inability to fulfill such a "basic" social, personal, and biological process. This devastation and subsequent frustration creates feelings of desperation, hopelessness, and intense turmoil, both within the individual and between the couple experiencing infertility. Thus, the cultural model of infertility includes feelings of failure, frustration, and anger, given the expectation of procreation for "successful" individuals in the United States.

However, there are actions that can be taken to make the experience of infertility less devastating. Many respondents mentioned their regret that they did not pursue professional mental health care during the course of their infertility treatment. As JS stated "everything happens for a reason and if I could have gone back, I would have never ever, if I could have controlled my emotions I would have probably gone to a therapist to get a hold of myself because I really was kind of spiraling out of control with
just, letting it consume me like it did and um, I would have done that because it’s, um, you mean, it makes your life miserable it, and it led to my infertility I’m sure of it” (lines 165-70.) Given the devastating effects that infertility can have on women and men’s psychological well-being, it is imperative that psychological care be a considered option for infertility treatment. Unfortunately, given the busy nature of medicine today, the dichotomy created between the mind and the body, and the secrecy surrounding infertility, it seems that this option may be years in the making. However, these exact features of the experience point to the urgent need for additional attention to be placed on the psychological well-being and support of those undergoing infertility treatment.

In addition to providing psychological evaluation and support during the process of infertility, additional attempts should be made to make infertility more noticeable in popular culture and subsequently less stigmatized. Recent treatments of infertility such as those in the very popular HBO show, Sex and the City, have helped. However, much more must be done to destigmatize this condition, particularly given it’s prevalence in society and its connections to society’s values and expectations surrounding femininity, masculinity, and adulthood.

Finally, more must be done to change the image of successful womanhood and appropriate masculinity. Women must realize that, while they may be able to have it all, they shouldn’t berate themselves for not being able to succeed in all levels of life at all times. In addition, it must become more acceptable for men to provide equally in the home as well as in the workplace. Too often, the discussion of gender transitions focuses
too much on the woman’s inability to balance both the home and her career and not enough on the choices that men make, between wanting successful careers and also being available to their families. While we must work to destigmatize infertility more generally and allow women to be imperfect, we must also grant men the same consideration, by redefining masculinity to allow men balance as well. Until we begin to reshape the experience of infertility, millions of men and women in the United States will continue to be affected by this stigmatizing and difficult condition, a disease that works to the core of against notions of masculinity, identity, and success.

Limitations:

Respondents may have been uncomfortable discussing issues of sexuality within their personal lives given the secrecy surrounding infertility. However, given the voluntary nature of this study and the results received, it appears that many respondents were nonetheless able to open up, at least to a great degree. Furthermore, as a study with a small sample size and a great deal of variation within the treatment experiences, socio-economic status, age, and life history of the respondents, it is difficult to determine exactly which elements of the infertility experience would be salient to the majority of individuals experiencing infertility in society and which are simply indicative of the issues faced by the women interviewed for this study. However, regardless, these results point to the difficulties that are incurred by women who receive a diagnosis of infertility. In addition, the results of this study also point to several additional themes of research
that would be worth exploring within a larger group of respondents separated by important experiential and demographic characteristics.

**Future Research:**

The lived experience of women who have the resources to undergo assisted reproductive technologies treatment is very different from those who do not have even basic health insurance, or the means and stability to pursue a demanding treatment regimen. While much has been discussed about the experience of infertility more generally, I believe that more research needs to occur on the experience of women from lower socioeconomic brackets and minority groups. In addition, a few respondents pointed to the limited number of both women and minority practitioners. This points to the need of additional research about the dynamics between physicians and their patients, particularly surrounding interactions between individuals of different ethnic, gender, and socioeconomic backgrounds. Furthermore, the experience of the LGBT community and single women need to be further explored in order to improve the experience and the support availability for those who pursue medical attention for infertility. Finally, more research needs to utilize the experiences of women who have conceived and delivered children as a result of assisted reproductive technologies in order to evaluate the experience and acknowledge the feelings of guilt and inadequacy that persist beyond the physician’s office. Ultimately, we must develop more initiatives that work to understand the needs of infertility patients, in order to improve standards of care and decrease the
psychological discomfort experienced. Finally, we must develop research and outreach programs that question our cultural model of success for men and women, in order to reduce the imperative to reproduce and thus begin to destigmatize infertility.
Appendix A: Semi-Structured Interview Questions

Details of Semi-Structured Interviews:

The following questions were asked. Additional questions were included in each interview in order to clarify information or to explore further areas that were brought up by the respondents in answering these set questions.

Introductory Prompt:
Hi. My name’s Tiffany Behringer and, as you may remember, I’m a masters student in the medical anthropology program at the University of Pennsylvania. I am interested in knowing about the experiences you’ve been going through after being diagnosed as infertile. Because I’m interested in your thoughts and feelings, there are no right or wrong answers. In addition, if there’s anything you don’t want to answer, just let me know and we’ll go on to the next question. You may also end the interview at any time. Does that sound okay? Do you mind if I tape record this conversation?

I. Infertility Experience
-Can you tell me how you came to be diagnosed with infertility?

Questions to Prompt with:

A. How and when did you realize that something was “wrong”?
B. How old were you when you were diagnosed as infertile?
C. What is your understanding of why infertility occurs?
D. How were you diagnosed?
E. What have you done differently (if anything) since being diagnosed as infertile?
F. How have you told about your diagnosis?
G. How have you been feeling (physically, emotionally)?
H. What kind of treatment have you pursued?
I. What has the treatment experience been like?
J. Who have you turned to for support (if anyone)? What kinds of support have each person provided? (Prompt: parents, partner, medical personnel, children, coworkers, friends)
K. How, if at all, has the experience of infertility affected your relationship you’re your significant other?
L. Is there something you wish people would have done to make your experience easier?
M. Knowing about your experience of infertility now, would you have done anything differently in the past?
N. Once you became pregnant, what was that experience like? Do you think your experience was different than women who have not experienced infertility?

II. Gender Roles
A. When you were younger, what did you think your life would be like at this age? Do you think your expectations were similar to other women’s experiences?
B. How does being diagnosed with infertility affect the way you see yourself as a woman?
C. How do you think being diagnosed as a couple with infertility affect the way men see themselves as men?
D. What does it mean to be a successful man in the United States?
E. What does it mean to be a successful woman in the United States?
F. Why is it important or not important to have children?

III. Infertility and the Life Story
A. How would you explain infertility, both generally and your experience, to someone starting to think about having a child?
B. Is there something you wished you’d known about being a woman that you didn’t know when you were younger? If so, what? Why do you think it wasn’t discussed?

IV. Demographics
Prompt: Finally, I just have a few questions about your background more broadly.
A. How old are you?
B. Higher education:
   1. Did you attend college? Complete it?
   2. Grad school?
C. Ethnicity
D. What is your career and job position?
E. Do you have any children?
   1. If so:
      a. How many?
      b. Age and gender of children?
   2. If no, have you ever been pregnant?
   3. If you haven’t been pregnant, what do you think pregnancy is like?
F. How many siblings do you have? How many did your father and mother have?
G. Who lives in your household or family now? Who lived in the family you grew up in?

V. Closing: Thank you very much
A. Is there anything else I should know about or should have asked?
B. Do you have any questions for me?
Appendix B: Demographic Information

Percent of Respondents by Age Range

- Over 42: 28%
- 40-42: 18%
- 38-39: 18%
- 35-37: 9%
- 30-34: 9%
- 25-29: 18%

Percent of Respondents by Ethnicity

- White: 55%
- Black: 45%
Percent of Respondents by Education Level

- High school diploma: 18%
- Graduate degree: 48%
- Some college: 18%
- Bachelors degree: 18%

Percent of Respondents by Marital Status

- Married: 91%
- Single with partner: 9%
Percent of Respondents by Number of Children

- Zero: 37%
- One: 36%
- Two: 27%

Percent of Respondents by Age Range at First Diagnosis

- 25-29: 37%
- 30-34: 18%
- 35-37: 9%
- 38-39: 9%
- 40-42: 9%
- 18-24: 18%
Percent of Respondents by Treatment Result

- Did not achieve pregnancy and quit trying: 18%
- Has "not yet" achieved pregnancy: 36%
- Achieved pregnancy through treatment: 37%
- Achieved pregnancy through treatment and is trying again: 9%
Sources Consulted:


Barg, Fran. Lecture at the University of Pennsylvania. Anth 437: Cultural Models and Health.


