

Conceiving Infertility: Negotiating the Biomedical Model

Author: Gretchen Sisson

Persistent link: <http://hdl.handle.net/2345/1103>

This work is posted on [eScholarship@BC](#),
Boston College University Libraries.

Boston College Electronic Thesis or Dissertation, 2009

Copyright is held by the author, with all rights reserved, unless otherwise noted.

Boston College

The Graduate School of Arts and Sciences

Department of Sociology

**CONCEIVING INFERTILITY:
NEGOTIATING THE BIOMEDICAL MODEL**

A Thesis

By

GRETCHEN SISSON

submitted in partial fulfillment of the requirements for the degree of
Master of Arts.

December 2009

© Copyright by GRETCHEN SISSON
2010

Conceiving Infertility: Negotiating the Biomedical Model

Gretchen Sisson

Stephen Pfohl, Advisor

ABSTRACT: Assisted reproductive technologies have transformed the way medicine responds to infertility, as well as the ways those who go through difficulty conceiving understand their bodies and their experiences. In many capacities, however, the biomedical model is insufficient: recognition is contingent upon attempts to conceive, diagnosis is often imprecise or unexplained, and treatments strive for solutions without cures – and are frequently incapable of providing even the former. Interviews with 26 participants with current or recent histories of infertility revealed the ways they negotiate the biomedical model: 1) going beyond medical treatment in making lifestyle changes; 2) pursuing alternative treatments; 3) questioning doctors and playing active roles in determining courses of treatment; 4) using religion, spirituality, or magical thinking to develop other, non-bodily ways of controlling infertility; 5) extracting meaning from the experiences, infusing the objective idea of “disease” with subjective purpose; 6) building personal, alternate models that encompass a wide range of ways of thinking about infertility; and 7) directly challenging the scientific authority of the biomedical model, resisting the terms of treatment, or questioning the ability of medicine to offer them solutions. No participants showed pure compliance – as all included at least one of the negotiations – and none showed full resistance – as all had sought at least some medical treatments. Understanding these negotiations leads to a better concept of patient identity and the “illness” experience; it can inform policy in regards to prevention, education, and insurance mandates; and it better reveals who society permits to pursue parenthood in what ways.

Introduction

The experience of infertility can be many different things for different couples – it is often frustrating, self-reflective, and emotionally, physically, and spiritually challenging. One thing it is not, however, is uniquely contemporary. Infertility has been a consistent aspect of the human experience, affecting a proportion of the population regardless of historical setting. Yet, contemporary infertility is understood almost exclusively within the context of a biomedical paradigm that models infertility as a physiological disease or impairment that should appropriately be treated through the efforts of medicine. The historically recent advent of various reproductive technologies has enabled more and more advanced treatments to become available to more and more individuals who seek solutions to their infertility from that biomedical model. While this approach is likely the best approach, given current understandings of the ways infertility can manifest, the authority ceded to this epistemology is nearly absolute, leaving individuals to negotiate their own experiences within this specific context. For some, such negotiations may be automatic concessions to the validity of the medical community; but for some others, these negotiations may represent an additional challenge to their self and bodily knowledges at a time when such knowledges are already subject to scrutiny.

Historical Models of American Infertility

The biomedical model is not the only way of understanding infertility, despite the dominance it currently has in defining that experience. Examining past models not only

illustrates alternate ways of framing infertility, but also reveals the way that medicine has come to establish itself as the primary model.

Early understandings of infertility were primarily derived from religious meanings. Judeo-Christian women especially recognized the struggles of Abraham and Sarah to conceive, as well as Hannah's long-hoped for and much delayed pregnancy with the prophet Samuel (Marsh and Ronner 1996: 10) – to say nothing of Elizabeth becoming pregnant with John the Baptist at age seventy. These frameworks alternately presented barrenness (as it was then called) as a sign of God's displeasure or as a test of faith. Either attribution made infertility a personal concern to be resolved as an individual, rather than a social concern.

These religious attributions were likely accepted because of a nearly complete ignorance of the role each partner played in conception. Shrouded in mystery, the problem was best left in divine hands. By the early 1800s, however, a biological understanding (though extremely faulty) began to develop, and infertility was modeled as a “woman's problem” that was best handled through self-help treatments for those affected. Such “cures” were promoted by various entrepreneurial pharmacists, among them were “Joseph Ralph, who bottled and sold ‘Ralph's Domestic Medicine’ ... Claiming that women's ‘complaints’ were ‘of a nature so delicate as to be far more properly treated by themselves than by any other person,’ he told women that by purchasing his medicine they could avoid the embarrassment of consulting personally with a (male) physician” (Marsh and Ronner: 27). Such constructions placed both the

blame and the solution at women's feet, holding them responsible for both cause and cure. Still, infertility remained an individualized and personal struggle.

In the late 1800s, however, infertility had evolved as a major social concern. Despite the fact that "sterility" was being responded to more and more by the medical community and treated by early gynecologists (who were slowly usurping female midwives in the handling of reproductive health), the attributions of science were in favor of social causes of the problem, namely inappropriate female behavior. The medicalization was complicated by one irrefutable historical fact: "women's reproductive organs have symbolic significance that other parts of the body do not possess" (Marsh and Ronner: 78). Given the rigidity with which gender roles were understood, that symbolism was insurmountable in attempting to create an objective science. The result was an inherently flawed "sexual science" that explained infertility as a flaw of women's behavior or character:

The core principle of sexual science was that the differences between male and female reproductive organs signified equally fundamental differences in their intellectual and moral capacities and social responsibilities. A corollary followed – that women had a biological mandate to marry and bear children. If they failed to do so, they not only outraged social condition but also contravened scientific laws. Women's health, therefore, required both childbearing and conventional social behavior. (Marsh and Ronner: 78).

This idea furthered the notion that if a woman could not conceive, it was because she was not fully a woman, or because she had somehow violated her role as a woman.

Furthermore, the idea that sterility was somehow volitional was also introduced (Marsh and Ronner: 81). These understandings increased the level of culpability handed to infertile women, blaming them for their condition under the guise and authority of

objective medicine. This model of behavioral causes was so absolute that when, in the 1870s, Emil Noeggerath suggested that gonorrhea was a major cause of female sterility, most fellow gynecologists rejected the idea as absurd. To acknowledge the theories validity “would have required them to reverse totally the prevailing etiological model that blamed a woman’s behavior for her infertility. To implicate a specific disease, and especially one that incriminated husbands, was too great a leap for most gynecologists” (Marsh and Ronner: 89). Thus, this model of infertility not only illustrates an alternate epistemology for understanding, but shows the dramatic ways that medicine is influenced by historical and social values.

The early 1900s saw a changing shift in the rights of women, which required a new sentimentalization to be attached to motherhood. Post-suffrage, the idea that women needed motherhood to be truly fulfilled in their lives gained wider prominence. Sterility was often equated with voluntary childlessness as a state of unwomanliness (Marsh and Ronner: 124). To be a woman was to be a mother, and to not want to have children (which was becoming more of an option with emerging strategies for birth control) was viewed with societal disdain. This sense of volition and blame was not new at the time, and has not gone away with more scientific developments. In fact, the interaction of volitional infertility and the blaming of infertile individuals (mostly women) has perhaps remained one of the most consistent models for understanding infertility:

An important theme in the American dialogue concerning infertility is that it is a biological expression of what Charles Rosenberg described in 1986 as “culpable failures of volition.” Rosenberg observed that “the desire to explain sickness and death in terms of volition – of acts done or left undone – is ancient and powerful,” especially when there is no consensus about the nature and treatment of a disease.... Significantly, the origins of infertility have consistently been linked to

individual choices or actions, suggesting that if infertile individuals cannot be blamed for the past tubal obstructions and genital infections directly responsible for their not having children, they can be blamed for the past actions that predisposed them to developing these conditions or that initiated the causal chain of infertility. (Sandelowski 1990: 39).

That such concepts can remain so consistent for so long reveals the persuasive power of using volition as a tool to explain illness and impairment. It is a tool wielded, however subtly, in the construction of medical authority.

Additionally, the early twentieth century saw the sentimental value of parenthood increase. Children were being less the economic assets that they had been pre-Industrialization, and more expensive, but very highly valued, members of the family. This sentimental value was reflected in the changing economic price of growing one's family: "In the 1870s, there was no market for babies. The only profitable undertaking was the 'business of getting rid of other people's (unwelcome) babies.' For about ten dollars, baby farmers took in these generally illegitimate children. Yet some fifty years later, adoptive parents were eagerly paying \$1,000 or more to purchase an infant" (Zelizer 1985: 169). While this idea of expensive adoption and the increasing "price" of children may seem irrelevant to models of infertility, it did establish, nearly a century ago, an escalating sense of parenthood as something worth purchasing. There is a sentimental value to parenthood that makes it both desirable and costly – those that cannot achieve it on their own become willing to pay for measures to rectify this.

Furthermore, the mid-1900s saw dramatic developments in understandings of human fertility. The discovery of estrogen and luteinizing hormones in 1920 followed quickly with new awareness of the menstrual cycle, ovulation, conception, and

implantation (Marsh and Ronner 1996: 138). Clearly, such new knowledges increased the efficacy of doctor's responses to infertility. Artificial insemination, though extremely controversial, became a successful means of achieving pregnancy. Additionally, gynecology developed itself as a specialty inclusive of infertility, which maintained the focus of infertility treatments on women. This focus continued even when the male was known to be the source of infertility: "Many a wife, apparently abetted by the family doctor, protected her husband from any suspicion that he might be responsible for the couple's plight... Nearly every fertility expert, whether male or female, confirmed the reluctance of most men to believe themselves responsible" (Marsh and Ronner: 154). While womanhood was equated with motherhood, masculinity was equated with virility. Thus, women were acting out their gender role in seeking fertility treatments because they were trying to achieve motherhood, while men's involvement in such treatments would represent a crisis of their gender identity.

This reluctance changed somewhat post-World War II. Some doctors formulated the idea that male infertility could be partially attributed to wartime experiences: "soldiers faced exposure to radiation and hazardous chemicals and were subjected to high scrotal temperatures, which practitioners suggested might have affected their sperm production" (Marsh and Ronner: 198). Though lacking in credibility, this theory focused attention on male infertility among physicians, and allowed men to attribute infertility to their veteran status, rather than a traditionally understood lack of virility. Regardless of the gender norms at play, the result was an increased attention to and incorporation of men into discussions of infertility for the first time in modern history.

Each of these progressive models has gradually built on the creation of a consumer-based medical model. In the most recent half of a century, reproductive technologies have continually developed, accommodating pregnancies through in vitro fertilizations, allowing for more advanced hormonal therapies and other forms of assisted reproduction. As these procedures become more common, they also become more acceptable, leading to a greater dominance of the medical model. Yet this model is no less culturally based and historically relevant than any of its predecessors, and its implications are no less profound for those couples experiencing infertility.

Infertility as Disease: The Implications of the Medical Model

The crux of the biomedical model is in presenting infertility as a disease in need of medical treatment. However, as illustrated previously, this equation is simply one way of understanding a bodily phenomenon. The fundamental difficulty in understanding infertility as disease is that it generally has no physical pain or suffering, represents no threat to ongoing health or quality of life, and is only recognized as problematic under very specific conditions – namely, when attempts to conceive are made. The diagnosis of infertility is made after approximately twelve months of unprotected sexual intercourse without conception. Thus, a woman who is unable to conceive but not trying to conceive would not recognize this condition as problematic at all, let alone a disease. It would not only be inappropriate to diagnosis this condition a disease, it would be impossible.

Infertility is identified, like most forms of disability, as a deviation from a norm. In this way, it is comparative, and by being comparative, it is social: “Disability then can be understood only in the context of normal abilities, and is inherently a *social* and not a

medical concept” (Rothman 1989: 143). As such, infertility is only a deficit under specific circumstances.

Furthermore, understanding “infertility” as a primary diagnosis groups together a wide range of possible physiological impairments that affect fertility differently. The capacity to conceive requires that anatomy, hormones, gametes, and timing all be working in favor of the specific couple. If any of these criteria are deficient in either partner, it will result in difficulty conceiving. Thus, “infertility” becomes a nonspecific term that encompasses a multitude of possible complications (each of which will generally receive their own diagnosis after testing). Additionally, there is an interaction effect between the partners that can affect their ability to conceive – an individual might have better chances of conceiving with a different partner, so the diagnosis becomes applicable to the entire couple. Yet, within an “infertile couple” there is a possibility that one individual has minimal or no impairment, but the diagnosis still extends itself to both parties. This application assumes that the choice of partner is immutable, thus impairment in one individual that prevents conception creates infertility in the other, as they are also now not able to conceive in the way that they want.

All of these considerations make infertility a questionable and imprecise diagnosis. Consistent with this awkward application of medical understanding is the way in which treatment of infertility is understood. Most fertility treatments do not represent a cure; in fact, most treatments merely divert the causes of infertility in favor of

increasing the odds of conception, without resolving the original problem.¹ A couple that successfully conceives as a result of new reproductive technologies is not likely to have an easier time conceiving again in the future should they chose to do so; the infertility is not “fixed” or “cured” as a result of the treatment. Feminist theorist Barbara Katz Rothman (1989) goes so far to suggest that such procedures are the equivalent of “important, non-medical ways of managing disability, ways that address the handicapping effects of the disability – like learning sign language, having wheelchair ramps” (144). Instead of fixing the underlying cause, reproductive technologies make the sources of infertility less important to fertility. If a woman has difficulty producing healthy eggs, she may be a candidate for a donor gamete – a response which does nothing to correct the original problem. Furthermore, certain assisted reproductive strategies are very likely to be applied to most cases, regardless of the reasons for infertility. As one woman said after going through a variety of tests:

Some of the things that they said were very enlightening. But what it seemed to be was that all they were talking about is tests. “We can do this test, we can do that test.” “This test tells us this, this test tells us that.” But the answer of what you do next, every time, is in vitro. The tests just gave a little more information about performing in vitro. But they didn’t have any other suggestions as to what to do as a therapy. And I actually asked them. I asked a question which was completely ignored. I asked “Is there anything besides in vitro?” When they heard my question, they all laughed, and nobody answered it. My question was totally serious. (Becker 2000: 17).

¹ Some treatments do, however, alleviate the cause and “cure” infertility. For example, the removal of a blockage from a Fallopian tube would presumably allow successful ovulation and implantation in the future. However, most common treatments (intrauterine insemination, in vitro fertilization, donor gametes, or surrogacy) do not address any underlying pathologies, but merely overcome them.

Here is an instance where the treatment seems to be independent of the actual physiological source of the complication. Indeed, the source of the problem is not only not being treated or cured, it seems irrelevant. The response is the same, regardless; in this case, that response is in vitro.

Furthermore, many variations of treatment do not even try to achieve what for most couples is the original goal: to have a child that is genetically theirs through a gestation of the biological mother. Although treatments do, in a variety of ways, accommodate conception, many options (donor gametes, surrogacy) change this goal. In such cases, not only does the treatment neglect to address the source of the problem, it changes the goal of the procedure to accommodate what is possible.

Despite the vast developments in reproductive technologies, the biomedical model still has tremendous gaps in capabilities. In 1987, ten years after the first successful in vitro fertilization birth, Sandelowski wrote that “the recent rediscovery of infertility by clinicians, researchers and the general public has not caused the etiology, treatment or prognosis of infertility to be substantially more definitive than they ever were” (73). Beyond this profound recognition of the continuing limits of knowledge, she suggests that the high amount of faith and confidence in biomedicine in fact represents an additional obstacle to those actually confronting infertility:

When infertility was viewed primarily as an affliction from God and few ‘cures’ existed, women were forced to accept their inability to have children, grieved, and then went on with the rest of their lives.... In contrast, the rediscovery of infertility as a medical problem subject to promising feats of diagnosis and treatment has engendered a crisis of ambiguity in the infertile whose expectations from medical management far exceed its capabilities. (1987: 73)

Here, the deficit of the biomedical model is its inability to acknowledge, on a social level, its own limitations, so that when individuals addressing infertility first interact with medical treatment, they must discover on their own that it does not necessarily offer them any answers.

Further criticisms of the biomedical model have challenged its framework of infertility as an individual problem. In *Killing the Black Body*, Roberts (1997) rejects the liberal market solution for reproductive technologies and is hesitant to adhere to the distributive solution, which would increase access for more disadvantaged populations, but would still “[restrict] the meaning of social justice to the morally proper allocation of material goods among society’s members” (288). Instead, faced with the abundant inequity in access to ART and the implications their use creates for determining who is deserving of parenthood, Roberts argues that the best of way eradicating the harmful and disparate effects of reproductive technologies may require deterrence of their use. Rather than the individual-focused diagnosis and treatment of infertility, many women (especially many black and other minority women) would

be better served by a focus on the improvement of basic conditions that lead to infertility, such as occupational and environmental hazards, diseases, and complications following childbirth and abortion. Increasing access to preventative health care and treatment for STDs would yield a far bigger payoff than increasing access to expensive fertility treatment. (Roberts 1997: 291)

Here, instead of (or in addition to) being a *medical* problem, infertility is a *public health* problem – a model which allows for a more comprehensive approach to the issue, and consequently more comprehensive, more equitable proposed solutions. Using reproductive technologies as a way to overcome these possible causes of infertility allows

them to “in fact mask the social and economic structures and inequities that give rise to the problem” (Shanley and Asch 2009: 852).

None of these arguments are meant to suggest that the medical setting is not an appropriate one for discussing and responding to infertility, but they are meant to illustrate the ways in which the model frames infertility as a “disease” and responses to it as “treatments” or even “cures” when those labels are not consistent with reality. They are examples of how the biomedical paradigm falls short of comprehensively addressing the nuances of experiences of infertility. While it may be the dominant model, it may even be the best model given the capacities of contemporary technologies, it is not the only model and it certainly is not inclusive of all understandings of experiences of infertility. Given the nearly absolute authority that the biomedical model has been ceded in contemporary culture, it becomes difficult to recognize that it is just that – a model, a way of understanding that is contingent upon historical context and current limits of knowledge. It is certainly not the only way of understanding disease, and although it may offer advantages now, it is probably not the best understanding we can achieve. Engel (1977) writes that “the historical fact we have to face is that in modern Western society biomedicine not only has provided a basis for the scientific study of disease, it has also become our own culturally specific perspective about disease, that is, our folk model” (196). In any culture, a single model will not encompass the lived experiences of diverse individuals. We should not expect it to do so for infertility.

Negotiating the Biomedical Model

The authority of the medical model is derived from a lengthy history of patriarchal influences. The history of gynecology, broadly, and infertility, specifically, has long presented a norm for who should want parenthood, how it should be achieved, what value (both monetary and sentimental) people should place on it, and who should be able to access treatment. Like any hierarchies of power, there is inevitably someone neglected, underserved, or deprived by a lack of access to the powerful end of the dynamic. Given the remnants of hierarchy ever-present in medical settings, it is quite possible the infertility patients find alternate ways to negotiate the biomedical model in the creation their identities as both infertile individuals and couples. These negotiations have the potential to represent “everyday resistances” against what Foucault (1978) conceptualized as biopower: “in contrast to large-scale, collectively organized, and visible resistance movements, forms of everyday resistance are manifest in ‘subjugated knowledges’... This suggests shifting attention from the sites of biopower, that is the institutions that develop and sustain discourses on the regulation of the social body” (Kielmann 1998). These resistances not only have the capacity to redefine individual experiences, but shift the locus of control within the power dynamic.

Furthermore, given the extreme levels of stress and anxiety elicited by experiences of infertility, these means of resistance may prove to be a way to understand infertility on one’s own terms and reduce the strain inherent in the experience – especially when stress compounds the occurrence of infertility and the efficacy of treatment (Boivin and Schmidt 2005), as well as willingness to continue with treatment

(Domar 2004). Thus, such negotiations might not only define infertility based on the patients' own terms, but might additionally act as a route to stress-reduction that acts to alleviate the condition that it defines.

Sandelowski (1987) also describes such negotiations as a way of coping with the large amount of ambiguity in the biomedical model, which encompasses “uncertainty about the causes of infertility, infertility diagnosis, treatment, and prognosis; pregnancy diagnosis and outcome; life pursuits and control; and infertile identity” (70). Framed this way, the uncertainty inherent in the biomedical model is an additional catalyst for seeking to regain control through negotiation.

The idea of negotiating with the biomedical model is not a new one for gynecological patients, particularly in the field of obstetrics. Alternative birth movements, particularly midwife-assisted births, have long been viewed as a form of resistance against traditional obstetrical models. Davis-Floyd (2003) writes: “within this [natural birthing] paradigm, birth rituals should affirm and reaffirm the unity and integrity of the family... instead of sending patriarchal messages about the primacy of science, technology, and institutions” (156). She goes on to argue that the “conceptual outcome” of a woman's birthing experience – that is, the woman's own interpretation of her experience as either empowering or victimizing, self-affirming or self-denigrating – is determined by the degree of correspondence between the biomedical model (what she refers to as the “technocratic model”) and the woman's own self concept of her body and her goals for treatment (187).

A natural corollary is that the conceptual outcomes for infertility patients will similarly vary, perhaps even more profoundly given that birthing is generally completed within the span of a few days, whereas infertility treatments span many months and can be influenced by the stress associated with damaged self-concepts. Indeed, Sandelowski (1995) comments on the process of “reconstruction” that former infertility patients undergo after having achieved parenthood, which encompasses the “epistemic stances toward infertility over time, adopting various combinations of scientific, historic, folk and/or metaphysical orientations to causation and proof” (129). However, these kaleidoscopic stances are not adopted simply in post-infertility reconstruction, but in active ongoing-infertility constructions while couples and individuals are still interacting with the medical model.

For individuals undergoing infertility treatments, the biomedical paradigm can have profound influences on how they reconcile their gender identities, interact with their own bodies, attribute their infertility, and understand their prospects of conceiving. Different individuals adhere to different models as appropriate to their circumstance. To varying degrees, they invoke previous models in concert with the medical understandings, thus negotiating the biomedical model in a way that works for their circumstances. For example, Jackie, a woman who cannot afford advanced reproductive technologies, attributes her infertility to religious or divine sources:

I am kind of letting nature take its course... I remember this woman – she was a psychic – and I remember her telling me that when I learned to love myself, then that is when I will have a baby. So I know I am going to have one. A baby is going to come out of this body. And it’s in God’s time, and it is going to be a miracle child. (Becker 2000: 20)

The medical model is inaccessible to this woman; she cannot afford to access it, thus she cannot apply that understanding to her circumstance. Like generations before more advanced bodily knowledges emerged, she is relegated to using a model that places authority outside of the medical community. More than a negotiation, this understanding is a rejection of the biomedical model – though whether the individual has rejected the model or vice versa is unclear.

The most common way of negotiating the biomedical model is not to elicit earlier or mutually exclusive ways of understanding, but instead to seek support and treatment beyond the medical responses. These measures do not deny medical authority, but they do recognize that medicine neglects to address the couple's entire experience, and that medicine is not the only appropriate framework for understanding their infertility. Support groups are reflective of this outlook. The most established network of infertility support groups is RESOLVE, a national organization offering networking, education, personal and collective empowerment, psychotherapy, and stress reduction (Becker 2000). Beyond these potential therapeutic benefits, RESOLVE also offers the potential for group organization, advancing challenges to the medical community such as lowering the price of reproductive technologies, focusing treatment for specific cases instead of widespread use of invasive nonspecific procedures, and being more responsive to patient needs. While some things as simple as support groups and networking may not represent a profound challenge to medical authority, it does make such authority more relatable and manageable to patient needs.

In a study on agency in infertile patients, Greil (2002) noted that

The biomedical model and the body as machine metaphor carry with them a clear ideological justification for medical intervention, that is to say, for treatment. If a machine is broken, the natural response is to repair it. The infertile women I spoke with found the medical interpretation of infertility plausible. They saw infertility as a physical problem for which the most appropriate course of action was to search for a physical solution. It is not surprising, then, that they turned to medical treatment as the most promising means of regaining a sense of control. (109)

However, the fact that women are seeking a hierarchical doctor-patient relationship within a historically patriarchal field of medicine in order to regain control creates a paradox not lost on Greil. The question then becomes not if women accept a biomedical understanding, but rather how they maintain agency and control within the pursuit of treatment once they have accepted that model. This careful negotiation warrants substantial further exploration.

It could also be argued that some fertility treatments represent a larger resistance to rigid cultural understandings as well (van den Akker 2001). Surrogate pregnancy and gamete donation challenge the definition of what creates a parent; the increased age range of women able to conceive changes concepts of who is able to achieve parenthood. Additionally, same-sex couples and single parents can now achieve parenthood through means other than adoption, allowing them a greater range of opportunities in creating their families. Thus, for some individuals, compliance with the biomedical model and adherence to fertility treatments might represent a larger resistance to cultural ideals of acceptable and achievable families.

Medicine has become the framework for understanding all things bodily in contemporary culture. This concept may seem intuitive given how complete it has become, yet it remains quite profound that one overarching framework should determine

so much of individuals' daily lives – what is too much to eat, how long is too little to exercise, when one has become too depressed or anxious for too long – essentially, what is the proper way to live one's life. While our understandings of the human body are constantly expanding and changing, historical reflection of medical authority reveals that such understandings are inevitably influenced by the cultural and social understandings. These variant models influence what is considered pathological, and what are appropriate responses to alleviate such pathologies. For an experience as emotional and challenging as infertility, recognition of the ways that these social influences operate can lessen the consequences to identity and health that occur when a dominant mode of understanding is inconsistent with an individual's experiences. As our knowledge of the body changes and the potential of new reproductive technologies grow, so too should the model of understanding infertility adapt itself to a changing culture. Thus, the following research will attempt to determine and describe the measures of resistance and compliance that those experiencing infertility make in their interactions with the biomedical model.

Methodology

Approach and Purpose. This study follows a descriptive phenomenological approach, combining elements of both inductive and deductive research to formulate an understanding of how couples structure their treatment choices and their understandings of their bodies in the face of infertility. Deductively, the inquiry was directed toward examining the ways in which individuals show resistance to and compliance with the Westernized biomedical model; inductively, other determinative factors will be

incorporated into constructing a comprehensive picture of the ways these important decisions are made.

Additionally, the research follows a feminist methodology, to the extent it attempts to engage the experiences of those deprived by the doctor-patient hierarchy and identity modes of resistance against historically patriarchal definitions of infertility. However, this theoretical approach should not be interpreted in a way that neglects the inclusion of male partners or male experiences with infertility. It is the entire history of infertility – both for men and women – that is patriarchal, and thus both male and female infertility patients must now negotiate their own understandings within that framework.

Setting. This research was conducted in Massachusetts, an important detail as the commonwealth is one of only fifteen states with mandated insurance coverage, and one of only four states (the others being Rhode Island, Illinois, and New Jersey) that mandates comprehensive coverage, defined as at least four cycles of assisted reproductive technologies (Henne and Bundorf 2008). Massachusetts General Law (Chapter 175, Section 47H) states that:

Any... general policy of insurance... which includes pregnancy-related benefits... shall provide, to the same extent that benefits are provided for other pregnancy-related procedures, coverage for medically necessary expenses of diagnosis and treatment of infertility to persons residing within the commonwealth. For purposes of this section, “infertility” shall mean the condition of a presumably healthy individual who is unable to conceive or produce conception during a period of one year.

Such a mandate fundamentally changes the experience of seeking infertility treatment.

Firstly, in the United States, assisted reproductive technologies (ART) cost on average between \$7,000 and \$11,000 per cycle (when using own gametes; the use of donor eggs

or sperm can drastically increase the price). Because it will often take a couple multiple cycles in order to achieve a viable pregnancy, the average cost per infant ranges from \$38,000 - \$50,000 (Henne and Bundorf 2008). Clearly, such steep costs will be prohibitive for a substantial proportion of the US population. For those who can access treatment without insurance coverage, the cost will have a tremendous influence on their options and their decision-making processes. Insurance mandates significantly increase utilization of ART (Henne and Bundorf 2008) and significantly increase fertility rates, especially first birth rates for women over age thirty-five (Schmidt 2006).

Beyond increasing use of services, and thus improving their cumulative success, insurance mandates can change how infertility patients make decisions. For example, if a prospective parent can only afford one cycle of ART, they will be more likely to transfer multiple embryos during IVF, to maximize the likelihood of having one viable pregnancy. This tendency results in more multiple pregnancies, with greater health complications for mother and babies. Mandates reduce the number of multiple births per ART birth (Henne and Bundorf 2008), and subsequently reduce the health risks and healthcare costs associated with them.

Compared to the \$7000 and up price tag per cycle in most part of the United States, most participants reported spending \$100 or less per cycle, depending on their drug protocol, their insurance's copay, and whether or not (and how frequently) they pursued non-covered treatments such as massage and acupuncture. Two of the participants had specifically moved to Massachusetts to be able to afford treatment; one additional couple had postponed treatment until a previously anticipated move to the

commonwealth. The impact of the insurance mandates on these participants' experiences cannot be underestimated.

Subjects. Subjects for this study were individuals and couples who have histories of difficulty conceiving, and have sought either treatment or support for that challenge. Additionally, the research was focused on those who were coupled – all subjects were currently in a partnered relationship, although both partners did not necessarily participate. While many single individuals will take routes to parenthood assisted by the same reproductive technologies that infertile couples use, they do not necessarily have the experience of infertility, nor do they face the same set of options and possible treatments (namely because they will require at least one donor procedure). This specification is further accounted for because of the desire to look at interactional factors of infertility, and how the individuals attempt to negotiate and understand infertility as a shared experience. Participants were recruited from RESOLVE of the Bay State, the Massachusetts chapter of a national infertility association. RESOLVE supports women and couples in making wider-spectrum decisions about parenthood, including efforts to conceive, adoption, and deciding not to become parents through support, education, and legislative advocacy. Participants were sought through web postings, e-newsletters, and print mailings.

In total, 26 participants were included in the research; twenty women and six of their partners. Information on age, education, and occupation were gathered for non-participating partners as well. At the time of the interview, the female participants' average age was 34.8 years old; however, their average age when they began trying to

conceive was 30.8 years old, well within the age range in which women can expect to be fertile. Partners' average age (at the time of the interview) was 37.4 years old. Nineteen of the women were partnered with men, and one with a woman. Eighteen of the couples were married; the remaining two intended to be in the future. The couples had been together an average of 9.2 years.

Demographically, the sample can be compared to both the population of all infertility patients, and the overall population. Racially, all of the participants were white, and ethnically, none were Hispanic/Latino. Although this homogeneity is not desirable, as it limits the scope of lived experiences available in the sample, it is not entirely inconsistent with the population seeking infertility treatment. Indeed, 80.9 percent of those seeking infertility care at Brigham and Women's hospital in Boston are listed as "Caucasian," with African American, American Indian, Chinese, East Indian, Hispanic/Latino, and Asian/Pacific Islander populations each making up less than 5 percent (Jain and Hornstein 2005).² These disparities are *in spite* of the fact that African American and Hispanic women are as likely or *more* likely to suffer from most types of infertility (Wellons, et al. 2008; Jain 2006; Bitler and Schmidt 2006). Additionally, infertility treatments have been shown to be less effective for African American patients (Dayal, et al. 2009; Seifer, et al. 2008), further suggesting the market for treatment is not

² Contrasted with the Massachusetts 2000 census data, the Chinese and Asian/Pacific Islander populations are overrepresented in the patient population (1.3 percent of the census population, verses 4.3 percent of the patient population, and 1.7 percent verses 4.8 percent, respectively); Hispanic/Latino populations were far underrepresented (6.8 percent verses 3.9 percent). African Americans were underrepresented, though not statistically significantly (5.4 percent verses 4.5 percent). The remaining patient population proportions did not differ significantly from their proportions in the general population (Jain and Hornstein 2005).

designed to serve these populations. It is important to remember, however, that the racial and socioeconomic disparities in accessing medical treatment are by no means unique to infertility; instead, they are the unfortunate norm in the American healthcare system, where African Americans and Hispanic individuals have less access to and poorer quality of care across the spectrum. While insurance mandates may increase access to advanced reproductive technologies, they have not been found to reduce these disparities (Jain 2006; Bitler and Schmidt 2006). Consequently, a representative sample of those pursuing infertility treatments should be predominantly white; however, contrasting the entirely Caucasian sample with both the patient population (80.9 percent Caucasian) and the general population (84.5 percent Caucasian) indicates that the sample is not racially representative. While the patient population is already disparate from the general population, the research sample was further pronounced in this disparity.

Furthermore, despite the insurance mandates available in Massachusetts, large disparities exist between the patient population and the general population based on highest level of education and annual household income – both strong indicators of socioeconomic status. While income information was not collected in this project, the education level of the sample was consistent with the patient population, though both differ from the general population. The sample proportion of women with at least four-year college degree (85.0 percent) and the patient population proportion (84.9 percent) were virtually identical. Both contrast distinctly with 31.4 percent of women with four-year college degrees in the Massachusetts general population (Jain and Hornstein 2005). Using education level as an indicator of socioeconomic status, we can infer that the

infertility patient population is of a higher status than the general population, and that the sample was appropriately reflective of these characteristics.

Of the twenty couples whose stories were represented, four had already become parents through the result of some combination of treatment (three of the four were preparing to re-enter treatment in the hopes of having a second child); three women were currently pregnant at the time of their interview (two of them with twins); two couples had stopped treatment and were actively in the middle of the adoption process. Two couples were not currently pursuing treatment, and considered it unlikely that they would return to treatment or pursue adoption – they believed childless living would be the most likely conclusion for them. The remaining nine couples were actively in the middle of treatments to conceive their first successful pregnancy. Seven of the couples had experienced miscarriage or perinatal loss in the course of treatments.

Of the twenty couples, six couples had no diagnosis in either partner and were relegated to the “unexplained” category; another six couples had ambiguous, partial diagnoses such as “poor responder to medication,” or “thick oocyte shell” – diagnoses where were not made until *after* treatments had failed. The remaining eight couples had one of the following diagnoses in one of the partners: high follicle stimulating hormone (FSH), polycystic ovarian syndrome (PCOS), endometriosis, varicocele, premature ovarian failure, and azoospermia. The former four are not considered fully prohibitive diagnoses; it is still possible, with treatment, to conceive with those conditions. Only with the latter two does medicine offer no solution, save donor gametes.

Depending upon individual circumstances and doctors' recommended treatments, medical protocol for infertility *most generally* follows this path: extensive testing to determine, if possible, sources of difficulty; cycles with ovulation detection, Clomid (or a similar drug to assist ovulation), and timed intercourse; intrauterine insemination (IUI) without injectible drugs; IUI with injectible drugs; and *in vitro* fertilization (IVF). Beyond these options, other treatments include frozen embryo transfer (FET), where frozen embryos (usually the result of previous IVF cycles) are implanted; IUI or IVF with donor sperm; or IVF with donor eggs. Fifteen of the twenty couples represented had undergone IVF; all but one of the remaining five had gone through between three and eight cycles of IUI. Thus, nineteen of the twenty couples have had very prolonged treatment experiences (the final couple had a very prohibitive prognosis, and abandoned treatment after two failed IUI cycles), and have been living the patient experience at an intense level for quite a long time. Indeed, the average time trying to conceive was 3.7 years, ranging from four months to ten years.

Beyond these characteristics, the sample represented a diverse group from across the state of Massachusetts. Professionally, they included a classical musician, a police officer, a professional athlete, housewives, business owners, several medical professionals, and many other diverse occupations. Overall, the participants represented couples who felt they had comfortably reached the point in their lives and their relationships where they were personally ready, financially capable, and emotionally committed to the idea of building a family. While they varied in age, religion, education,

social class, and diagnosis, they shared one fundamental goal – they wanted to be parents, and they were having trouble becoming so on their own terms.

Interviews. Subjects were interviewed in a location of their choosing to ensure ease of participation; most chose their homes, nearby coffee shops, or work offices. The interviews lasted on average eighty minutes. One subject chose not to be interviewed, and instead responded to the same questions in written narrative.

Interviews were semi-structured out of a necessity to address a wide range of possible experiences: some subjects were still trying to conceive, some were currently expecting, some were in the midst of the adoption process, and some had already achieved parenthood. Stories were marked by failed treatments and pregnancy loss, as well as profound successes and happy endings. This wide variation required an interview guide (included in Appendix A) flexible enough to encompass the range of lived experiences. Questions were designed to be open-ended, with follow-up questions addressing the individual's unique circumstances.

Confidentiality. Given the highly personal nature of the material being discussed, extra measures were taken to ensure the confidentiality of all participants. In order to protect this sensitive material, interviews were coded anonymously with identifying information – including specific dates, places, and names of treatment providers – removed; all names included in the final report are pseudonyms. Additionally, participants were offered the option of reviewing excerpts from their interview before they were included in the final report. Eight participants chose to take

advantage of this option, and none of them chose to exclude any of the selected excerpts from the final report.

All research was conducted in accordance with Health Insurance Portability and Accountability Act (HIPAA) for maintaining the confidentiality of Protected Health Information (PHI) through written consent and authorization from individual subjects. Additionally, as mentioned above, all PHI will be de-identified following the guidelines of the HIPAA De-Identification Certification Form.

Analysis. Interviews were transcribed and organized following an analytic inductive process, which included data reduction along emergent themes, data clustering to derive conclusions, and conclusion drawing to make sense of the participants' stories (Miles and Huberman 1984; McGuffey 2008). The data clusters were grouped according to general themes (such as "Ambiguity"), aspects of the patient experience (such as "Interactions with Physicians and Nurses"), and ways of making meaning (including all answers to the question "Why do you believe you and your partner are going through infertility?"). From these clusters, ways of coping, practices of resistance, and new models of understanding infertility became apparent.

With the focus of identifying varying degrees of compliance with and resistance to the biomedical model, both in practice and in belief system, each must be operationalized. Compliance with the model could show through strict adherence to physician's recommendations, incorporation of medical diagnoses and language into understandings of their body, or limited pursuit of non-physician prescribed treatments. Resistance will be to varying degrees by questioning the doctor's opinion, pursuing

options that fall outside of Westernized medicine, expressing incongruities between the biomedical model and their understanding of their experiences. However, these concepts will need to be contextualized within each individual's experiences. Some patients' doctors may encourage them to pursue non-traditional treatments, thus making them less challenging. Additionally, some people who follow their physician's instructions strictly may be resistant to the medical model in terms of defining their identities as infertile individuals. Thus, these operationalized definitions are flexible enough to acknowledge such subtleties, as the goal of the research is to identify the ways in which these potential delineations influence overall experiences of infertility.

Resistance to the medical model might also be indicated by adherence to an alternate explanation for their infertility, such as a religious or social cause. Depending upon the way in which they are structured, these attributions have the potential to represent an entire rejection of the biomedical model in favor of a separate paradigm. The partially inductive nature of this form of analysis leaves open a broad spectrum for participants to define their own resistance and individualized ways of understanding their infertility beyond these proposed operationalizations.

Importantly, each explanatory model represents a personal framework for going through infertility. Each individual story had elements of both compliance and resistance, of challenge and coping, and of emotional struggle and resilience. These findings are not meant to suggest that *beliefs* divergent from the biomedical model necessarily promote *behaviors* that are resistant to that model; instead, both beliefs and behaviors become ways of making meaning of a challenging experience. This research is

intended to reveal patterns in the way those experiencing difficulty conceiving are, as a collective group, already negotiating a wide range of possible models and responses.

Findings

The Patient Identity. The accounts of participants did indeed reveal a complex negotiation with and critique of the biomedical understanding of fertility. In order to understand the development of such negotiations, it is important to realize the lived experiences of those with infertility. Under the biomedical model, these individuals assume the patient identity and follow a treatment protocol that will frequently require daily medication and injections, regular (sometimes daily) medical appointments, and constant lifestyle alterations.

Kimberly, who has been trying to conceive for four years, described the consuming nature of the experience:

[Infertility] affects every single aspect of your life, in a million, trillion different ways. It's financial, it's emotional, it's medical, it's physical, it involves your family, your friends, every single thing – I can't walk down the street without dealing with it. It involves everything.

Kimberly was also one of three women who had either given up or scaled back their careers directly as the result of infertility. Letting down coworkers, having inflexible bosses, missing work to make appointments, and being too emotionally and physically drained to perform as they would like on the job, many gave up previous goals and professional identities in order to accommodate the demanding patient identity.

Charlotte, pregnant after over three years of treatments, justified this decision as a way of transitioning into the identity she hoped to ultimately assume, as a mother:

I took a step down because I just... I really just felt like I was always letting someone down. I was missing early morning meetings because I was going into get ultrasounds in the morning, and I felt like I was totally zonked out at work after a cycle, and I didn't have anyone to talk to at work about it. I just felt like I wasn't doing my job well, and I had a lot of people who reported to me, and I felt like I was short to them. I'm not doing a good job at work and I'm not getting pregnant, probably because I'm stressed at work.... I took a decent step down purposefully to be able to not have to devote as much time to my job so I could focus on trying to have a kid... I love the job right now, and I actually, because I think I've mellowed out in so many other ways... I don't need a career.

Beyond such professional sacrifices, many couples reported feeling stalled, as they delayed major decisions while waiting to see how their infertility would be resolved, and trying to be prepared for all options. Julia, now the mother of a one year old son after three years of infertility, reflects:

You feel very stagnant in your life. For two years, I felt like I couldn't make a job change, it was hard to plan vacations, it was scary to spend big amounts of money – for example, a car, or a kitchen renovation, because I didn't know if we'd be paying for an adoption. That was the only thing, I just felt sort of stuck. You don't know what's gonna happen... You didn't want to feel three, four, five years have gone by, and you haven't redone the kitchen, and you haven't gotten your new car, because you've been waiting for five years to figure out if you're gonna have a baby. I felt like, in some ways, I was wasting time.

The sacrifices, the waiting, the inability to plan – these represent the larger struggles of living as a patient indefinitely.

Regarding the smaller scale of daily experiences, the participants struggled with the daily reality of being constantly medicated. These were not challenges of merely physical side effects (though those certainly took their toll), but went beyond that. These women did not feel like themselves; they felt like their selves and their identities were compromised by the medications:

Sarah: This drug [Clomid] made me crazy. I usually am a pretty even-keeled person, and I would cry at the drop of a hat... I remember lying in the living room downstairs and I would lie on the couch under a blanket, weeping the entire time. Just for no particular reason. And as they were doing the ultrasounds, they'd call that day and say "The

follicles really aren't growing, it doesn't seem to be working, come back in a couple days." So I was always being kind of strung along... I think I just need a break from it. And I really thought I'd never get to this point... But I really finally reached a point where I need a break. I need to breathe. I keep saying, I need to get back to me. Mentally and physically. Mentally it's made me a much more bitter and angry person, that I *hate*.

Mary: Everybody I know, we all just call [Clomid] "Evil in a Bottle." I just felt that I was so depressed and so fluctuating in my personality, in my level of function. At one point, I felt that I was suicidal. I was able to recognize that and I was like, "Why do I feel this way? I haven't felt like this since I was a teenager. I don't want to be in this place anymore!" It was really horrible.

While the medications take a physical and emotional toll, the logistical aspects of treatment are similarly demanding. Many couples were driving over an hour for their treatments, getting up before five o'clock in the morning to go to an ultrasound appointment (which they must do daily when in the middle of a cycle) and still arrive at work on time, or fundamentally rearranging their schedules to accommodate doctor's visits. Such demands make it nearly impossible to not always be aware of one's patient identity.

For Karen, the toll of treatment became too much:

Just the thought of having to go through that again just literally exhausted me. It had been the worst six months of my life, emotionally, physically, mentally, it was so draining, and I just – I couldn't do it. So I thought, well, I'll just take the summer off. And then when summer passed and fall came and I was back on my antidepressants and I was feeling good and I was exercising everyday and I had lost the weight I had gained, and I thought, oh my god, I can't go through that again. The thought of it – even today – a friend of mine said, "Well, have you thought about checking out this hospital?" The thought of going through that process again... all I think about is being exhausted and miserable. So I just never went back.

For her, the patient identity was too burdensome, and she began to give up her goal of becoming a mother rather than assume it once again. For most, even though they expressed profound hatred and dread involving treatment, the elusive goal of parenthood was what maintained their strength to continue in the process (either by continuing with

treatment or pursuing the similarly expensive, lengthy, and emotionally draining adoption process), while still managing the other aspects of their lives:

Ashley: It consumes so much of what you are, and so much of what you do goes into trying to get pregnant. Sometimes I think you forget that there's other things that you have in your life that are really good... I can deal with the injections, I can deal with the procedures. I can deal with being in the hospital. For the most part, I can deal with being in pain. But, I can't deal, or live, without being a mom.

Robert: This whole process happened, and in the meantime, you've gotta keep living. You gotta keep working. It's not like you're taking a year off to decide what you're gonna do and go to therapy and go hiking in the mountains and sit out in the fields and reflect. No, you're working. You gotta make it happen. Collectively trying to save money and working towards a goal, and I think we've both done things collectively that have made us work as a team to try to get this to happen.

Perhaps Sarah, in her third year of treatment, succinctly stated it best: "I absolutely want a family. And that's why we keep going."

The Need to Negotiate. Living within the patient identity dictated by the medical framework requires sacrificing a large amount of control and losing the ability to plan. This disempowerment was not just the result of the illness, but of the treatments; Amy commented that, instead of empowering her, the "treatments are taking control away on another whole level." To regain control, participants showed a wide range of behaviors that allowed them to feel more empowered in the course of treatment.

It is vital to remember that the majority of couples began treatment with no definitive diagnosis as to why they were having difficulty conceiving. Those with unexplained infertility truly struggled with this ambiguity; Kate commented that "The hardest thing about all of this is the unexplained aspect... The unexplained thing is like... such a crock. I get so mad. I'm like, 'It's explained, you just haven't figured it out.'" Others shared this frustration:

Hannah: I remember being at the sperm donor seminar because we were the only couple there that didn't have azoospermia, that don't make any sperm. And of course, the woman leading the group was like "What the hell are you doing here?" But I was so jealous of the people there, that they had a diagnosis. I was just insanely jealous of them. The not knowing is hideous.

Charlotte: I would say globally, not having a diagnosis [was the hardest part]. That made me crazy, that really bothered me. That was a thing that I kept just being like... "Why aren't you more curious about this? Why don't you want to find out what this is?" to doctors. So that was a global stress – we can't fix this because we don't know what's wrong and no one wants to know. We were frustrated that we felt they were kind of satisfied with just saying, "Well, we don't know why, but let's just do an IVF cycle." To us, that was a huge deal... They just very casually, I thought, were like "Eh, IVF. Go do another one."

Even Meredith, who was diagnosed with premature ovarian failure, was able to acknowledge the benefits of having an answer: "As shitty as [the diagnosis] was, you could kind of move right on to the grieving part, and not waste a whole lot of time." In a world where an answer – any answer, even a bad one – is a luxury not always provided by Western medicine, it is no wonder patients frequently seek to challenge the biomedical model.

Importantly, women seemed to feel the need to negotiate more than men; most likely because most treatments focused on their bodies, which were the site of virtually all intervening procedures. This disparity was, of course, hard on female participants who felt that they were failing as women; it was also hard on their male partners, who felt limited by what the medical treatments allowed them to do. Amy and Brian, who were preparing to go into their fifth IUI, share:

Amy: I'm so hormonal, I'm just not myself. And sometimes I think, as a woman, you definitely feel that your body is failing you. Which is really hard. You feel like part of what you're supposed to do as a woman is have children and my body can't do that right now. And it's hard not to know why. Part of me wishes... I know if I had a blocked tube, I could have surgery and – boom – be done. Or, if I had endometriosis... at least it's something. But this kind of unexplained is what's really hard.

Brian: There can't be perfect equality in this thing, because my body is not going through the same thing she is, and I think it's very hard for her when I'm not totally sacrificing, she feels as though I'm not owning up to my end of the bargain. Whereas I just get so frustrated, and I'm doing the best I can, I've made a lot of changes. It really feels like I'm trapped until we get this done. I don't know. It's definitely... it's taken a toll on me in the last couple of months, too. It really has. In a way that it didn't before that.

Because men reported feeling slightly more removed from the process (physically, if not emotionally), they did not seem to view the negotiating behaviors as likely to improve the outcome. They were, in some ways, *more* disempowered by the situation, but without the luxury (or burden) of finding ways to regain control. Andrew and Kelly reflect:

Andrew: [The hardest thing is] mostly just seeing her go through it all, because it all comes back to her in one way or another. Not in the sense that I feel like everything's her fault, but everyone goes to her ... they try to console her, or ask her... She bears the brunt of everything. I try to be supportive, but other than that I just kind of show up.

GS: *Do you think it's harder on you?*

Kelly: I don't know. I don't think I'd want to be in his position, to not really do much. There's nothing more he can really do than do the injections for me... I think I have more control over the injections. I'm at every doctor's appointment. I know what's going on more than he does. And I know how I feel, and he doesn't always. I think it's more frustrating for him.

From Kelly's perspective, her greater ability to regain control – through such negotiations as will be discussed in more detail – makes it easier for her than her husband who has limited ability to influence the situation through either the treatments or the negotiations.

The most common response to the loss of control was to “do everything possible” – pursue medical treatments, engage in any number of negotiations (which will be further explored), and begin considering other solutions such as gamete donation and adoption. “Doing everything” was the only way to avoid guilt and self-blame when treatments failed:

Laura: [My husband] tries to prevent me from blaming myself, because I'm always trying to think of... you know, with the baby loss, trying to think of how I could do differently, or what I could have done differently. He keeps saying there was nothing we could do. And almost every day he's like, "We're doing everything we can, that's all you can do. Stop beating yourself up. You can't do one more thing than you're doing." Again, that's why I think I'm pretty lucky that he's been so supportive of me.

Connie: I know what I want and I will do what I have to do to make my chances the best they can be and hopefully that will all pay off and it will work. If it does not work out for us, I do not have any regrets because I know I have done everything I can do to make this work.

What did "everything" include? Participants exhibited eight levels of varying compliance, negotiation, and resistance to the biomedical model: 1) outright compliance with the model and faith in the ability of medicine to resolve their infertility; 2) negotiating by going beyond medical treatment and making profound lifestyle changes that may or may not be endorsed by their physician; 3) negotiating by pursuing alternative treatments not endorsed (but perhaps not dismissed) by their physician; 4) negotiating by seeking information and advocating for themselves as patients, enabling them to question their doctors and play a more active role in their own treatment; 5) negotiating by using their religion, spirituality, or magical thinking to develop other, non-bodily ways of controlling infertility; 6) negotiating by extracting meaning and learning lessons from the experiences, thus infusing the objective idea of "disease" with subjective purpose; 7) negotiating by building personal, alternate models that encompass a wide range of ways of thinking about infertility; and 8) directly challenging the scientific authority of the biomedical model, resisting the terms of treatment, or questioning the ability of medicine to offer them solutions. No participants showed pure compliance – as all included at least one of the negotiations – and none showed full resistance – as all had sought at least some medical treatments. Rather, they built their own strategies and

models for maintaining control while operating under the patient identity and interacting with the biomedical model.

Compliances. Compliance with the biomedical model would seem to be the default choice for those seeking medical treatments, and for many it was – at first. Negotiations and resistances were gradually integrated as they realized that one cycle with Clomid, one IUI, or even one IVF would not result in the pregnancy. There was always a point at which the medical treatments were no longer viewed as sufficient, and they decided to go beyond or around them.

Men were far more likely to show higher levels of compliance and faith in medicine than their female partners, likely as a result of their lesser control over the situation. With fewer ways of negotiating the situation, their coping mechanism became reinforced faith in the doctors. While his wife actively sought information about alternative treatments online, Joseph resolutely stated: “I personally try to collect my information from the doctor, because there’s a lot of opinions online. You don’t know where the information’s coming from, and if it’s valid or not.” In this construction the doctor is the highest authority, and the best possible hope of solution.

Again, Andrew and Kelly similarly illustrated this gender difference. They began trying to conceive at age twenty-five and twenty-six respectively, and after one surgery for Kelly, seven IUIs, and three IVF cycles, the doctors have offered them no explanation for their lack of success. Indeed, following similar protocols, Kelly made thirty-one eggs on the first cycle and two eggs on the second, revealing to a large extent the lack of consistency that can be assured in infertility treatments.

- Andrew: I haven't looked up much, I haven't read much. Yeah... it's not really like me, though, cause I'm just kind of trusting the doctor that he knows what he's doing. And I don't really want to know too much. I can only cope with so much. I trust Kelly and the doctors.... It's too much. It's just so much. It is overwhelming, because there're a billion different possible answers, and everyone has a different one, too. You could go to ten doctors and get ten answers.
- Kelly: Especially in our case.
- Andrew: And maybe ten of them would be the right answer, too, out of all ten.
- Kelly: But he's definitely been more optimistic about each cycle individually than I have, at this point. Which is different for you.
- Andrew: I think we [husbands] have to be.
- Kelly: *You* have to be.

For Andrew, trusting the doctors, trusting his wife, and having a high level of optimism that treatments will work is the best way for him to deal with the absence of another possible solution.

Andrew is fully accurate in his statement that husbands are more optimistic – all participants in heterosexual relationships commented that the male partner was more confident that medicine would provide a solution. While interviewing Sarah and talking about other couples that had become pregnant after IVF, her husband Jeremy belatedly came to join the interview.

“We like success stories, don't we?” Sarah asked him as he walked in the door.

“Absolutely,” he responded, “Because we are one.” When I asked Sarah how certain she was that she would be a mother one day, she said fifty percent. I asked Jeremy the same question:

I'm in the high nineties, mid to high nineties. [Sarah laughs.] There's that little bit of... as far as, if you're gonna break it down and ask how certain are we gonna adopt? I couldn't tell you. I couldn't give you a percentage. I flip flop in my mind minute by the minute. But as far as... what we're going through now, how certain am I? Because I keep the positive mind frame, and I'm not trying to trick myself, I'm still up in the high

nineties. But my ninety percent isn't me being positive and sunny and "Oh, if you keep thinking positive, good things are gonna happen." Because I know that's not the truth. But I sincerely feel that, in my mind, my strong-headed mind, is the fact that we did get pregnant, that it is a good sign, that it's gonna happen again.

This gender difference in levels of optimism represents that women will be more likely to seek other negotiations of the biomedical model; lack of faith in the model is the first prompting to seek other solutions.

For most, following medical treatments meant ceding control, and negotiations became a way to attempt to regain it. However, another participant, Janet stated that "[her] coping mechanism was to give up control." The mother of a young daughter after six years of treatment, Janet pursued medical interventions elsewhere in the country, where she believes the science of infertility treatment lags behind the standard of care offered in Boston. After moving across the country in order to benefit from Massachusetts' insurance mandate, she felt tremendous relief to be able to hand over her care to her doctor:

The idea of somebody with a professional degree being in control of this process instead of me – and then the fact that they're in control also means that they're responsible for it if it goes wrong – was a huge relief. It just made it feel like I could continue... I didn't care about being put on all the drugs, because I was like, "Great, if I don't get pregnant, it's their fault." [Laughs.] That's how it felt! All I had to do was stay on the stupid protocol. All I have to do is follow the rules, and I'm just gonna trust that they're gonna do the best they can, that they're gonna give me the best shot, and if this doesn't work, I will feel like it's not because I don't have enough money... it's because I really can't get pregnant... The system worked really great for me. The main thing it did... it made me feel like if something went wrong, it would not be my fault. The clinic was responsible for the process. I'm sure some people find that disempowering, but for me, I found it a huge relief.

For Janet, compliance was the best solution. "Interfering in the process" – as she phrased it – would have placed the burden on her, and led her to question anything she did, had

she not succeeded in getting pregnant. By constructing the medical model as blameless, compliance becomes a relief, and relinquishing control a way of relinquishing burden.

Furthermore, the construction of infertility as a disease justified treatment as a primary means of resolution. Participants suggested other ways of resolving, such as adoption or living without children,³ but all pursued at least some medical treatment because they believed it offered some hope that they would be able to achieve the family they had originally envisioned: one with their own biological children. For many, this pursuit of treatment was justified by understanding their infertility as a disease deserving of treatment. Kimberly describes what she says to those who challenge her right to treatment:

There's all these arguments of "Why would you do IVF anyway, you can just adopt!" I say that infertility is a disease, and that you should have a right to treat it the way you treat any other disease. If you want to look at everybody that has diabetes – let's use it as an example, because I feel that it's kind of a managed care. ... "Your FSH is too high"... "Well, your insulin is too high, we're not gonna treat you." It's a disease. There are instances where it's untreatable, like any disease. If you're over a certain age for some people... it's untreatable at that point, and I understand that. I don't know what I say to those people. I say "Are you kidding me?" I believe that having children and not having children is an inherent right.

Seeking medical treatment for a disease is more easily constructed as a right than pursuing expensive, stressful interventions (which may not work) to become parents.

Kimberly straightforwardly states she believes having children is an inherent right, but that "right" is much more complex and more difficult to defend than a "right" to

³ Pursuing treatment did not mean that they were not also considering adoption: 16 of the 26 people interviewed felt very open to adoption; another 8 participants were considering the idea, but felt that they were too early in the process to have a fully formed opinion, or were dealing with partners more reluctant to pursue this option than they were themselves. None viewed childless living as a positive option for them, although two of the women seemed to accept that that would probably be their most likely resolution.

treatment. The disease model simplifies the debate by removing other complicated questions: do these people deserve to be parents? If they deserve to be, do they have the *right* to be? Do they have a right to pursue biological parenthood when many children already born need to be adopted? These are the darker questions that lurk behind understandings of infertility treatment, and participants often alluded to them, and such questions certainly deserve much consideration on a social scale. However, the disease model offers a way around them: it is not a question of who deserves what; it is fundamentally a question of treating a disease. Broadly, we expect Western medicine to provide solutions for diseases, we expect people to have access to these treatments, and we do not question patients' right to or pursuit of such treatments. Here, conceptual compliance with the biomedical model and the disease construction removes the burden of determining who is worthy of intervention (and consequently, questioning whether oneself is), because, quite simply, everyone who has the disease has the right to treat it.

Finally, for those that had become pregnant through treatment, there was a retrospective respect for the biomedical model, even if participants had shown negotiations or resistance at the time. Nicole's husband had azoospermia, which prohibited him from biologically fathering a child, and they could not afford adoption. For her, using a sperm donor was the only practical way to have her daughter. She reflects:

I'm just glad that the medical field is glad to do [donations]... I'm just happy that those options are out there. I think sometimes people are embarrassed or worried about using donors, but people do that because they want to help, and I'm glad that it's there.

In instances such as this one, Western medicine is providing a solution. Even if it is not the solution the couple originally wanted, even if it required re-envisioning their way of having a family, even if nothing was done to “cure” the infertility, a resolution was provided when other options would have been prohibitive. It is important to remember that, although nearly all participants actively sought to negotiate and resist the biomedical model in a way that made them feel more comfortable and in control of the treatments, most were still grateful that medical treatments offered a possibility of a resolution – even a suboptimal resolution – that had not been available to previous generations.

Negotiation: Lifestyle Changes. Even those patients who had high levels of faith in the biomedical model felt the need to go beyond medical treatments, often by making lifestyle changes. Frequently, these changes were framed within the context of becoming overall more healthy, and were done with the encouragement of physicians. However, they were often done as a way to go beyond medical treatment and to gain more control over one’s fertility. In this capacity then, such lifestyle changes that become ways of negotiating, without denying, the determinative authority of the medical model.

Most frequently, these changes involved making changes in diet and exercise.

Kate describes the changes she and her husband have made:

We have changed our lifestyle. We’ve been cooking at home more and eating out less, for multiple reasons, this is one of them, though. There were certain key ingredients that we wanted to try to get into our diet. Everyone says craziness, but it makes me feel a little bit better. Sweet potatoes, apple juice. It’s all things that we like anyway, so I’ve just been buying them more. And we like to cook, but we had gotten away from it. So we’ve been cooking more now, trying to be a little bit more healthy, know what’s going into our bodies. I wouldn’t say it’s been working out horribly well, but a little bit. We dusted off the treadmill. I hate to run, so my husband’s been running. I bought a yoga tape. Never thought that I would, but I really like it... I think it actually does relax me.

So at night now, instead of watching TV, I am doing that and then I read. And it seems to work out.

Kate's account is very consistent with the stories of most participants, at least early on in the treatment process. Participants cut back on (or completely eliminated) alcohol and caffeine and began eating only organic foods. They also described a tremendous range of "miracle foods" that they had heard about from acquaintances or read about online: drinking ginger tea and wheat grass, eating only warm foods while ovulating, completely eliminating dairy-based foods, exclusively eating high-fat (and primarily dairy-based) foods. Female participants also began shunning foods typically off-limits to pregnant women, such as sushi and soft, unpasteurized cheeses, and began taking prenatal vitamins. Exercise represented a trickier decision for most, as some wanted to lose weight to improve their chances, others felt too much exercise would hurt their chances, and most who regularly worked out were extremely reluctant to give up what they viewed as a reassuring, invigorating, part of their daily routine.

Most participants reached a point, however, when the rigor of upholding such self-conscious lifestyles became too burdensome. This strength of this negotiation is that it gives participants many variables they can control (what they are eating, how much they are exercising, how well they are taking care of their bodies); the weakness of this negotiation is that it places a tremendous amount of pressure on participants to maintain the high standards of behavior. Ultimately, when treatments continue to fail, most participants abandon this negotiation:

Laura: Well, I've gone from being really, really strict to not being strict at all. I get massages once a month for stress. When I first started out this process, I wasn't drinking caffeine. I wasn't drinking alcohol. I was eating very, very healthy, lots of grains and

fruits and vegetables and beans. But, over the courses of the last five years... I eat whatever I feel like, including fried foods. I went through a process where I was drinking quite a bit; I finally got that under control. But it's fluctuated, how I've been taking care of myself. There's only so long... you're going for five years of never having a drink, never eating sushi because I might possibly be pregnant. It just kind of got silly.

Mary: I was just more aware of what I was eating... I don't drink a lot of caffeine, either, but I made sure to monitor the caffeine intake. The cheeses, alcohol intake is actually something that I just really eliminated. And then I at one point just said... screw it. Obviously, that's not working. It's not that I started up heavily, but I would have a drink here or there. I was exercising. When you're during an IVF cycle, they're very, "Oh, you shouldn't be lifting more than five pounds." Hello, I have a job! I lift people all day. You have to do your laundry. You have to do things to live. You have to pick up a pan to cook... Why can't I exercise? I realize that I use exercise as an outlet to burn off extra energy, especially because this is so stressful. I really had decreased my exercise over the past year, I decreased a lot.

Ultimately, lifestyle changes are an early negotiation that most readily fulfill the need to "do everything" possible to ensure conception. As a negotiation, they do not deny the potential of Western medical treatments, but recognize that medicine will work best under "optimal" conditions that they can work to ensure. It helps participants to regain a sense of control, without challenging the biomedical model directly.

Negotiation: Alternative

Treatments. Alternative treatments were viewed by most participants as an extension of the lifestyle changes that they were making. However, as a negotiation, they represent something distinctly different. None of the participants' reproductive

Table 1. Use of alternative therapies among female participants (n=20).

Practice	Frequency
Acupuncture	18
Eutony	1
Herbal Remedies	4
Homeopathic Remedies	1
Massage	4
Meditation Exercises	5
Mind-Body Clinics	3
Physical Therapy	1
Reiki Treatments	1
Therapy (Couples)	3
Therapy (Individual)	5
Yoga	6

Note: This table includes only treatments sought by female participants. Of the six men included in the sample, only one pursued an alternate practice (yoga) at the encouragement of his wife.

endocrinologists discouraged any lifestyle changes (although they may have been skeptical of their efficacy), and frequently the lifestyle changes were made with the doctors' encouragement. Alternative treatments, however, involved the introduction of another practitioner (such as a massage therapist or acupuncturist), or practices specifically discouraged by physicians (such as herbal remedies).

For some, alternative therapies and practices represented valid treatments that, through their own therapeutic properties, would improve their chances of conceiving:

Amy: The yoga and the acupuncture have helped, absolutely. Definitely with stress reduction, but I think also with my temperature. My temperature is getting more steady. And I can tell, after a treatment, my temperature will go up. I'm definitely a believer on that. And I think the yoga is really important for the relaxation and concentration and trying to get back to being calm and getting out of my head a little bit.

Like Amy, many saw their basal body temperature become more cyclic (a sign of regular ovulation and menstrual cycles), and believed that treatments improved blood flow to their reproductive organs. Other participants remained skeptical of the potential of alternative therapies to induce bodily changes, but viewed them as invaluable ways to help them relax, reduce stress, alleviate side effects of various medications. Meredith, who was diagnosed with premature ovarian failure and left with extremely few medical options, used both acupuncture and herbal remedies before ultimately moving on to adoption:

Meredith: I did not expect [the alternative treatments] to restore my fertility necessarily. They were very effective at addressing symptoms I was having... Also, there was definitely just feeling like, because I basically was told that there was not anything that I could do medically, it made me feel like I was doing something. So, that was a big motivator. It was just something concrete to do, to channel the energies. And, it had these positive, these therapeutic effects as well.

Almost all of the participants who used alternative therapies had extremely positive experiences with them, and viewed them as an integral part of treating their infertility.

By far the most common alternative treatment was acupuncture; 18 of 20 female participants pursued it for at least one cycle of medical treatment. The prevalence of this treatment raises the question: can acupuncture truly be called “alternative” if such a large majority of participants engage in it? If it has become a routine part of infertility therapy, does it still represent a valid challenge to Western medicine? Given the context in which participants framed their use of acupuncture, yes. While no reproductive endocrinologists discouraged patients’ use of acupuncture, none encouraged it, and most responded to their patients’ use of acupuncture with indifference. Kimberly describes:

One of the things that I think about all clinics and all doctors and everything to do with IVF and infertility – nobody’s willing to really endorse any [alternative treatments]! Nobody wants to get on board with it, they think just in case it’s not right for the individual. So, the Center is very poster-in-the-lobby for the acupuncture.

This “poster-in-the-lobby” approach was frequently noted; waiting rooms at doctors’ offices had literature on acupuncture, Mind-Body clinics, and other treatments, but doctors never directly mentioned them. Pursuing such therapies was truly patient-driven. In some cases, participants framed their use of acupuncture as definitively resistant to their doctor’s approach:

Charlotte: [Acupuncture] made me feel like I was doing something. Not that you don’t feel like you’re doing something when you’re pursuing treatment and giving yourself injections and everything else, but it felt like something I could be in control of and make the appointments myself, and be like “I’m doing acupuncture, doctor, I don’t care what you say.” It was satisfying.

From this approach, it does not matter how common acupuncture is. If participants *view* it as resistant to Western medicine, it *becomes* resistant; it becomes a way for them to negotiate by working outside the medical treatments that are failing them.

The power of seeking treatments as a negotiation lies in the recognition that the Western medicine alone does not have all the answers, and it may not have the answers at all. A few participants felt they had made this realization before – Mary, for example, in her professional work with stroke survivors, and Laura, after seeing her mother die from cancer. For both of them, the transition to alternative treatments was intuitive and began early on; they had already witnessed the insufficiencies of Western medicine first hand. For most participants, however, infertility was the first time they had come to this challenging realization, and pursuing alternative treatments represented a paradigm shift in understanding how their bodies functioned and how they would most likely achieve the much longed for result.

Negotiation: Information Seeking and Patient Advocacy. In contrast to actively pursuing non-Western medical treatments, advocating within the medical setting may seem to be a less challenging means of negotiating. However, if it is remembered that *all* participants pursued medical treatment, regardless of the extent to which they also incorporated alternative therapies, the working within the system as their own advocate becomes a critical way of responding to the biomedical model. By doing so, they are acknowledging themselves as a valuable authority on the course of their treatment.

While this paper is not about whether participants liked their doctors, as such discrete interactions – either positive or negative – do not necessarily represent the

participants' interactions with biomedical conceptualizations, it is important to note that most participants *did* like and trust their physicians and nurses. While some had patient horror stories of insensitive practitioners or mistakes that resulted in missing cycles, most referred to their care as “fantastic” and their doctors as “genuinely caring.” Even if they did not personally like their doctors, they acknowledged they were “totally professional” and “very competent.” This satisfaction, however, is due in part to the high level of patient advocacy in which participants engaged as a means of negotiation. To put it quite clearly: if they did not like their doctor, they left. Hannah describes the seeking a new doctor after becoming discontent with her current reproductive endocrinologist:

I decided I needed to go someplace else for a second opinion, which was coincidentally scheduled on the same day as my follow-up appointment with my current doctor to review my cycle. So, when I saw him, I said “What do we do?” And he said “We’ll just keep doing the same thing until it works.” And my husband and I think he was pretty content with the idea that it was a numbers game, and I think he felt like that means we’re doing the right thing, and we just have to wait until it works. And I was... not satisfied with that answer. So we went to a different doctor who said basically that, that we’d done the same thing twice and it hadn’t worked twice, so why do the same thing a third time?... So, I was very much in favor of that.

Changing doctors was rarely done simply because the participant did not like the doctor, but instead because they, after educating themselves about their care, fundamentally disagreed with how they were being treated. Still, seeking second opinions or changing doctors was one of the most frequent and least challenging form of patient advocacy (eleven of the twenty couples had switched doctors at some point). As a negotiation, it attributes the lack of answers to the individual doctor or medical practice, but it does encourage them to think more critically about their care.

The second level of patient advocacy was information seeking; 16 of the 20 female participants reported actively seeking out information on their diagnosis (or lack

thereof) and various treatment protocols. This information was not simply for their own elucidation, it often became a way for them to suggest different procedures. Julia, herself a healthcare professional, suggested a couple different treatment protocols to her doctor, who actually followed through with those suggestions. She describes her process of seeking information and requesting these treatments:

Book after book after book, internet all the time, talking to tons of people, reading magazines... I sought information from every end. For me, that was important. I felt like I need to go into this with as much knowledge as I could. As much as I loved, and still do love, my doctor, they don't give you all the answers. A lot of what we did along the route was stuff that I read about and mentioned. I had read that some clinics will do, when you're doing an IUI, they'll actually do two. I remember talking to my doctor about it, and she's like... "Listen, the research doesn't support that that makes any difference, so that's why we don't do it, but if you wanna do it, we can try it. If it'll make you feel like you're having a better chance this month, then let's do it." And she let us do it. She never volunteered that information, but I had read about it... That kind of stuff, you have to just be your own advocate. For me, the way to do that was just to read as much as I could.

While Julia had the advantage of a scientific background, she was not alone in embracing this advocate role. After being repeatedly let down by the medical treatment, advocating for themselves seemed intuitive to most women:

Laura: I used to put a lot of stock in doctors' knowledge and doctors as knowing. Over the years, I've learned that I know myself better than anybody else and I know my body, and I need to be an advocate for myself. I respect people's knowledge, but I always ask for another opinion. I've done a lot of second opinions at this point. I guess what I say is that I'll take their suggestions and their advice under advisement, and make the decision that I think is best for me.

Kate: Information's out there for a reason, we should all be educated, and I do feel like sometimes there's some flaws in the medical system, and you do need to question your own healthcare. You're your only advocate, right? I definitely turned into that... I feel like I'm responsible for relaying all the information – of course, because there's no one else.

Serving as an advocate enabled them to take responsibility for their treatment. Instead of resisting the biomedical model, they were negotiating by attempting to gain more control

over it and the options with which they were provided by it. Additionally, they did not cede the authority to their physicians, but instead delegated themselves as capable of understanding and directing their own treatment from the position of the empowered patient advocate.

Negotiation: Religion, Spirituality, and Magical Thinking. While all previous negotiations have functioned in different ways, they have shared a focus on the body as the site of infertility and different ways of maximizing the impact of treatments. Yet, as in all important experiences, religion and spirituality became a way of understanding infertility for many; in this study, for half of the sample (13 of the 26 participants). For most, it was a simple practice of praying more, or having faith in God's plan for their families.

Rebecca: When I was going through the infertility, I would pray about it a lot... I prayed, and just because I prayed about it doesn't mean... I have to have faith and believe that there's a reason for these things to happen and everything. But I guess my faith is tested a lot. I'd be a good parent. My husband doesn't go to church a lot, I'm not saying he doesn't believe in God, but he doesn't go to church. But then, if we're talking about infertility, there have been times in the past where he's said... "Well, God must not want us to have a child." I just think it's really funny that he says that, because he doesn't go to church. I don't want to blame Him. Maybe He's more of a... well, I know He does great things... but maybe He's more of a passive observer.

Meredith: Personally, I'm not surprised this is how it's unfolded. I never really necessarily pictured myself as having children biologically. I just kind of always had this feeling. I kind of feel like, for me, it's a spiritual thing, trying to discern what God's will might be for your life and trying to go with it and not fight against what life is offering you. The adoption thing is really, really scary; it's this huge thing. My thing is that I want to have that experience with Robert. My thing isn't that I need to be pregnant or I need to have a baby, but I want to be a parent with Robert. I just think that's how it's meant to be.

As a negotiation, religious and spiritual models do not negate the capacity of the biomedical model, but instead hearken back to earlier understandings, in which infertility

and its potential solutions are out of human hands. Thus, spiritual models provide hope: there is a plan, even if it cannot be realized at this moment; with patience, a solution will be found. If treatments fail, it is not because the patient was not “doing everything,” it is because they were not meant to. From this perspective, spiritual models can alleviate self-blame.

However, while many found solace and removal of blame through religion, for others it was a challenge that boiled down to one question: does God want me to suffer?

Sarah: I get teary, cause you sit there [in church] and you listen to the scripture and these homilies that talk about the grace of God and the good things, and all this. And I just kind of sit there and go... He wants me to suffer? But, I've kind of come in the past few weeks to pray for just things in general, and not feel so much that I'm being punished specifically – that He's sitting up there saying “You're going to get pregnant but, oh, I'm going to take it away.” ... And this whole process has made me flip back and forth between a ton of emotions, a ton of feelings, so with religion I feel a back and forth between... there's some sort of grand plan, things will work out when they're supposed to work out verses... what the hell? What's going on?

Janet: It's had a very bad impact on my relationship with God, on my relationship with spirituality and stuff. Just because I'd been so clear – I felt like I'd asked for what I'd wanted, and I'd done all the right things. I led a good life, I'm a decent person, and I felt like I wanted to have a baby for the right reasons, not for some crazy, bad reason or something. We play all these games with God. I hadn't asked for anything like this before. I don't ask God for things all the time. This is the only thing I'd really asked for... Part of me just felt like... God has it out for me. I'm being punished for something that I don't understand. Jews aren't big on God punishing you, but I was having trouble drawing other conclusions.

For these participants, the struggle with these blame-based religious understandings may seem self-punishing, but they are in many ways a natural extension of the “doing everything” approach to treatment: am I truly doing *everything*? Am I being a good enough person? Am I deserving of this? These challenges are another example of where the biomedical model, despite the tremendous burden it can place on patients, can in many ways be less blaming than alternatives.

The final extension of spiritual-type understandings of infertility was through types of magical thinking. In these cases, the participants recognized that their reasoning was irrational, but were still seeking order from the seeming randomness of why treatments were continuing to fail:

Cynthia: There's a couple times when someone's pregnant, and not that I get jealous, but I think... oh, they're pregnant so that means I'm not gonna get pregnant. That crosses my mind. There's a pregnant person so that means I'm not. Also, where there's three... I'll do that too. Someone will tell me someone's pregnant, and there's one, and then the second one, and then the third, and I missed it!

Julia: There were times were I was like... maybe I'm being punished because I married someone that wasn't Jewish. Another friend of mine who also went through infertility, who was also in an interfaith marriage, she used to say the same thing, she's like "I know, I think about that, too." I know deep inside that that's not the reason, but those are some of the things that go through your mind when you're in that position.

This break from logic, which was readily acknowledged by both women, does not necessarily represent a negotiation. Instead, it illustrates the extent to which the need to find meaning, no matter how irrational it may be, drives the experience of infertility. While not a negotiation in and of itself, magic thinking derives from the same need as such negotiations.

For those participants who felt that their spirituality or religion was influencing their understandings of infertility, it was often a very large factor in how they were handling the experience. However, for the majority of people – 14 of the 26 interviewed – there was little or no relationship between this medical diagnosis and their faith.

Kimberly assertively states:

To say that any higher power, whoever it may be, makes these kind of decisions when you see crackheads getting pregnant and people who are malnourished in Africa getting pregnant, with AIDS. It's not... I believe that my body, for some reason, there's something going on. It's not how much I drank in college or anything like that. There's a medical reason for it, it's not because God has so chosen me to be barren... I don't

believe that it has anything to do with a higher power. In my opinion, and again I don't wanna – infertility, it's everyone's choice to believe what they want. I believe that anyway. But if you don't believe in that, I don't think you can believe in evolution. So, I kind of... I guess we'll leave it at that. I find it kind of ignorant.

For Kimberly, and many others who shared her reasoning, seeking spiritual models meant that a higher power had judged her not worthy of being a parent, which she refused to accept.

In many ways, contemporary spiritual and religious models are still reminiscent of the pre-biomedical models. The fact that they still endure is a testament to the continuing ambiguity surrounding infertility. In many ways, the women interviewed here have much in common with the “barren women” of the past. While they may have more insight into their conditions (and many may not), they still do not have ready solutions. Without them, they still look to the same sources of meaning. As a negotiation, this model reveals that infertility is *more* than simply a diagnosis, and treatments are more than simple medical procedures. These treatments are about the process of becoming parents and creating a family. These are the facets that medicine cannot directly address, and that many participants felt were important to finding meaning and seeking comfort during the challenging process.

Negotiation: Extracting Meaning and Reaching Others. Participants also sought meaning in many other ways, outside of the religious and spiritual spheres. This approach serves as a negotiation by imbuing a medical diagnosis, which is typically conceived as objective – with subjective meaning. By extracting meaning, infertility becomes more than a diagnosis; it becomes a catalytic and transformative experience for those going through it. Given the extent to which treatment protocols dominate the

schedules, bodies, and minds of patients, by framing it as a “learning experience,” participants were able to feel they were getting something from failed treatments. While the goal of conceiving a child of course endured, it was no longer just about medical success. Some questioned this premise; Charlotte commented: “In the end... it’s funny, I’ve talked to other people about this before, and it’s like... I need to say anything positive has come from this, aside from a baby. It’s like ‘Oh, well, I learned so much from it’ – this is not an experience I needed to have, you know?!” However, the majority felt that they were better able to approach the experience as not *merely* a biomedical process, but more holistically as a meaningful, subjective, and frequently transformative, experience.

The most common lesson learned was repeated, almost word for word, by many of the women interviewed: “I’m stronger than I ever thought I could be.” Participants who had successfully negotiated and continued with treatments felt empowered by their ability to keep going. Several also said that, despite many challenges to their relationships, they felt that their marriages were stronger than they had previously been, and that they and their partners were better prepared to be parents than they would be had they not gone through infertility. Michelle, who was pregnant with twins through egg donation at the time of her interview, reflects:

I often had strong opinions about things and sometimes could be a little more narrow minded – with things that I wanted for myself. I feel like I was pretty open for other people, but I used to see myself doing it this way, or I used to see myself being that way. And now, after going through this when everything’s been blown, all my ideals have been blown – I didn’t conceive naturally, these children are not genetically tied to me – I didn’t foresee any of this. So it’s made me much more open, and flexible as a person.

Generally, participants considered themselves to have grown through the experience, without having to actively seek lessons learned. As a result of the challenges associated with the patient identity, as with any profound and ongoing personal struggle, it was easy for most to identify lessons learned and strengths gained from the experience.

Frequently, these lessons were framed as being in service of the ultimate goal. For example, they were now more patient, more flexible, more prepared for the unexpected – characteristics which they believed would help them become better parents. Thus, infertility treatments not only served their goal of parenthood through medical accommodation, but by preparing them psychologically, emotionally, and spiritually for the experience of parenthood.

Many participants also created meaning by reaching out to others. The simplest form of reaching out was increasing education amongst women about their own fertility:

Karen: When I started learning how prevalent infertility is, I was just shocked that this is not something that women were told... I think it should be something that girls are taught, you know, in seventh grade when they're talking about reproduction. I think it's imperative that people learn about this.

Many viewed this increase in information as imperative, and suggested many channels through which this might happen: high school health class, early conversations with gynecologists and other health providers, and increased willingness on the part of infertility patients to speak about their experiences. Indeed, this desire to make issues of fertility and the patient experience more visible was often one of the primary motivating reasons why individuals elected to participate in this research. As a negotiation, this reaching out challenges the idea of illness as focused on the self and the individual

patient body, and builds a supportive community between patients while recognizing the non-biological, more subjective aspects of the illness experience.

Beyond sharing information, some participants suggested an alternate way of reaching out to other patients – while at the same time subverting what they viewed as an unjust insurance system – by sharing unneeded medication. After trying to conceive with her own eggs for five years, with a devastating a second trimester pregnancy loss to show for her many efforts, Laura has moved on to egg donation. After stopping her own treatments, she had no use for the drugs she had accumulated:

I had squirreled away and saved up all this fertility medication for me, and then because I didn't need it anymore, I did a random act of kindness on somebody I had met, a friend of a friend of a friend, through the blogs. I showed up on her door step the day I picked my cousin up at the airport – I showed up on this woman's doorstep, I'd never met her before, and gave her all my injectible medications, and she ended up getting pregnant from it. But I didn't even have those to use.

Similarly, even though Kimberly is still pursuing treatment, she receives more drugs per cycle than she needs to use:

At first [my sister-in-law] got pregnant really easily [with treatment], and I was like... "Oh, damn. One IUI and she gets pregnant." Then she has a miscarriage. It's tough. But now, it's interesting that we have become so much closer, her and I. Because we're in this boat. And she lives in Maine and can't do IVF because there's no way they can afford it. So I'm stockpiling drugs for her. We haven't had to do that yet, but I've told her – they give me so much, it's so sad, because there are people that can't afford it and they give me enough for two cycles in one cycle. My fridge is stocked.

For those with insurance coverage, there is sometimes a surplus of medication which can often be safely passed on to other women without such generous coverage. Medication sharing is not only a way of creating personal and social meaning, but also a way of addressing an inherent inequity between those with insurance coverage and without.

Beyond negotiating with the biomedical model, then, this behavior attempts to subvert the structure of the American healthcare system.

All if these ways of extracting meaning – through identifying lessons learned, gleaning strength, reaching out to others, and framing the patient experience as preparation for parenthood – serve not only as coping mechanisms making the infertility experience more manageable, but as a way of bringing personal relevance to the generally impersonal medical paradigm of illness. In this way, these negotiations make the objective biomedical model more subjectively relevant, and imbue science of diagnosis with personally constructed meaning.

Negotiation: Building Alternate Models. For many, it is not merely the adherence to a single negotiation that helps them address the inadequacies of the biomedical approach, but the gradual building of a more personal model which incorporates a wide range of individualized understandings. Often, biology plays a significant, if not dominant, part in this explanation, but it has bolstered a language and framework that makes it quite different from the medical model. Meredith, who has stopped treatment and is pursuing adoption, describes her model:

I feel like why, on the one hand – just, biological fluke. Sometimes I really seriously do wonder why, and it can be rather unnerving when you feel like your body – one of your organs has failed... I always come back to the greater idea of why... you know, this is God's plan for our life. We have so many great things in our life, we have so many blessings, maybe this is what we're destined to do, to provide a nice life for some poor kid or a couple of kids who are living in some shitty orphanage somewhere. Maybe there is some greater purpose to it all. And, even if one does or does not believe in that on that level, it's a good thing. What's bad about it? It seems like it's the right... for me, it feels like the right choice.

Although biology is the primary variable she mentions, she couples it with the word “fluke,” implying a large amount of randomness and reducing it to of little explanatory

value. She moves on to incorporate her religion and her sense of a greater purpose – explanations which reaffirm her decision to follow through with adoption.

Other participants built their models similarly, while coming to drastically different conclusions:

Laura: I think I'm always looking for what I did wrong. Like, I wonder... I was on the birth control pill for years, I was on depo-provera for a long time. I noticed on the egg donation sites that they'll ask if you've ever been on depo. So, I'm questioning whether it was years of trying not to get pregnant through birth control means, chemical means, that could have contributed to it. I thought maybe it was drugs and alcohol from when I was younger, but doctors have said that none of that was a cause of this. Maybe stress, I've thought. I've led a stressful life, what with my mom being sick and my dad also has cancer now. I have a really stressful job. So, I thought maybe stress contributed to it. And maybe, but how do I know? It's not tangible, I can't say for sure that stress caused it, or that *this* caused the stress.

Kimberly: When I look at it as my disease, a disease that I have, I don't think that they have found the reason. I think there's a reason. They just don't know what it is. So, one, it's not unexplained. That term is honestly...I guess it's unfound more than unexplained, because they just don't know. There's gotta be a reason. There's a reason for everything, you could argue. That being said, why do I have it? Then why does anybody have anything that they have? That's a theological question, I guess, I don't know. But, yeah... I feel like there is a medical reason, and that's one of the things that in the back of my mind – if this doesn't work, get a second opinion... And there's so many things that need to come together for this to happen, and all the hormone levels, and everything else, and there's two people involved, as well, it's not just one. So that's what I would say. I would say yes, they haven't figured it out yet. They might never, but there is a reason.

Laura addresses the insufficiencies of the medical model by adding to it, by identifying other factors in her life that may have influenced her diagnosis and the lack of success she found in treatment. In contrast, Kimberly addresses the same inadequacies by focusing on the capacity of the biomedical model to add to itself, through the accumulation of future knowledge. She believes that answers will come through medicine, even if they are not currently offered. Both women recognize the deficits of current medical knowledges; Laura negotiates by offering her own, complementary possible explanations, while Kimberly negotiates by recognizing the limitations of

knowledge as temporary and likely to be resolved through additional discovery and research.

Through these alternate models, which never fully deny the role of biology and the potential of medicine, participants still bring in a wide range of other possibilities that contribute to their infertility such as past behaviors, divine plans, bad luck, karma, stress, and the ever present “undiscovered” factors. These explanations represent the incorporation of participants’ histories, belief systems, and social realities *with* their medical diagnoses and treatment prognoses to build explanatory models for infertility most relevant to them, so that they might move forward with a comprehensive approach that best addresses their needs. The amalgamated models that result reveal the ways in which the biomedical model is not wholly sufficient, and the ways those experiencing infertility negotiate with this insufficiency by building their own explanations.

Challenges and Resistances. Participants were often acutely aware of the shortcomings of interventions and the limits of medical knowledge, an awareness that reflects the lack of explanations or solutions they were given. Only eight couples, a minority of those included, had a diagnosis that was made independently of failed treatments. Thus, most participants began treatments having little or no idea why they were having trouble conceiving on their own, and many continued treatments without any retrospective explanation given for why they were not working. With such a high level of ambiguity, even for those who were able to successfully conceive, it is no wonder that many directly challenged the authoritative knowledge of the biomedical model.

After four years of trying to conceive, one surgery, four failed IUIs, and three failed IVFs, Kimberly's doctor suggested that they changed her medication protocol by altering the timing of her trigger shot (given once per cycle to signal the ovaries to "release" the egg) by an hour. She reflects: "When I heard an hour, I'm like, 'An hour?!' That just seems so... we're dealing with an hour?!" For her, and other participants asked to make seemingly minute changes, the alterations signified a large amount of randomness and guesswork on the part of physicians, which felt inconsistent with their ideas of what "science" and "medicine" should be. Several reflect:

Hannah: It makes me really believe that, if you're an infertility patient, and you manage to get pregnant, it's 80% luck. I very strongly believe that. Because they never figured out what was wrong.

Amy: There's no answer, it's almost more like an art versus a science. Like, come in in two days, let's shoot up your follicles a little bit. Oh look, this one's bigger and that one's smaller. Some days I'm like, I don't even know if they know what they're doing. They're just guessing. And that part is, like, oh my god, you don't know what you're doing and you can't give me an answer and you're a doctor. This is what you do all day, and you can't tell me what's wrong? Like, what do you do with that information? I feel like it's like... let's just inject you with a bunch of drugs and see if this works, and see you later.

Sarah: And because the way they do it, they just kind of shoot it up there and pray – you don't know what the deal really is. It definitely – it really is a hope and a prayer. There are a number of websites and message boards that you read, and women do have success, and it's fabulous. I wish I could be as hopeful. It just wasn't working.

In these descriptions, the treatments are an "art" instead of a "science," based on "guesswork" and "a hope and prayer," and success becomes a matter of "luck." Such language does not merely signify frustration or pessimism; it goes beyond that to reveal an entrenched criticism of the biomedical model and skepticism that Western medicine has the capacity to provide answers not just to their own cases, but infertility as a whole. Even when treatments *do* result in successful pregnancies, that critique endures. Janet,

who did become a mother after six years of treatments, dryly notes: “It’s sort of like they can force the car to start and force it to run and push it down the street, they don’t really know how to fix the car.” Medical solutions are not answers to the “why” of infertility, and because of that, the biomedical model does not comprehensively explain what those going through treatments need it – or something else – to explain.

This tension is not lost on the medical practitioners in the infertility field, either. Charlotte, who was pregnant at the time of her interview, tried for over three years and went through three IUIs, four IVFs, one fetal embryo transfer (FET), and two miscarriages, before she was referred to a hematologist who discovered a rare clotting problem that likely contributed to her pregnancy losses:

[The hematologist’s] idea was basically, “We don’t know a lot about hematology, Factor 5 Leiden just got discovered a couple years ago, and that’s something that has been found to cause gazillions of heart attacks. There’s probably a lot more going on that they don’t know. You’re not a typical case, but maybe five years from now, you’re going to be *the* most typical case of – oh my God, *this* is why all these woman have unexplained infertility.” So, try it and see what happens, and it seems to have worked.

Such recognitions of the limits of medical knowledge seems almost reassuring for participants; it validates the sense they already have that current understandings are *not* sufficient, and the frustration they feel in response to ambiguity is justified. Janet’s reproductive endocrinologist went beyond acknowledging the limits of understanding, to recognizing (albeit ironically) the large part of the *practice* of infertility treatments that is beyond medical control:

I took all of the drugs I had ever taken as part of this protocol, the protocol where they throw every drug they know at you in the highest concentrations they can think of... I was talking to [the doctor] about this, and I said “The previous [protocol] was called the ‘patch protocol,’ what do you call this protocol?” He’s an Orthodox Jew, and he said, “We do have a name – an informal name for it, because it’s not very nice.” And I said “Come on, tell me. What’s the informal name for it?” And he said, “Well, we call it the

Hail Mary.” Basically, it’s your last chance. I thought it was very funny that I got pregnant on the Hail Mary protocol, being Jewish and having an Orthodox Jew treating me.

Here, the doctor himself makes light of the fact that the outcome of infertility treatments is beyond the physician’s control. Similar sentiments were expressed by many participants who repeated their doctor’s words: “I can’t believe that didn’t work!” or, more seriously, “I’m so sorry that didn’t work; I truly don’t know why.” Patients are not the only ones who struggle with the shortcomings of medical knowledge; it seems from the second hand reporting participants that the doctors similarly recognize and are challenged by the deficiencies of the medical model.

Mary, an infertility patient who works as an occupational therapist with patients with brain injuries, grapples with the limits of Western medicine on both personal and professional levels:

I just think it just makes you realize how little we know about the human body. Because, as they say, we have so many hormones in our body, and maybe one of mine is one we don’t even detect, yet. Neurology is another whole thing. Because I deal with stroke patients, and families ask you, “Oh, will they recover?” I don’t have a magic ball. I think the same thing goes for fertility. It’s an art. It’s not a science. It’s not black and white. Nothing in Western medicine is black and white.

This model, like many of the others before, represents a critical deconstruction of the authority, objectivity, and capacity of Western medicine. Given the profound cognitive dissonance that results from the *behaviors* of actively pursuing medical treatment, despite the *beliefs* that the biomedical model is deficient in knowledge and insufficient in practice, the negotiating behaviors in which patients engage seem intuitive ways of coping with a conceptual model that does not fully meet their needs as patients, who want a solution, or people, who want an answer.

Regaining Control. Ultimately, the goal of negotiations and resistances is to regain control within the patient experience. The lack of control was truly scary to many, and it was through adapting the biomedical model that they were able to recapture their sense of empowerment:

Sarah: It's funny, because this process, it's made me feel a little powerless, because as much control as you have over taking your medication on time and seeking out the right doctors, you really have no control over what's happening. But, I know that I can seek out the information that I need to and be proactive when I need to.

Hannah: I felt like I didn't have enough control. Well, you have no control. So, I wanted control wherever I could find it. I mean, if it's only reading or surfing the net, or becoming involved with Resolve, or joining a support group – it was something that made me feel like, at least if I'm not in control of what happens, at least I'm in control of my care... Towards the very end [I felt like I gained control]. I feel like by choosing the doctor I chose, and by choosing to consult with another doctor, and by making the choice to spend June in Israel if we needed to, and adopt... I feel like I was taking back control of the situation. I wasn't gonna leave it up to whoever did my transfer that day.

Mary: This has made me realize that I you really have no control over things. I feel like at some point, I started, not ignoring, but just not always abiding by the rules that [the doctors] give you. I found that by my not exercising, for example, that I really was just not feeling well. So, I actually started to just go back into my regular exercise routine during my last cycle. Learning a balance.

For all of the participants, the need for greater empowerment was palpable and predominant in their accounts. Without it, it was difficult if not impossible to continue to hope that the treatments would work, or that the goal of parenthood would be achieved – regardless of what pathway it takes to get there. Here, these three women are speaking for all the participants who shared their stories, and the constant struggle with ceding control to a model that likely cannot tell you why you are infertile, cannot guarantee that treatments will work, and can rarely offer an explanation for why treatments have failed. To not have control over one's own pursuit of parenthood is a startling and disempowering experience, and through only through the negotiations previously

described were participants able to regain not only their control, but their sense of themselves.

Resolutions: Moving beyond the Patient Identity. For those participants who had ended treatment – either because they had successfully conceived, moved on to adoption, or decided they no longer had the emotional or financial resources or to continue – there was a gradual return to their former selves. These participants gladly shed the patient identity, while still recognizing the enduring changes that going through infertility had made to their lives and personalities:

Hannah: Now I feel like my old self. I feel like things come out of my mouth that I haven't even considered saying in so long. It's like there was this blockage in there, and it's so much... it's so different now that I've reached this point in my pregnancy.

Holly: I am [in a good place]. It's been a while. I just told somebody... if I only have my body back, can I have my life back? Maybe not my whole body, but I feel human again. I feel like I'm part of the world to an extent again, at least. But I'll never be the same. It takes away a little bit of the care-free, everything's perfect, everything works out if you work. That was another book that I had read, that says you were always taught that in school if you study hard and do what you're told and you work hard, you get what you want. You reach the goal. This is something, you can do everything perfect and you're still not gonna reach your goal. So, that kind of hardens, I think it changes you a bit. I'll be changed from it. I'm changed from it. I don't think it's bad, it's just different.

The changes that Holly acknowledges in herself are not the only ones to which she had to adjust. She also spoke at length about “grieving” the loss of the biological child she would never have, while still “embracing” the adopted child she was eagerly anticipating.

All but one female participant anticipated or reported increased anxiety once they became pregnant, going so far as to call it “horrifying” and “nightmarish,” while at the same time being “more grateful” and “more aware.” Additionally, many felt that they would be (or were) different parents than they would have been, had they not gone through infertility. Sarah states: “I'm sure every parent is super thankful and loves their

children, and when they're born, it's this great miracle. But I've *gotta* believe it's gonna be a little bit more so for us." Others shared her thoughts, and went a bit further:

Kelly: When you're initially thinking about [having a baby], you're like... Oh, babies are so cute, dress it up, and everybody will love it. And then the longer you have to wait you think of the crappy moments too. And I'm so ready for that, too. When we have to bring it to the emergency room, or having it get hurt or sick – I'm ready to stay up all night with a sick baby. I want it all.

Julia: There are times I get frustrated being a parent, or my son... he's a healthy, normal child, but he's really active, and there are times I get frustrated. I feel like I'm having a bad mom day, where I do something that I'm like... oh, I shouldn't have done that. There are times where I need to, as frustrating as he can sometimes be, I need to be like, "You know what, I worked really hard to get him, and this is just one of those moments, and it will pass." In that way, I try to look back on my experiences – I could still be trying to get pregnant, and I'm just dealing with a kid who's pulling every Tupperware out of the cabinet.

Meredith: Infertility takes all of the romantic notions that you have of all of the sudden you're pregnant and you have all of these moments that you're gonna experience of telling your husband, telling your family, this and that, to this whole other realm of "Would you take a baby with half an arm?" [when filling out adoption paperwork.] The attachment issues... it's two ends of this spectrum. Sometimes it's hard to negotiate some happy medium somewhere in between them. It's an ultra-realistic approach to parenthood, if not somewhat more focused on the negative aspects.

Infertility changes family-building from the joyous experience that these participants expect it to be into an ongoing struggle that involves many challenges and much compromise. When looking at something as important as how a family is formed or how a mother understands parenthood, the impact can be profound – not just for the impacted family, but for how society conceptualizes of the idea of the family.

These changes are long-lasting. Nicole and Janet, both of whom have successfully had children, still feel the repercussions of infertility in their daily lives:

Nicole: I wonder sometimes if people once they, say, resolve it and get to the baby, do they still think about it, is it still important, everything that they went through? I always get choked up thinking about anything that I ever went through, and I always feel like it's just so fresh, like it was just the other day. And it's been years.

Janet: I feel like I'm not comfortable with the reality that the world works that way. I don't understand why this really unfair thing happened to me... The world is not as trustworthy of a place as it had been.

For Nicole, Janet, and the rest of the participants, infertility had fundamentally changed the way they understood themselves, the way they imagined their families, how they interacted with their partners, the way they envisioned parenthood, and how they understood the world around them. These essential and enduring changes are why it becomes so important for the biomedical model to be deconstructed, so that by recognizing and addressing its insufficiencies patients' needs can be more fully met throughout the course of treatment and beyond.

Discussion

Despite the overwhelming authority of the biomedical model, these participants have shown a complex understanding of their infertility, drawing on old models, building alternate ways of understanding, and infusing meaning in their experiences in a way that challenges the construction of infertility as a purely biological phenomenon. However, in addition to the deficits of the strict medical model, there are benefits to many of these couples as a result of having such a model available. Most powerfully, medicine provides the framework for presenting infertility as a straightforward illness or condition requiring comprehensive treatment. While this objective and uncomplicated model does not, as we have seen, reflect the lived experience of infertility, it does remove many of the very fraught judgments and questions made of and posed to those pursuing treatment. Popular discourse surrounding infertility is generally not accepting of individual's right to pursue treatment, and resolutely opposed to providing insurance coverage for such

procedures. In an online discussion on *The Washington Post's* website specifically discussing coverage (Mundy 2009), comments included:

It's a choice, not a right, to seek these treatments. I'd really like my insurance company to pay for a Botox treatment because I'm older and getting wrinkles. It's cosmetic, not life threatening. To many women, like me, who do not want children, it almost seems like a vanity project that is fed by emotion, the fertility industry and now TV... What happened to Darwinism and survival of the fittest?

Enough already! ... Here's a novel idea -- sometimes you can't have EVERYTHING you want in life and you should count your blessings.

Having your own biological children is not a right and I really wish more people would choose adoption or even becoming foster parents. It may be a more difficult route but it's also one that is very rewarding in the end.

If someone has tried for one whole year to get pregnant, that's not significant. The human body doesn't always work exactly on schedule, and rushing off to spend tens of thousands of dollars on specialists and invasive procedures because one doesn't get pregnant the instant one wishes to, is ludicrous.

Society doesn't accept infertility as a legitimate disease. That is because for most recipients, it isn't a disease -- they've just aged beyond the point were conception is supposed to occur.

These arguments are at the least judgmental, if not ignorant or simply incorrect.

However, they do reflect the many challenges that couples reported hearing from others while they attempted to resolve their infertility: Why don't you just adopt? Why do you really want to be a parent? Why does this deserve to be covered by insurance?⁴ When entrenched in a physically, emotionally, spiritually, and financially draining experience, attempting to answer such question seems an insurmountable task. Citing the biomedical

⁴ These are legitimate questions, and the infertility community can – and *does* – provide answers to them. However, widespread misinformation about the causes and experiences of infertility, along with high profile cases misuses of infertility treatments (such as “The Octomom,” Nadya Suleman, a single mother of fourteen children born within seven years, including octuplets born in January 2009; or even Jon and Kate Gosselin, the parents of twins and sextuplets, whose marriage very publicly dissolved on their reality television show) (Mundy 2009), structures these challenges in a judgmental way that does not recognize the true experience of those with infertility.

model and explaining infertility as a disease becomes a simple way of transferring the authority of medicine to what is, in popular discourse, a questionable and undeserving diagnosis. Thus, even those that are skeptical and challenging of the strict application of the medical model to infertility are still reliant on it to provide a legitimacy which society seems reluctant to cede. Only by embracing biomedicine can the infertility community structure debates about insurance coverage and best practices in a way that will be recognized (if not accepted) by the rest of society. The impact of this benefit cannot be underestimated; it is the reason why, even if individuals' experiences challenge medical authority, the biomedical model remains (and will likely continue to remain) the dominant way of understanding infertility.

Yet, because the biomedical model remains focused on the individual, any benefits derived from its employment (such as the argument for insurance mandates) still structure the problem on this microcosmic level. Furthermore, because insurance mandates have not been shown to reduce racial and socioeconomic disparities (Jain 2006), they do not truly represent a social justice-based solution to the problem of infertility. Instead, social justice efforts should focus on 1) reducing public health disparities in access to all healthcare, in rates of sexually transmitted infections, in access to safe birth control, abortion, and childbirth; 2) improving the safety of workplaces and the environment by reducing potential exposure to toxins that compromise fertility; 3) improving the structure of the American workplace and the gendered division of family labor, so that women and their partners would be better able to accommodate child-rearing earlier in their careers, should they so choose (Shanely and Asch 2009). The

social justice perspective recognizes the interconnectedness of overall wellbeing and the capacity to reproduce, without denying the biomedical model as a solution for those cases where infertility does arise. The two models – the prevention-focused, social justice-oriented, public health framework and the treatment-focused, (re)distributive-oriented use of medicine to justify insurance coverage – are not mutually exclusive. However, employing the former will only strengthen the case of the infertility community in their use of the latter, while at the same time reducing both the scale and disparity of infertility.

An additional benefit of the social justice framework is its attention to the varying experiences of infertility based on race and ethnicity. An oversight of most examinations of contemporary American infertility, which this research neglects to correct, is the incorporation of such diversity. Due to the mandated insurance benefits available to all participants in this study, it is likely that they represented a wider socioeconomic background than most of the infertility patient population; this likelihood is further expressed by subjects' self-evaluations of social class, although quantitative data on this variable was not gathered. Despite this variation, however, the sample remained racially and ethnically homogeneous. Such homogeneity is a disappointing deficit, as cultural variation is extremely likely to lead to different meanings of parenthood, pregnancy, Western medicine, and, consequently, infertility. The greater the cultural variation, the less accessibility to the biomedical model, the more disparate the models (van Balen 2009).

In an essay tellingly entitled “The Only Black Woman Walking the Face of the Earth Who Cannot Have a Baby,” Ceballo (1999) describes how long established images

of black woman as hypersexual and hyperfertile has left black women who struggle with infertility feeling even more isolated. Such isolation makes them less likely than their white peers to pursue treatments, despite being more likely to experience infertility (Jain 2006). Infertility for these women is marked by self-reliance, unspokenness of the problem, reliance on religion and faith, and the internalization of the stereotype that only white women should have difficulty conceiving (Inhorn, et al. 2009; Ceballo 1999). For those black women who do pursue medical treatments, race becomes another ground for conflict with the medical model; providers seemed incredulous when they insisted they had no history of sexually-transmitted infection, abortion, or previous pregnancy to which they could attribute infertility. One woman “developed a cautious, healthy skepticism, of the medical establishment. She relied on their knowledge and services but not without attending to issues of race and condescending paternalism” (Ceballo 1999: 7). Race appears to be another motivation for negotiating with the authority of the medical model, with the most profound negotiation being the drive to avoid treatment all together. Yet, for those who did choose treatment – even if they found race to be another issue that required negotiation – the negotiations themselves did not seem to vary greatly from their non-black counterparts.

Other cultural groups show similar variation in their understandings infertility. Latina women in particular showed high reliance on models involving religion (particularly Catholicism) and the cultural values of *familismo* and *marianismo*, which dictate that marriages without children are unsuccessful, and that women’s self-esteem is derived from her ability to mother. Hispanic couples rarely used the term “infertility,” in

the fear that labeling the condition as such would “jinx” future attempts to conceive (Inhorn, et al, 2009). These alternate models, combined with socioeconomic limitations and language barriers, made them far less likely than non-Hispanic couples to pursue medical treatment. As a result, they were likely to use humoral medicine, massage by a *sobadoro*, and “hot” remedies (to fix a “cold” womb) which were designed to raise body temperature (Inhorn, et al. 2009; Becker, et al. 2006). Such alternate models and therapies show that as the biomedical model becomes more logistically and conceptually inaccessible to various groups, they become significantly more likely to pursue negotiations and exhibit resistance in response to this model.

Facing similar economic constraints and language barriers as many Hispanic families, Arab Americans experienced similarly limited access to the medical model. As an additional prohibitive factor, Islamic scriptures are quite limiting in regards to what treatments they will allow: infertility is understood as “God given,” and gamete donation and adoption are disallowed (Inhorn, et al. 2009; Inhorn and Fakhri 2006). Thus, while many Arab Americans prevail to religious models due to the inaccessibility of the medical model, they find little solace in the very limited solutions that Islam allows. For them, the religious model does not supplement the biomedical model – frequently it supplants medicine as the primary paradigm for understanding infertility and prohibits access to assisted reproductive technologies. This example is perhaps the most direct

conflict between models available to those experiencing infertility, in which an earlier model directly creates a barrier to treatment.⁵

Overall, future research efforts into how individuals experiencing infertility interact with the medical model ought to focus on incorporating a great diversity of experience, including not just racial and ethnic variation, but more male voices as well. While this project has included as many male partners as were willing to participate, and while the non-response of men has been well-established on this subject (Lloyd 1996), the fact that men seem more likely to embrace the authority of medicine and have faith in its ability to provide a solution warrants a continued exploration as to whether this gender difference is generalizable and enduring across medical fields.

While broader incorporation of more a more diverse patient population will provide greater insight into an even wider spectrum of negotiations, resistances, and alternate models, the diversity of responses that emerged from these participants reveals the complexity and struggle of the infertility experience, even within a relatively similar segment of the population. Their experiences provide not only insight into their personal challenging of the biomedical model as a means of regaining control, but also the acceptance of that deficient model on a community level as a means of presenting with legitimacy. The key to better addressing the shortcomings of the biomedical model is not to refute the biological basis for infertility or to deny the medical setting as a place for

⁵ While strict Catholicism could present the same barrier that strict Islam does to the use of some reproductive technologies (particularly IVF), it did not present as a barrier to any of the Catholic participants, who chose simply to ignore their church's objects. Whether Muslim Americans would be similarly willing to pursue treatments that are denied by their faith remains to be examined.

treatment, but instead to build a more holistic approach which 1) acknowledges infertility as a public health (and not just individual) problem, which is often preventable; 2) returns control to the individual and the couple, to help make all options for family-building – including treatment – more accessible to all groups; and 3) incorporates individuals’ beliefs and needs as valid and valuable contributions to the treatment process. Most importantly, the legitimacy of infertility must be derived from the suffering and challenges inherent in the experience, and *not* from a biomedical model that neglects to meet the needs of those who must operate under its constraints.

References

- Becker, G., M. Castrillo, R. Jackson, and R. Nachtigall. 2006. “Infertility among low-income Latinos.” *Fertility and Sterility* 85(4): 882-887.
- Becker, G. 2000. *The Elusive Embryo: How Men and Women Approach New Reproductive Technologies*. University of California Press: Berkeley.
- Bitler, M. and L. Schmidt. 2006. “Health disparities and infertility: impacts of state-level insurance mandates.” *Fertility and Sterility* 85(4): 858-865.
- Boivin, J. and L. Schmidt. 2005. “Infertility-related stress in men and women predicts treatment outcome one year later.” *Fertility and Sterility* 83(6): 1745-1752.
- Ceballo, R. 1999. “The Only Black Woman Walking the Face of the Earth Who Cannot Have a Baby” in *Women’s Untold Stories: Breaking Silence, Talking Back, Voicing Complexity*. Ed. M. Romero and A. Stewart. Routledge: New York.
- Davis-Floyd, R. 2003. *Birth as an American Rite of Passage*. U. of California Press: Berkeley.
- Dayal, M., P. Gindoff, A. Dubey, T. Spitzer, A. Bergin, D. Peak, and D. Frankfurter. 2009. “Does ethnicity influence in vitro fertilization (IVF) birth outcomes?” *Fertility and Sterility* 91(6): 2414-2418.
- Domar, A. 2004. “Impact of psychological factors on dropout rates in insured fertility patients.” *Fertility and Sterility* 81(2): 271-273.
- Domar, A. and J. Boivin. 2007. “Two Views: Should mental health professionals encourage infertile patients to try complementary therapies?” *Sexuality, Reproduction, and Menopause* April 2007.
- Engel, G. 1977. “The Need for a New Medical Model: A Challenge for Biomedicine.” *Science* 196(4286) 129-136.

- Foucault, M. 1978. *The History of Sexuality*. Knopf Publishing Group: New York.
- Greil, A. 2002. "Medicalization, Metaphor, and Agency" in *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*. Ed. M. Inhorn and F. van Balen. University of California Press: Berkeley.
- Henne, M. and M. K. Bundorf. 2008. "Insurance mandates and trends in infertility treatments." *Fertility and Sterility* 89(1): 66-73.
- Inhorn, M., R. Ceballo, and R. Nachtigall. 2009. "Marginalized, Invisible, and Unwanted: American Minority Struggles with Infertility and Assisted Conception" in *Marginalized Reproduction: Ethnicity, Inferility, and Reproductive Technologies*. Ed. L. Culley, N. Hudson, and F. Van Rooij. Earthscan: London.
- Inhorn, M. and M. Fakih. 2006. "Arab Americans, African Americans, and infertility: barriers to reproduction and medical care." *Fertility and Sterility* 85(4): 844-852.
- Jain, T. 2006. "Socioeconomic and racial disparities among infertility patients seeking care." *Fertility and Sterility* 85(4): 876-881.
- Jain, T and M. Hornstein. 2005. "Disparities in access to infertility services in a state with mandated insurance coverage." *Fertility and Sterility* 84(1): 221-223.
- Kielmann, K. 1998. "Barren ground: contesting identities of infertile women in Pemba, Tanzania" in *Pragmatic Women and Body Politics*. Ed. M. Lock and P. Kaufert. Cambridge University Press: Cambridge.
- Lloyd, M. 1996. "Condemned to be meaningful: Non-response in studies of men and infertility." *Sociology of Health and Illness* 18(4): 433-454.
- Marsh, M. and W. Ronner. 1996. *The Empty Cradle: Infertility in America from Colonial Times to the Present*. The Johns Hopkins University Press: Baltimore.
- Massachusetts General Law, Chapter 175, Section 47H. 1987. "Infertility; pregnancy related benefits."
- Miles, M. and A. M. Huberman. 1984. *Qualitative Data Analysis: A Source Book of New Methods*. Sage Publications: Beverly Hills.
- McGuffey, C. S. 2008. "'Saving Masculinity': Gender, Reaffirmation, Sexuality, Race, and Parental Responses to Male Child Sexual Abuse." *Social Problems* 55(2):216-237.
- Mundy, L. "Jon and Kate Plus Healthcare." *The Washington Post*. June 29, 2009. Online discussion available: washingtonpost.com/wp-dyn/content/discussion/2009/06/26/DI2009062603401.html
- Roberts, D. 1997. *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*. Vintage Books, Random House: New York.
- Rothamn, B. K. 1989. *Recreating Motherhood: Ideology and Technology in a Patriarchal Society*. W. W. Norton & Company: New York.
- Sandelowski, M. 1995. "A Theory of the Transition to Parenthood of Infertile Couples." *Research in Nursing and Health* 18(2): 123-132.

- Sandelowski, M. 1990. "Failures of Volition: Female Agency and Infertility in Historical Perspective" in *Ties That Bind: Essays on Mothering and Patriarchy*. Ed. J. O'Barr, D. Pope, and M. Wyer. University of Chicago Press: Chicago.
- Sandelowski, M. 1987. "The Color Gray: Ambiguity and Infertility." *Image: Journal of Nursing Scholarship* 19(2): 70-74.
- Schmidt, L. 2006. "Effects of infertility insurance mandates on fertility." *Journal of Health Economics* 26: 431-446.
- Seifer, D., L. Frazier, and D. Grainger. 2008. "Disparity in assisted reproductive technologies outcomes in black women compared with white women." *Fertility and Sterility* 90(5): 1701-1710.
- Shanely, M. and A. Asch. 2009. "Involuntary Childlessness, Reproductive Technology, and Social Justice: The Medical Mask on Social Illness." *Signs: Journal of Women in Culture and Society* 34(4): 851-874.
- Van Balen, F. 2009. "Infertility and Culture: Explanations, Implications, and Dilemmas" in *Marginalized Reproduction: Ethnicity, Infertility, and Reproductive Technologies*. Ed. L. Culley, N. Hudson, and F. Van Rooij. Earthscan: London.
- Van den Akker, O. 2001. "The acceptable face of parenthood: the relative status of biological and cultural interpretations of offspring in infertility treatment." *Psychology, Evolution, and Gender* 3(2): 137-153.
- Wellons, M., C. Lewis, S. Schwartz, E. Gunderson, P. Schreiner, B. Sternfeld, J. Richman, C. Sites, and D. Siscovick. 2008. "Racial difference in self-reported infertility and risk factors for infertility in a cohort of black and white women: The CARDIA Women's Study." *Fertility and Sterility* 90(5): 1640-1648.
- Zelizer, V. 1985. *Pricing the Priceless Child: The Changing Social Value of Children*. Basic Books, Inc.: New York.

Appendix A Interview Guide

Introductory Script: Thanks very much for taking the time to speak with me. Your input is invaluable to informing my research. Although many of the questions are quite personal and will ask you to describe your decision-making process, please know that I'm not asking you to defend your decisions, but simply to provide me with greater insight into them. All of your responses will be treated with the utmost confidentiality and respect. That being said, if you feel that any of the questions are asking information which you would rather not share, please feel comfortable letting me know and we can move on to a different area of discussion.

Background information: Current age, partner's current age, profession, education, length of relationship, length of time trying to conceive.

I'm interested in learning about when you first decided to try to get pregnant. How old were you at the time? How long had you and your partner been together? Ideally, how many children were you hoping to have when you first decided to start a family? Did you anticipate that you would have difficulties conceiving?

When did you first decide to seek medical advice or intervention for help getting pregnant? How long had you been trying to conceive at the time? Please describe what initial testing, treatments, or modifications were suggested by your healthcare provider, and which suggestions you and your partner adopted. How were you feeling at this point about your body? How were you feeling about your prospects of conceiving?

Did you and/or your partner have any medically diagnosable conditions that contributed to your difficulty conceiving? If so, how did you feel about this diagnosis? If not, how did you feel about the lack of diagnosis? How did this influence your feelings about your body?

Have you sought any forms of treatment not directly recommended by your physician? How did you come to learn about them or what made you want to try them? Do you feel these measures were at all effective? How did they make you feel about your doctor's understanding of and approach to your infertility? How did they make you feel about your own infertility?

How has your partner responded toward your struggles as a couple to conceive? Has this process changed your relationship? In what way?

How has your experience with infertility changed your understanding of pregnancy? Of parenthood?

How has your religion or spirituality influenced or been influenced by your experience with infertility?

What support systems have you utilized during your time trying to conceive? How do you think this influenced your ability or willingness to continue trying to conceive?

Why do you think you're infertile?

Have you learned anything from your infertility?

Has your difficulty conceiving resulted in any changes in your life that we haven't yet discussed?