

**“Choosing” Parenthood through Fertility Treatments: The Importance of Biological Children and the Difficult Roads in their Pursuit**

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IMPORTANCE OF BIOLOGICAL CHILDREN AND THE DIFFICULT ROADS  
IN THEIR PURSUIT**

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In memory of Hanni, my grad school cat.

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## **Abstract**

This dissertation is a qualitative study based on 28 interviews with both women and men who have used, or are currently in the process of using, any type of fertility treatment. My major research question is what is the social process of fertility treatments? In pursuing that question, I also ask why do people want their own biological children? How do people understand genetics? What is the diagnostic process of fertility treatments and what are the gendered implications? What is the treatment process? How do people view the treatment they received and what amount of agency did they take in their care?

My first analytical chapter finds that majority of the men in the study felt strongly about having a genetic connection to their own child, and both men and women wanted a biological child in order to fit into a “normal” family model. Even if using donor genetic material to accomplish that goal, having a biological connection made them feel like they had some control over their child’s physical, health, and personality traits. I also find that both men and women have an simplistic view of genetics. The second analytical chapter finds that women initiated contact with the medical community and their bodies were the focus of fertility testing and treatment. Receiving an infertility diagnosis mostly had negative effects on women, such as anger, guilt, and blame. Further, I posit that the specific diagnosis of polycystic ovarian syndrome is a new case of the medicalization of women’s bodies. The third

analytical chapter explicitly outlines the numerous physical and emotional difficulties of going through the treatment process. Finally, chapter seven explores the relationships between physicians and their patients. In it, I outline some questionable physician behaviors and attitudes and find that patients responded in various ways, from deference to physician authority, to taking agency in self-help, to switching physicians, and exploring alternative treatments.

## **Chapter One: Introduction**

### **Background**

This study is an exploration of the social processes of fertility treatments. In it, I explore the experiences of individuals who have pursued fertility treatments in their effort to have children. Fifty years ago, infertility was a “non-issue” as the topic was not discussed socially and little was known about it scientifically. Now, however, there are countless media reports, more infertile women in the population, and a larger proportion of infertile couples seeking treatment in a fertility industry (Balasch 2000) that is estimated at 3 billion dollars annually (Sabourin 2006). Rates of voluntary childless marriages in the U.S. have grown since the 1970s but still remain quite low; for most of this century the rate has ranged from 5-10 percent. Rates of involuntary childlessness are also increasing. According to the medical industry, a couple is considered infertile if neither spouse is surgically sterile, they were having frequent enough intercourse, had not used contraception, and had not become pregnant during the past 12 months or longer (CDC 2008).

The Center for Disease Control (CDC) reports that in 2002, 7% of married couples experienced infertility (CDC 2008). By 2007, it was reported that 1 in 7 men and women experience infertility (Mundy 2007). As is the case with other health care services in the US, the poor cannot afford to seek

medical help for infertility as the average cost of treatments thousands of dollars. At the low end one can spend a few hundred dollars if initial drug therapies are successful, and at the high end one can spend over \$100,000 on surrogacy (Mundy 2007). Others, however, are able to afford these costs and the CDC reports that by 2004 12% of women of childbearing age in the United States received an infertility service, which equates to hundreds of thousands of treatment cycles. Interestingly, women under 35 years old are by far the largest group of women using high impact fertility treatments such as in-vitro fertilization (CDC 2008).

Further, this is a global phenomenon. Fertility treatments are not only used in other advanced countries but services cross borders. For example, some women in the US order sperm from Scandinavian countries in order to get a certain ethnic background (Mundy 2007) and wealthy couples in the US “rent out wombs” of surrogate mothers in India (Kuczinsky 2008). Today’s failing global economy only perpetuates the selling of bodies and body parts (Kuczinsky 2008; Beck 2008).

## **My Study**

As a graduate student I spent years immersed in studying gender, the body, medical sociology and the sociology of families literatures until the light bulb went off in my head that studying issues surrounding fertility treatments would bridge these literatures and tap into my knowledge base.

The rising trends in infertility and fertility treatment usage, especially among younger women, begs for sociological analysis, yet research in general on infertility remains sparse. Given that the first successful in-vitro fertilization took place a mere 30 years old there is yet to be a large body of knowledge on the subject. Further, because this medical specialty of reproductive endocrinology is constantly changing and being refined, each study lends a new snapshot of the current situation. Currently most sociological literature on fertility treatments is focused on the ideas of family formation and bonding based on qualitative studies or is theoretical. Further, most studies focus on in-vitro fertilization, surrogacy, or sperm insemination but omit the pharmaceutical treatments and egg donation. Whereas most studies focus on women there is a small and growing literature on men.

This study is an exploration of the social processes of infertility treatment. I look at 28 people's motivations to pursue fertility treatments and their subsequent experiences with fertility treatments. This dissertation follows these people's stories sequentially, beginning with their desires for children and ending with the success or failure of fertility treatments. Several interrelated research questions guide this study. I am primarily interested in understanding why couples choose to pursue medical treatment for infertility and their perceptions of the experience of being treated for infertility but then I also look at why people want their own biological children. How do people understand genetics? What is the diagnostic process of fertility treatments

and what are the gendered implications? What is the treatment process? How do people view the treatment they received and what amount of agency did they take in their care?

The study is ethnographic in its use of interview data and is guided by the tenets of symbolic interactionism in its focus on social processes and meanings. My major findings are that my male respondents feel strongly about having a genetic link to their offspring, and both men and women want biological children in order to construct a “normal” family, even if this requires using donor genetic material. Further, they believe that having a biological link to their children increases their chances for controlling their children’s traits as they tend to have simplified views of genetics. I also find that the infertility diagnosis is somewhat arbitrary, yet almost always focused on the woman’s body, which puts women through a great amount of psychological and physical pain. I also contend that the diagnosis of polycystic ovarian syndrome is a new case of the medicalization of women’s bodies. The treatment process is equally, if not more so, trying as it disrupts peoples schedules, inter-personal relationships, makes many impose isolationist lifestyles upon themselves, and takes a huge emotional and physical toll on women’s bodies. Many report some insensitive, impersonal physician treatment during their course of treatments and some women respond to the diagnosis and treatment with deference to physician authority, whereas

others become disillusioned during the process and take an amount of patient agency such as self-education or even seeing homeopathic doctors.

These people's stories are divided into four analytical chapters, each discussing the different sociological issues that arise in the different segments of these people's journeys. I outline these chapters in the paragraphs below.

Chapter Two, my literature review, delves into three main bodies of sociology literature. The first is from the sociology of families theories on parenthood. Not only is this literature a good fit as I explore people's motivations to become parents in my analysis, but the study of how families are constructed based on cultural and legal norms is pivotal to this research. . The family has so many expectations, ideals and myths surrounding it. Families are the basic building blocks of society, biologically and socially creating future history. Families are primary agents of socialization both as children form into adults, and it continues to play a significant role in the lives of family members even after children leave home. . Families shape our social statuses and their influences can be seen in many other social contexts.

Families have changed dramatically over the past few decades, from household composition, to views on parenting behaviors, to the number of and role that children play. The postmodern family is more fluid in constructions of biology due to reproductive technologies with donor egg and donor sperm. Have these new family forms shifted people's ideas of family?

As such, I explore people's conceptions of what family means as they attempt to create a biological, and possibly genetic, family.

The second main body of literature comes from medical sociology. In the US, medical sociologists have a long history of analyzing health care practitioners, health care settings, types of health insurance and their implications, and the relationship between doctors and patients. Since the 1960s medical sociology has turned a more critical eye to the institution of medicine as large themes of class, race, and gender privilege emerge. This becomes helpful in my analysis of the for-profit fertility industry, the medicalization of women's bodies, physician-patient interactions, and patient agency.

Last, I outline the current sociological studies on fertility treatments to provide the background for my research and findings, which mostly reinforce the existing literature. I also point out what is still lacking in this literature, which paves the way for some of my new findings.

In Chapter Three, my methods chapter, I discuss how I gathered all 28 interviews then present demographic information of my sample such as race, gender, sexual orientation, age, treatment length and type of treatment, as well as treatment outcome. Last, I discuss grounded theory as it applies to qualitative data generally then how I specifically used it to analyze my data.

My analyses chapters follow these individuals' stories sequentially. In Chapter 4 I start with the basic question of why respondents decided they



wanted to have children, and why it was important for them to have their own biological children. In Chapter Five I focus on their journeys as they go through the process of seeking a medical diagnosis and deciding to pursue medical treatment for infertility. . In Chapter Six we see the many emotional and physical trials and tribulations of undergoing fertility treatments and in Chapter Seven we see patient thoughts on how they were treated by physicians and their reactions. Finally, Chapter Eight is a discussion of my major findings, larger societal implications, and suggestions for future research.

## **Chapter Two: Literature Review**

### **Introduction**

This study is an exploration of the experiences of couples who pursue fertility treatment in order to have their own biological children. To situate the study in the context of sociological literature, I examine their views of family and genetics, and their experiences with the infertility diagnosis, the fertility treatment process, and reactions to their medical care. This literature review draws on three main bodies of work. First, I look at sociology of families literature on theories of why people want to become parents, specifically the sociobiological, social psychological, and other sociological perspectives and their applications to fertility treatment studies. This chapter then reviews relevant aspects of dominant sociology theories --structural functionalist, political economy, symbolic interactionist, and postmodern theories-- that they apply to my analysis of fertility treatment recipients and other related medical sociology studies. I then give an overview of the history and types of fertility treatments and sociological studies on fertility treatments as these too serve as comparisons to my study.

### **Brief History of Parenthood**

The biological production of children was historically seen as the natural outcome of marriage. Short of sexual abstinence, herbal vaginal suppositories and cervical caps, the rhythm method, or crude forms of

abortion there was little a sexually active couple could do to prevent pregnancies. Over time, the value of children in families increased. Children may have been a hardship in foraging societies based on subsistence economies where the food supply was limited, but with the emergence of settled agricultural societies children became seen as an important economic asset. Women in colonial America gave birth to an average of eight children yet household size was smaller than that due to the high child mortality rate (Grabill et al 1973). Although there is disagreement on the exact number of the average household, it ranged from five to seven persons, including slaves and servants (Demos 1972). At this point children were the property of fathers and the community-at-large as well (Demos 1986; Mintz and Kellogg 1989).

As industrialization emerged as the dominant economic system and brought more people to the cities, children were not needed for their labor on the land. This, coupled with the voluntary motherhood and birth control movement, changed fertility rates as people had fewer children, spaced them closer together, and ceased childbearing at earlier ages (Mintz and Kellogg 1989). Childbearing, once taken for granted now, became an option even though the value placed on children increased as they were seen as the emotional center of families, which in turn created higher expectations of what parents should provide. Further, the separation of work from the home created a division between public and private spheres. As white, middle-

class women began to stay home in this period they began to take control over the “private sphere” and claim the duties and importance of mothering (Bernard 1974), also known as “the cult of true womanhood” (Welter 1973).

The separate spheres of family life and responsibilities became the American ideal until white women pushed to work outside the home in the 1970s (Bernard 1974), yet still today many institutions and cultural ideas are still organized around some semblance of the separate spheres ideology with an emphasis on the nurturing and socializing aspects of motherhood (Miall and March 2003; Wall and Arnold 2007).

### **Theories of Parenthood**

Having and rearing children continues to be important to the vast majority of couples. Theorists have sought to understand this desire for children, and the theories generated can mainly fit into the three categories of sociobiology, social psychology, and social/cultural theories. In this section I outline these theories and bring in relevant findings on parenthood or fertility treatments more specifically that fortify or contradict these theories.

In reference to my study specifically, the motivations for parenthood that my respondents report can be framed by biological, sociobiological, or social/cultural theories. My study is not designed to “prove” or show more psychological factors but there are hints of psychological desires for wanting children.

## **Sociobiology**

When social and biological scientists began to theorize about the desire for children many assumed that it was innate. Rossi's (1977) earlier work is one bioevolutionary account of how the sexual division of labor essential to hunter-gatherers became built into the human physiology and thus women have a hardwired "maternal instinct." Rossi's later bioevolutionary approach (see Rossi and Rossi 1990) merged sex and gender: "...women have a physiological edge in attachment to infants that is inherent in pregnancy and birthing, which is further intensified by the fact that women do the major job of parenting young children" (p.18/19) due to economic factors. Then gender socialization equips girls to have better parental skills by the time they reach adulthood.

Few current sociologists are sociobiologists, and many critique this theory as essentialism and argue that one cannot discount social pressures nor the many "outliers" of women *not* wanting children such as nuns or those who engage in infanticide and abortion. The biological approach is also challenged by the fact that some non-human animals also do not want their babies (Bernard 1974). Many in the general population, however, believe in natural or instinctive urges to mother, or more recently genetic influences, in part because this is the current rhetoric coming from scientific and medical communities (Kahn 1995). Yet this is not the only ideological influence: Bobel's (2002) interviews of "natural mothers" reveal women who eschew

medical models and adhere to such philosophies as home birth, home schooling, homeopathy, and stay at home mothering believe that their way of mothering is a genetic need, intuitive, and instinctual. When asked why all mothers do not mother in this instinctual fashion, they have no answer or think that working mothers have a false consciousness that drives them to be too materialistic.

Arendell (2000) and McDaniel (1988) state that an ideology of natural mothering holds strong within culture despite the diversity of family forms and significant changes in women's other roles. Even some of the childless women who Fisher (1992) interviewed report having physical needs to be pregnant, give birth, and/or breastfeed yet do not want to raise children. Whereas pregnancy, birth, and breastfeeding are biological processes, these women do not address their socially constructed ideas elements, or the meanings that our cultures attach to make them important.

Many studies also find that many women who have gone through fertility treatments have strong ideologies based on biological family and never seriously considered alternative paths to parenthood (Crowe 1985; Parry 2005; Roberts 1998; Ulrich and Weatherall 2000; Williams 1990). As Miall (1987) states, a traditional ideology of family is like a gold standard and has led to the social construction and medicalization of infertility. To Bartholet (1994) this shows that assisted reproductive technologies capitalize on deeply

rooted *social* biases that ultimately ignore children that need good adoptive homes.

Where do men and fathering fit into the picture? Miall and March (2003) found that men are more likely than women to embrace a sociobiological view of motherhood, stressing the role of female biology in predisposing women to motherhood yet many also noted that they have observed that not all women have the instinct. Many in the study also felt that fatherhood is more learned than instinctual. Those who thought that fatherhood was instinctive focused on the act of sex itself or the desire to pass on genes. Neither men nor women talk about women having instinct to have sex thus "fathering" a child means impregnation and "mothering" means nurturing and some women in Crowe's (1985) study said their husbands would rather have no children over adopting because they did not think they could fully bond with someone else's biological children.

Parry (2005) found that most respondents have what she calls heteronormative ideas about family where they equate marriage with children, especially biological children, as natural life course steps and thus use fertility treatments to maintain this ideology. Those who successfully conceived became even more committed to traditional ideas of biological family. When Parry (2005) asks why biological children are so important to their conceptualizations of family, many women express a desire to pass on their genetic material due to a biological urge (p. 282). They also state that they

want children who have both physical and personality traits of themselves and their husbands, but the study does not fully discuss why these traits are important to the respondents. For other respondents this connects to how they plan on parenting, thinking that they know a child's potential based on his/her genes. Those who were unable to conceive broadened their perspective of who could be defined as family realizing that the goal was to parent and have emotional intimacy, irrespective of biology or pregnancy. For example, they included friends as family members, and one couple adopted children and allowed the children's biological parents to be part of their lives.

Thompson (2005) also points out the general binary thinking that most have where there are two biological parents; kin is divided into blood relations and non-blood relations, yet acknowledges that others refute the strict biological interpretation and say that gestating a baby is a more intimate biological connection that is uniquely characteristic of motherhood.

### **Social Psychology**

A second set of theories have looked more at the social psychological basis for parenthood, especially for women. Chodorow (1978) still remains one of the best known in the field of feminist psychoanalysis as she asks why women mother, stating that mothering is not merely a set of activities that someone can be trained or forced to perform. As such, she denies bioevolutionary and role learning theories, and criticizes past psychological



works that ignore women. Instead, she reinterprets past psychoanalytic theories based on clinical case studies because she believes that psychoanalysis offers "an analysis and critique of the reproduction of sex and gender" on unconscious and affective (ideas, wishes) levels (p.40).

Chodorow (1978) focuses on how certain psychological capacities are necessary in order to mother and how parenting affects children's unconscious psychic structures and processes. She states that current familial arrangements of female dominated childcare is taken for granted because women are the ones who get pregnant and breastfeed, but this does not mean that *childcare* necessarily has a biological connection to women as the task requires socializing and nurturing a child. She concludes that larger structural factors, such as the economy, affect the organization of gender roles. Women's mothering, then, is a result of a male dominated public sphere.

Both Chodorow (1978) and her contemporary, Dinnerstein (1976), assume heterosexual parenting and believe this mothering arrangement is a central element in the social organization of gender, which is then reproduced in children through personality development-- women produce daughters with the desire and capability to mother and thus women mother because they find it gratifying and/or empowering. Chodorow's (1978) feminism emerges as she writes of a psychological need in women to maintain traditional gender roles, which reproduce gendered ideologies, including male dominance.

Critiques of Chodorow (1978) include her theory containing contradictions due to the merging of different types of psychoanalysis (DiQuinzio 1999). Bart (1984) says that Chodorow (1978) does not account for women who reject motherhood, or class or race differences and that both she and Dinnerstein (1976) attribute problems between the genders to socialization by the mother (mother blame) and say this will go away when men do childrearing.

There is also a body of psychology literature on parental motivation that can complement sociological theories. These discuss the love of children, obtaining pride and achievement from parenthood, finding pleasure in childrearing activities and companionship of children, the desires to establish a close relationship with another human being and actively participate in a child's development and education (O'Laughlin and Anderson 2001).

### **Social/Cultural Theories**

Finally, sociological theories have looked at how dominant ideologies and social structures shape the decision to parent. Parenthood has long been a socially and culturally defined vital role for married couples with mothers and fathers having separate and distinct roles (Wall and Arnold 2007). Current sociological studies on parenting attitudes show that although fathers are now presented as being more involved, media presentations still

position mothers as primary parents with particular parenting roles (Wall and Arnold 2007). Seventy-six percent of respondents in Miall and March's (2003) large-scale study felt that motherhood was a very important role for women, and 55% of men and 73% of women felt that fatherhood was an important role for men (but not as important as motherhood is for women) because it provided the family with stability. Fathers had different qualities to contribute: leaders, guides, breadwinners. A minority thought that fatherhood is not too important because work roles provide men more rewards than fatherhood.

### Feminist Critique

Because motherhood is such a culturally important role for women, some feminist scholars see motherhood as "an impediment in the effort to define female identity outside the essentializing discourse of motherhood" (Grob and Rothman 2005). They critique a pronatalist ideology where a person's social value is linked to biological procreation, with a strong connection between femininity and motherhood (Bartholet 1994; Crowe 1985; Fisher 1992; Ulrich and Weatherall 2000; Williams 1990) that restricts women from participating in institutions structured around the male body such as work, politics, military (Bernard 1974; Kahn 1995). Feminists have been quite critical of the structural functionalist view motherhood as the sole or primary

occupation for women, and Davis (1993) believes that fertility treatments maintain this ideology.

Because of dominant ideologies, some women, especially those who are younger, feel a sense of familial responsibility to their parents and/or husbands to have (biological) children (Fisher 1992) and feel guilty and ashamed if they cannot (Williams 1990). (Why these have to be biological children is a question that remains unexplored in this, and other, studies.) From a socialization perspective, one outcome of the pressure placed on women to mother polarizes mothers and childless women (also see hooks 1984; Rich 1980). Greil et al (1988) interviewed infertile women who believe that being childless holds a social stigma, and some childless women are even called “selfish” (Fisher 1992: 46).

Some literature notes positive aspects seeing pregnancy and childbirth being a potential source of power for women. Many respondents in several studies (see Miall and March’s 2003; Ulrich and Weatherall 2000) thought that motherhood was fulfilling and important to their self-development. It made them feel worthwhile and gave them a new perspective on life that was beneficial, rewarding, and built character.

Although dominant ideologies uphold the value of motherhood, women have choices about how, if, and when to assume that role. Those choices are influenced by such factors as family and cultural histories, financial and material resources, place in the marriage market, political and legal

conditions, medical options, and the physical and mental health of women and those close to them. Thus, as circumstances change, so might choices as well as the meaning of family/childlessness (Fisher 1992).

The meaning and performance of motherhood also varies based on other social statuses such as sexual orientation (see Bos et al 2003), or one's class and/or racial background (see Brooke and Bigner 1991). Mainstream ideologies about motherhood often reflect a white, heterosexual, middle-class bias (Bobel 2002; Davis 1993; hooks 1984). Whereas mainstream feminism has often focused on the costs of motherhood, women of color have looked at motherhood as a source of activism for women, and a source of meaning and control for women or teenagers in an otherwise harsh world. There are also rewards and high costs of motherhood as well as kinship and friendship networks to rely on for childcare (Collins 1991; Davis 1993; Hill 2005; Hondagneu-Sotelo 2005).

It is not surprising that research shows that infertility is more stressful for women and affects their feelings of self worth. They even often take responsibility for infertility, regardless of which partner is actually infertile (Greil et al 1988; Jordan and Revenson 1999). Less is known about how men feel as Martin-Matthews et al (1994) find that women are more open to talking about their infertility. Jordan and Revenson (1999) find that there are more similarities than differences in how husbands and wives cope with infertility yet on the other hand Griel et al (1988) find that women and men

deal with infertility issues differently. There are also a few studies on fertility treatments that include men that find that masculinity affects the roles the men see themselves as playing (see Webb and Daniluk 1999). These findings segway and overlap into the medical sociology literature.

### **Medical Sociology Theories**

While family and feminist theories have debated the motivations for and consequences of motherhood, the fact remains that most women want children, and many who are unable to have them turn to fertility treatments. Most literature on fertility treatments currently is situated within the families and/or feminist literature. The bulk of my analytical chapters take a different approach as medical sociology theories help us to understand the experiences of those who decide to deal with their inability to have children by seeking a medical help. My analysis draws upon the four major theories in [medical] sociology outlined below, as well as other literature in medical sociology.

### **Structural Functionalism**

The earliest of these theories, structural functionalism, offers some insights into the traditional doctor-patient relationship, one based on physician authority and patient compliance to all treatment regimens. Talcott Parsons' (1952, 1964) analysis of the medical field focuses on the complementary roles of physicians, patients, and their families and how the medical system

acts on conscious and unconscious levels as an agent of ideological and direct social control for both patient and physician. The medical diagnosis puts the person into a “sick role” that essentially becomes an achieved master status as it requires an active duty to see a physician and the passive roles of avoidance of obligations of other membership statuses (Gerhardt 1991). This sets the tone for my analysis on patient agency and patient status.

### **Political Economy**

Political economic sociologists mostly take a macro approach in studying the effects of the power and control that rest in the hands of the few who own the means of production in the US and globally as they create consumer dependence on medicine. The subsequent economic inequality is reflected in health care, one of the biggest industries in the US driven by politics and corporate will rather than popular opinion with an increasing disparity of who can or cannot receive medical services (de Kadt 1982; Navarro 1984; Waitzkin 2000), which is especially poignant in the fertility for-profit industry.

Newer writing on medicalization, what is now called “biomedicalization,” also incorporates the larger industry profit motives in creating medical definitions for natural processes that require medical intervention (Clarke et al 2003; Conrad 2005). I explore this concept as I

examine the diagnostic process in terms of the (bio)medicalization of women's bodies.

### **Social Constructionism**

As I examine fertility treatment recipients' ideas about and reactions to family and medicine, much of my analysis comes from a social constructionist, or more specifically, symbolic interactionist perspective. Basic tenets of symbolic interactionism include seeing the self as an active, rather than passive recipient of social stimuli, or "symbols," as they form and guide their own conduct and attach meanings to these symbols. These meanings are created through interacting with others, thus behaviors are contextual. Although there are set rules and norms in every situation, these are either maintained or changed by the individuals in that context (Blumer 1969; Mead 1934).

Medical social constructionists highlight the idea that medical knowledge and practices are continually being socially constructed and often act as mechanisms of social control (Brown 1995; Bury 1986; Friedson 1970; Mishler 1981; Nicolson and McLaughlin 1988). Constructionists look at the somewhat subjective character of the diagnostic process as it adjusts and readjusts treatment (Robinson 1988) where the physician engages in "diagnosis and treatment behavior" (Freidson 1988:207). One critique is that diagnosis depends on selecting certain signs and symptoms as relevant,



leaving other psychosocial factors out (Anderson and Bury 1988; Jobling 1988; Scambler and Hopkins 1988), which creates a gap between the medical profession and what people are experiencing in their everyday lives, which is apparent also in the data that I present.

The diagnosis affects what Mechanic (1982) calls “illness behavior,” how a person defines illness and how this definition affects subsequent actions (see Freidson 1988; Goffman 1968; Jobling 1988; Miles 1991; Morgan 1988; Pinder 1988). Identity work and status passage into patient and professional identities (Goffman 1963) is also of interest as the illness label becomes one of the primary identities that is both attached to and subsequently internalized by people (Kelleher 1988) as a person continually reconstructs this new identity and copes with the social implications (Freidson 1988). The effects of illness on the self are the basis of my analysis chapters on diagnosis, treatment, and patient agency.

## **Postmodernism**

Whereas modernism is marked by the western Age of Enlightenment's emphasis on science and rationalism, postmodernism in the social sciences emerged in the latter half of the 20<sup>th</sup> century in part as a response to some of the rigidity of the previous structural theories. There is no one postmodern theory, in part due to the eclectic nature needed for multiple critiques of various modern institutions, yet postmodernism generally critiques the

rationality that has produced both fragmentation and institutions, practices, and univocal discourses that legitimate forms of domination (Turner 1992). Kleinman (1988) finds that the rational medical field attempts to maintain order and control but cannot adequately contain or predict the inherent chaos in life. As Turner (1992) states, “Neither health nor disease are straightforward matters” (p.125), which is also reflected by some of my interviewees.

The rational versus lived realities then create a sense of disconnect between patient and practitioner (Turner 1992) so biomedical power and control get contested (Stacey 1997; Williams and Calnan 1996). Resistance is an indication of the fragmentation of our society as we both rely upon and fight against the medical establishment. As Williams and Calnan (1996) state, the public is increasingly “built around a reflexively organized dialectic of trust and doubt” (p.1612). Most postmodern writing on resistance focuses on the individual level (Pitts 2000); because power is decentralized, resistance must also be. I too find this in the individualized types of patient agency that my interviewees take.

Although postmodern writing often overlooks the reality that power is unequally distributed, it does show that no one is completely powerless (or powerful) in the maintenance or challenge to the hegemony of western medicine. Power, then, is not localized in one institution or person and requires maintenance and reproduction (see Fox 1994).

## **History and Overview of Fertility Treatments**

The late 18<sup>th</sup> century brought about a technocratic model of medicine and gave birth, literally and figuratively, to the science of obstetrics (Starr 1982) and ultimately the early beginnings of Assisted Reproductive Technologies (ARTs) (Davis-Floyd and Dumit 1998). During the twentieth century an array of reproductive technologies emerged, many focused on prenatal testing; for example, the 1960s saw chorionic villus sampling to detect genetic abnormalities (Rapp 1999), which now has its own higher tech version for in vitro fertilization (IVF). The first live birth from IVF occurred in 1978 in England and three years later the first IVF procedure was performed in the US. (CDC 2008; D'Adamo 1988; McShane 1988). During IVF a woman's eggs are collected following hormonal stimulation, fertilized with sperm outside the body, then transferred to the uterus.

Since then, other fertility treatment technologies have emerged, some expanding on IVF such as use of donor egg. Others include Intracytoplasmic Sperm Injection (ICSI), which punctures the removed ova with a fine needle for direct injection of sperm (cornellurology 2008), and Preimplantation Genetic Diagnosis, which takes a biopsy of an IVF fertilized embryo (Genetics and IVF Insitute 2008). Other less common ARTs include gamete intrafallopian transfer (GIFT), the transfer of eggs and sperm into the fallopian tube, and zygote intrafallopian transfer (ZIFT), where the zygote is transferred

into the fallopian tube (webmd 2008). All of these procedures can also be performed on a surrogate mother.

There is also a booming market for the array of pharmaceutical hormonal treatments that almost exclusively focus on women's bodies. However, one drug, Clomid, which stimulates the ovaries to release eggs, is sometimes administered to men with low sperm count despite its low success rate on men (and women for that matter) (Webmd 2008).

Another more common procedure is the artificial insemination of sperm. Whereas an image of a turkey baster may be conjured up, even this procedure has become quite medicalized. Inseminations now mostly consists of "washing" the sperm in a solution to separate the sperm from the seminal fluid that is toxic in a uterine environment in order to do an intra uterine insemination (IUI) whereby the sperm is directly injected into the uterus by guiding a small catheter through the cervix. One can use fresh sperm, sperm that has been removed from the testicle if ejaculation is not possible (Webmd 2008), or frozen, donor sperm.

### **Sociology Literature on Fertility Treatments**

As stated earlier, much sociological writing on fertility treatments focuses on ideas of family, basically what are people's conceptions of a "normal" family and what motivates them to want biological children. Further, this literature comes in the form of theoretical works or studies based on

qualitative data gathered from individuals who used IVF or donor sperm. In the sections below I outline some of the themes that have emerged from the existing work then discuss what has so far been omitted.

Of the more positive aspects, fertility treatments provide people several opportunities to become parents. Although having more choices can sometimes lead to confusion and stress, these treatments can also allow for some freedoms. They give people the ability to claim or disown ancestry through using their genetic material or that of others (Roberts 1998). Fertility treatments also give the opportunity of parenthood for diverse groups (Cussins 1998; Hertz 2006; Lewin 1995; Ratcliff 2002; Roberts 1998).

The rewards of fertility treatments, however, must be considered within the context of the economic and moral issues they present. Genetic material is increasingly commodified (Grace et al 2008), and as Marxist feminists point out, selling sperm and eggs encourages parents to treat their children as commodities that one picks and chooses like any other item that is subjected to quality control (Ratcliff 2002; Rothman 1988). These genes are “designer” as certain traits are deemed better than others. Semen from sperm banks gets personified through the very detailed catalogue descriptions; it is racialized and gendered in a hegemonic masculine way as it sells the “good” qualities of men (Schmidt and Moore 1998).

Unfortunately, access to these technologies is restricted to those who can afford the high cost (Currier 2002; Davis 1993; Mundy 2007; Padamsee

2004; Ratcliff 2002). Political economists point out that infertility has become a large industry; the conception industry is estimated at \$3 billion dollars annually (Sabouin 2008). Infertility clinics are in competition with each other and some have become chains with public stock; for example, the ovum transfer (OT) program in the US was financed by investors through the stock exchange, who also sought to patent the entire procedure as well as the instruments (Lasker & Borg 2002; Ratcliff 2002). Many semen banks are owned and/or operated by physicians but are subsidiaries of medical services corporations, and with marketing have become a multi-million dollar industry (Schmidt and Moore 1998).

Proponents of privatization state that this system guarantees funding, high quality, and uniformity of performance. Others note that the commerce of conception serves the interests of the pharmaceutical industry, biomedical and genetic technology companies, and biological research and analysis laboratories. Sociologists critical of rampant capitalism believe that it does not guarantee quality or efficiency (Lasker & Borg 2002) and that it actually leads to many recommendations for unnecessary procedures (Ratcliff 2002).

Further, some procedures may be over-recommended for profit purposes for technology manufacturers, insurers, and/or physicians (Conrad 2005). These may be reasons for the disparity between the World Health Organization's definition of infertility (2 years of unprotected intercourse with

the same partner) and the medical industry's one year; in fact, some doctors only wait 6 months before starting treatments (Sabourin 2006).

Feminists also point out that the medical focus is on women's bodies even when approximately 40% of the time the infertility problems are with the male partner and another 30% of the time the problem is unknown. Women and men also internalize this assumption as most people assume that the fertility problem lies within the woman's body (Stanway 1980). To some, ARTs are another example of the masculine epistemology of scientific knowledge and authority seen in a history of making women's bodies the object of scientific knowledge and experiment as they conform to patriarchal class and family norms (Thompson 2005).

Other studies discuss the rhetoric of control espoused by the medical model that leaves little room for consideration that people define health, pregnancy (Davis-Floyd and Dumit 1998), or family differently. This medical knowledge is predicated on controlling problems on individual and biological levels, rather than structural and social levels. For example, ARTs are supposed to enable parents to control children's traits based on genes, without mention of socialization. Further, cures for infertility are invasive rather than focusing on stress reduction or larger environmental causes.

Influences in the medical decision-making process are women's personal reproductive histories (Rapp 1999), social and political conceptions on religion, abortion, disability, and maternal responsibility (Bouchard et al

1995; Casper 1997; Erikson 2001; Layne 2000; Lippman 1999; Moatti et al 1990; Rapp 1999; Rice 1992; Singer 1999 et al; Sjögren and Uddenberg 1988). Much of women's knowledge, however, comes from strong recommendations from medical staff (Aro and Jallinoja 2001; Laurén et al 2001; Rapp 1999; Ratcliff 2002; Rothman 2001). What some have found important is that [educated] women have *time* to reflect on the information and integrate it into their own knowledge bases (Lippman 1999; Rapp 1999; Sjögren and Uddenberg 1988; Watson et al 1991). Mitchell and Georges (1998) find that generally the middle class embraces medical discourse, irrespective of race and education.

What is absent from this literature is discussion is situating fertility treatments in the context of medical sociology literature, a look at hormonal therapies, how people view the transmission and power of genetics, an in-depth look at the rationale and selection of personal characteristics of donor egg and donor sperm, and an intense investigation of the psychological, interpersonal, and physical costs of all types of fertility diagnoses and treatments.

## **Conclusion**

In conclusion, I have outlined the sociological literature on parenthood, medical sociology, and more specifically fertility treatments in order to situate



the perspectives which I draw upon in my study as I compare and contrast my findings as well as fill in some of the gaps.

## **Chapter Three: Research Methods**

### **Introduction**

Sociologists have long understood that qualitative research approaches offer in-depth, rich descriptions of the processes whereby meanings, thoughts, and action take place (Lee 2008). Qualitative studies offer descriptions of social processes and are especially useful in pursuing new areas of research. This approach complements the understanding of the major research questions in my study: what is the social process of fertility treatments? Why is having one's own biological child so important? It also complements the other research questions that emerged from my data such as: how do people view the influence of genetics on personality, health, and physical characteristics? Why do people decide to pursue medical treatment for infertility? What are the implications of a diagnosis of infertility? How does the treatment process affect people physically and emotionally? What are people's experiences with physicians and how have people reacted to these experiences?

Although there have been some studies on fertility treatment recipients, this is a relatively new area of inquiry and every rich analysis adds more to the knowledge pool. This study not only builds on existing knowledge, and thus strengthens overall findings, it also illuminates some themes that have had little attention in the extant literature such as

respondents' views of genetics, diagnosis and the medicalization of women's bodies, social isolation, physician authority, and sibling bonding.

This study draws on in-depth interviews with 28 people. In this chapter I first discuss the methodological theory that I use—grounded theory, then my sampling and data collection. Finally I discuss my data analysis and its application to grounded theory.

### **Grounded Theory**

Qualitative analysis generates a large amount of data whose outcome can rarely be predicted in advance due to the specificity of the setting (Turner 1981) and/or population. A particularly cogent method of analysis for qualitative data gathered from such sources as semistructured interviews is called “grounded theory” (Charmaz 1990; Lofland 1976; Turner 1981).

Grounded theory was developed at a point in history when the prevalent opinion was that only quantitative or deductive studies could provide systematic scientific research. Glaser was a quantitative sociologist and Strauss was a symbolic interactionist in medical sociology (Fendt and Sachs 2009:431), and as they joined forces they coined the term "grounded theory" to describe how they engaged in research into American health institutions. Instead of relying on existing theories, they intended to discover theory based on their data; thus the researchers developed a theory by “grounding” the information from the data rather than testing or verifying

existing theories (Glaser and Strauss 1967). Essentially, codes and concepts came from data and not from preconceived hypotheses (Fendt and Sachs 2009). This approach enables researchers to develop their own theories about their work, since, at times, there are no relevant or adequate theories to draw upon (Turner 1981) and this enables scholars to add new information or finer distinctions to existing theories.

Grounded theory has changed since its conception. Methodologists now acknowledge the researcher in more of an active role where s/he attempts to grasp the complexity and particularity of a situation and creatively mold her/his theory to the data (Turner 1981). Newer works on grounded theory also stray from some earlier positivist tendencies (Fendt and Sachs 2009) and point out that the theory is not after truth with a capital "T." Rather, as Charmaz (1990) states, the point is to show the meanings that participants give to phenomena and raise analytic issues about them. Grounded theory is particularly useful to gain a better understanding of basic processes and issues that people experience and to capture them in their variable, non-stable states (Glaser and Strauss 1967).

Charmaz's (1990) writings on qualitative methods and methodology are widely cited and accepted in sociology and, given that she studies medical sociology, I am drawn to her paradigm. Charmaz's (1990) grounded theory is based on social constructionism. In the context of medical sociology, she states that social constructionism is 1) ill people's creations of

taken-for-granted interactions, emotions, definitions, ideas, and knowledge about illness and self and 2) researchers' constructions that are developed by studying ill people's constructions (p.1161). This is exactly my approach as I examine such issues as people's interactions with physicians and their views of their bodies.

Charmaz's (1990) paradigm also draws more specifically on symbolic interactionism, phenomenology, and Marxism. Symbolic interactionism assumes that human action and ideas of self are dependent upon the meanings that people ascribe to their situations. This can lead to an overly rationalized view of the individual, so a phenomenological perspective complements it by studying emotions and assuming that there are multiple dimensions to subjective realities. This approach is particularly helpful in my study as the inability to conceive a child and the hardships of treatment are very emotionally difficult.

Last, Marxist theory links subjective consciousness and choice to larger social structures, studies how individuals reproduce dominant ideas, and allows for a critical stance when studying the data (p.1161). This perspective was helpful in my explorations of dominant ideologies of the heteronormative family, genetics and medicine, and women's roles.

As such, Charmaz's (1990) paradigm can be a flexible means for studying both interactive processes as well as more stable social structures

(p.1162), which helps me as I link my analysis on micro, meso, and macro levels and discuss larger social influences in people's lives.

## **Sampling**

This study is based on 28 in-depth interviews with people who have used fertility treatments in their pursuit of parenthood. After obtaining approval from the human experimentation committee at the University of Kansas (file/approval number 16357), I began with a pilot study of two people—a man and a woman—who had gone through the fertility treatment process 20-30 years ago. This initial interview enabled me to become comfortable with the flow of my interview questions, begin to develop my interview style, and even add a question to my interview guide. Following these pilot interviews, I conducted interviews with 26 additional respondents, 19 women and seven men, who themselves and/or their partners were currently in treatment for infertility issues, or had been in the last five years. In other words, some of the men interviewed did not have fertility issues themselves, but were involved partners and active in decision-making as their spouses went through treatments. Of these 26 people 6 were couples, some interviewed jointly, others separately, yet my unit of analysis is the individual. All interviewees were married and the two lesbians in my sample were in long term partnerships. Throughout my analysis I refer to people's "partners," not as an indicator of their marital status, but in efforts to be sensitive to the

heterosexual privilege that exists in today's society as far as who can, and cannot, get legally married. I also gave pseudonyms based on mnemonic devices to all my participants and their family members who are mentioned in their direct quotes or otherwise in my analysis.

The sample was recruited from various sources. As an adjunct instructor at Washburn University I had access to their faculty and staff list-serv, where I posted my call for participants. This rendered 10 interviews (including one pilot interview) and one from their on-line alumni newsletter. Although this by far was the most fruitful of my attempts contact interviewees, this also yielded a response from the professor in charge of human subjects review advising me to get approval from Washburn's human subjects' board for the study, which I did obtain (IRB # 07-99). I obtained 12 interviews through personal connections: I interviewed two people who I knew personally, got five referrals from friends of mine who knew people who had gone through fertility treatments (I had my friends send them my solicitation via email to several others so they remained anonymous to me), and this led to a snowball sample of five additional interviews. The final five interviews were from various sources, one from the Larryville list-serv, which is a Lawrence list-serv where people post services and items for sale, one interview from the Lawrence La Leche League list-serv, one pilot interview from the Lawrence Jewish Community Center newsletter, and two interviews from the Mercantile Co-op newsletter.

Through snowballing from a variety of sources I got a few emails from people out of state or even one out of the country and I kept them as possibilities if I could not get enough face to face interviews; I did not end up using those contacts.

I also had to “recruit” a counselor—the Human Subjects Committee at the University of Kansas specified that due to the sensitive, emotional subject matter of my interviews, I had to give the name and contact information of a counselor on my solicitation letter. I got a recommendation from a fertility specialist at the KU Medical Center. I contacted this counselor who was willing to be listed as a contact (see Appendix C).

My sample is not statistically representative of the larger US population in regards to gender, race, and class, but seems to be fairly representative of the subpopulation of individuals who use or have used fertility treatments when comparing their demographics to other studies. For example, fairly educated and middle-class people tend to use treatments more than those who are less educated. In my sample, three individuals had some college, 12 had Bachelor’s degrees, nine had Master’s degrees, one had a JD and three had a PhD.

Table One provides demographic data. It shows 20 are women and 8 are men, of whom 24 are white, one is Arab, and three are Latinos. 26 are in heterosexual and two are in lesbian “marriages.” Both lesbians had fertility issues and were not only using fertility treatments because of the absence of



a male partner. Treatment length spanned from several months to seven years, with the average being almost 4 years. Sixteen recipients had at least one successful pregnancy, two of these resulting in twins, one resulting in triplets. Table One also gives the age of the interviewees at the time of their treatments. Ages ranged from 24-60 years old, with the average age at 33 years old. There were many younger people, as both the mode and the median are 30 years old.

Table Two represents which partners of all 28 couples had fertility problems so we can see if there was male factor, female factor, both, or unknown fertility issues. Broken down by gender, 19 women and 6 men were diagnosed with fertility problems. This table also displays a wide range of treatment diversity of maximum treatments, meaning the last treatment option the individual utilized, because many progressed from lower to higher impact treatments. These include the use of fertility drugs, drugs with inseminations, drugs with inseminations of donor sperm, in vitro fertilization (IVF), IVF with advanced genetic testing, advanced IVF, advanced IVF with donor egg, IVF with frozen embryo transfer, advanced IVF with donor egg and donor sperm, and gamete intra-fallopian transfer. We also see that there were 16 live births to 13 individuals or couples.

Table Three shows that eight recipients supplemented their medical care with complementary and alternative medicine. It also shows if they got pregnant and if the result was a live birth (as seen in Table Two as well) and if

it was a singleton, twin, or triplet. We also see that 10 women experiences at least one miscarriage or induced abortion. The number of times they miscarried or had induced abortions is not counted in the table. One woman had one miscarriage, many had two, and one woman had seven miscarriages. Table Three also shows that four women had unexpected pregnancies after they stopped treatments.

Table Four identifies which fifteen women took ovulatory drugs and their success rates. There were 12 pregnancies to ten women and eight live births to six women. This information is not necessarily included in the other tables, which represent the maximum treatments, as some women started with drugs and moved on to higher impact procedures.

Because all my subjects were volunteers the study is subject to self selection bias. Persons who are talkative and/or critical are more likely to volunteer than those who are private, quiet, and/or accepting (Rossi and Freeman 1989). Also those who are ill or have less energy due to treatments or hard pregnancies might not have volunteered.

I obtained five of the 28 interviews from snowballing--referrals from those who I had already interviewed. Further, although 28 is an acceptable sample size for interview data, it is not large enough to make my study generalizable. It may, however, have "empathetic generalizability" where "findings are valid to the extent that they resonate with the experiences of others who have experienced the phenomenon in question." Thus, the

information is “self-validating” if it accurately describes the phenomenon (Osborne 1994:171,180).

Table One: Basic Demographics

Pseudonym	M/F	Race	Partnership	Age*	Treatment Length®	Live Birth	Birth Type
Ada	F	W	Hetero	33	1 year	N/A	N/A
Bob Hollander	M	W	Hetero	54 60	3.5 years (T1) 6 months (T2)	Y Y	Single Single
Christine Hollander	F	W	Hetero	41 47	3.5 years (T1) 6 months (T2)	Y Y	Single Single
Cassandra	F	W	Hetero	26	2 years	N	N/A
Leslie	F	W	Hetero	39	2 years <sup>∞</sup>	N	N/A
Cary	M	W	Hetero	40	2 years <sup>∞</sup>	N	N/A
Cameron	F	W	Hetero	29 32	< 6 months (T1) < 6 months (T2)	Y Y	Single Single
Edward	M	W	Hetero	30	1.5 years	N	N/A
Ellen	F	W	Hetero	29	1.5 years	N	N/A
Ella	F	W	Hetero	34	4 years	Y	Single
Erin Garcia	F	W	Hetero	29 33 35	2.5 years (T1) 6 months (T2) 1 attempt (T3)	Y N N	Single N/A N/A
Ramon Garcia	M	Hispanic	Hetero	31 35 37	2.5 years (T1) 6 months (T2) 1 attempt (T3)	Y N N	Single N/A N/A
Hillary	F	W	Hetero	31	1 year	Y	Triplets
Iris	F	W	Hetero	29	6 years	Y	Single
Jaime	F	W	Hetero	26	9 months <sup>∞</sup>	N	N/A
Jalila	F	Arab	Lesbian	28	2 years	Y	Single
Julie Marley	F	W	Hetero	30	2 years <sup>∞</sup>	N	N/A
Kevin Marley	M	W	Hetero	29	2 years <sup>∞</sup>	N	N/A
Marita	F	Latina	Hetero	26 28	6 months (T1) 6 months (T2)	Y Y	Single Single
Mai	F	W	Hetero	24	4 years	N	N/A
Patty	F	W	Lesbian	33 37	2 years (T1) 1 year (T2)	Y unknown	Single N/A
Peter	M	W	Hetero	39	1-2 years	Y	Twins
Reece	F	W	Hetero	30	4 years	N	N/A
Robin Vick	F	W	Hetero	28	3 years	Y	Twins
Kirk Vick	M	W	Hetero	29	3 years	Y	Twins
Sasha	F	W	Hetero	35	3-4 months	Y	Single
Terry	M	W	Hetero	30	1 year	N	N/A
Tonia	F	Hispanic	Hetero	30	< 6 months	Y	Single

Shaded coupling of rows represent partnerships.

\*Age—approximate age at onset of treatment process

®Treatment length numbers are rounded and approximated. The time period begins with the diagnostic process until the conclusion of treatments or time of interview if currently still in treatment and include short waiting periods in between treatments

T1—"Time 1," or first round of fertility treatments

T2—"Time2," or second round of fertility treatments

T3—"Time 3," or third round of fertility treatments  
 ∞--treatment is still ongoing

Table Two: Fertility Issues and Treatments

Pseudonym	M/F	Fertility Problem	Partner has fertility problem	Maximum Treatment	Live Birth
Ada	F	Y	Y	N/A	N/A
Bob Hollander	M	Y	Y	Advanced IVF with donor egg and donor sperm	Y-- T1
Christine Hollander	F	Y	Y		Y—T2
Cassandra	F	Y	N	Drugs +IUI	N
Leslie	F	Y	N	IVF	N
Cary	M	N	Y		
Cameron	F	Y	N	Drugs	Y-- T1 Y—T2
Edward	M	N	Y	Drugs + IUI	N
Ellen	F	Y	N		
Ella	F	N	Y	IVF w/advanced genetic testing	Y
Erin Garcia	F	Y	Y	IVF w/advanced genetic testing; frozen embryo transfer (T3)	Y—T1
Ramon Garcia	M	Y	Y		N—T2 N--T3
Hillary	F	Y	N	Drugs	Y
Iris	F	Y	?	Advanced IVF w/donor egg	Y
Jaime	F	N	Y	Drugs + IUI	N
Jalila	F	Y	N/A	Drugs + IUI w/donor sperm	Y
Julie Marley	F	Y	N	IVF	N
Kevin Marley	M	N	Y		
Marita	F	Y	N	Drugs	Y-- T1 Y—T2
Mai	F	Y	N	Drugs	N
Patty	F	Y	N/A	Drugs + IUI w/donor sperm	Y
Peter	M	N	Y	Advanced IVF w/donor egg	Y
Reece	F	Y	N	IVF	N
Robin Vick	F	Y?	Y	Drugs + IUI	Y
Kirk Vick	M	Y	Y?		
Sasha	F	Y	N	Drugs	Y
Terry	M	N	Y	GIFT	N
Tonia	F	Y	N	Drugs	Y

IUI—intra-uterine insemination  
IVF—in vitro fertilization  
GIFT—gamete intra-fallopian transfer

Table Three: Treatment Usage and Success

Pseudonym	M/F	Maximum Treatment	CAM Usage	Live Birth	Miscarriage/ Induced Abortion*	Unexpected pregnancy**
Ada	F	N/A	Yes	N/A	N/A	No
Bob Hollander	M	Advanced IVF w/ donor egg and donor sperm	No	Y--T1	Y--T1	No
Christine Hollander	F			Y--T2		
Cassandra	F	Drugs +IUI	Yes	N	Y	No
Leslie	F	IVF	Yes	N	Y (twins)	No
Cary	M		N/A			
Cameron	F	Drugs	No	Y—T1 Y—T2	N	No
Edward	M	Drugs + IUI	N/A	N	N	Yes
Ellen	F		Yes			
Ella	F	IVF w/advanced genetic testing	No	Y	Y	No
Erin Garcia	F	IVF w/advanced genetic testing; frozen embryo transfer (T3)	Yes	Y—T1	Y	No
Ramon Garcia	M		No	N—T2,3		
Hillary	F	Drugs	No	Y (triplets)	N	Yes
Iris	F	Advanced IVF w/donor egg	No	Y	Y	Yes
Jaime	F	Drugs + IUI	No	N	Y	No
Jalila	F	Drugs + IUI w/donor sperm	No	Y	N	N/A
Julie Marley	F	IVF	No	N	N	No
Kevin Marley	M		N/A			
Marita	F	Drugs	No	Y—T1 Y—T2	N	No
Mai	F	Drugs	Yes	N	N	No
Patty	F	Drugs + IUI w/donor sperm	No	Y	Y	N/A
Peter	M	Advanced IVF w/donor egg	No	Y (twins)	Y	No
Reece	F	IVF	No	N	N	No
Robin Vick	F	Drugs + IUI	No	Y (twins)	Y (one triplet)	No
Kirk Vick	M		Yes			
Sasha	F	Drugs	Yes	Y	N	No
Terry	M	GIFT	No	N	N	No
Tonia	F	Drugs	No	Y	N	Yes

CAM—complementary and alternative medicine

\*Miscarriage/Induced Abortion during treatment process

\*\*Unexpected pregnancy after stopped fertility treatments

Table Four: Clomid/other ovulatory drug Success Rates\*

Pseudonym	Clomid/Other drug	Miscarriage/ Induced Abortion	Live Birth	Birth Type
Cassandra	Clomid	Y	N	N/A
Leslie	Other	Y	N	N/A
Cameron	Clomid	N N	Y Y	Single Single
Ellen	Clomid	N	N	N/A
Ella	Clomid	N	N	N/A
Erin Garcia	Clomid	Y	N	N/A
Iris	Clomid	Y	N	N/A
Jaime	Other	N	N	N/A
Jalila	Clomid	N	Y	Single
Julie Marley	Clomid	N	N	N/A
Marita	Clomid	N N	Y Y	Single Single
Mai	Clomid	N	N	N/A
Patty	Clomid	Y N	Y unknown	Single N/A
Robin Vick	Other	Y (lost one triplet)	Y	Twins
Tonia	Clomid	N	Y	Single

\*Most women are not on these drugs for longer than 6 months

### Data Collection

These interviews were conducted between April 2007 and March 2008.

I began each session with a short demographic survey (see Appendix A).



Some of this data is represented in my sampling chart and some of this information also helped me during my interviews for knowing what questions and follow ups to ask with such things as how many times my respondents had been pregnant, and what types of physicians they utilized. It also helped me make connections in my analysis such as between educational status and physician authority.

Because my theoretical framework follows in the tradition of symbolic interactionism where the creation of meaning is a dialectical process between individuals and thus changes depending on different contexts in a person's life, interviews seemed to be the best method to gather the bulk of my data, which contain sensitive, detailed, and explanatory information. Interviewing in itself is a symbolic interactionist process, or what Levesque-Lopman (2000) calls "conversational interaction."

Compared to pencil and paper inventories, interviews maximize trust and cooperation between interviewer and interviewee (Dooley 1995). Although one may not want too much rapport (see Lee 2008), in this situation an amount of trust was necessary because private and sensitive matters emerged during the interviews.

Methodologists write about interviewers statuses and their effects on the interviewees (see Lee 2008) and in this situation I think my status as a woman helped because much of the discussion was about reproductive issues. My own status as mother was only revealed to those who asked, and

those who asked were parents themselves, those who were not successful did not ask. I was also close in age and educational status to many of the respondents. I also tried to present myself as professional, but not too professional, as I chose to wear business casual.

I digitally tape recorded responses to my open-ended interview schedule (see Appendix B). As Dooley (1995) suggests, I asked one question per item and gave my respondents the option of expanding on their answers by either letting them explain their answers and/or talk about them in depth or by asking probe questions. Although less on a conscious level, I also used several tactics for clarification that Spradley (1979) mentions such as using contrast questions, repetition to make sure that I understood the picture presented, plus I expressed (genuine) interest to get more discussion.

Pacing was also an issue; as Charmaz (1990) states, one must know the right questions and when to ask them. The pacing of questions was dependent on respondents verbal and non-verbal cues, something Berg (1998) and Dooley (1995) remind interviewers to look for. I had to take small breaks quite a bit, as almost everyone cried at some point during the interviews. When people cried it was hard to know what to say; they usually apologized and I told them that it was okay and that I am sorry that they have gone through such hard times.

Part of keeping pace was letting my interviewees' stories unfold. What I ultimately found is that I began each interview with the same question and

the respondents' stories flowed from there. As such, I kept asking questions based on what they were saying rather than strictly following the order of questions in my interview guide. By the end of their interview I found that almost all or all of the questions on my interview guide had been answered; if any were unanswered I asked them at the end. Despite the different order of questions the interviews were timed well. My initial request for participants stated that interviews would last one hour (see Appendix C) and for the most part they took one hour for a single individual or two hours for a couple. Pacing was most difficult at the end; it was especially hard to end interviews that did not have "happy endings."

The interviews were conducted in a variety of locations: five in my office at KU, 10 in the homes of respondents, and 10 at respondents' offices. Two interviews with people that I know well were done over the phone. One interview was done in my home when no other options were available. I knew that this woman had been successful (i.e. had a child) so I decided that it would be alright to have her come to my home, a place where it is obvious that a young child resides.

Of the six couples in my study, four were interviewed together, one was interviewed separately, and for the last couple the woman was interviewed first and then her partner joined us after about an hour and then they were interviewed together for another hour.

Many of my participants showed interest in seeing my final product and I will give them a 2-3 page summary of my dissertation and, if they express further interest, an electronic copy of the manuscript.

I spent about eighteen hours on the road to and from interviews for almost 29 hours of interviews. Each hour of interview took about four hours to transcribe. I did the first half of the transcriptions and then I employed two Haskell Indian Nations University undergraduate students to transcribe the latter half to speed up the process and give me time to start analyzing the data from the completed transcriptions. The transcribing was done verbatim or very close to verbatim as we tried to capture as much as possible, sans the body language.

Other sources of data I utilized were a journal that one of the interviewees gave me that he wrote during his and his partner's two year fertility treatment process. I also used on-line reports of information and statistics, several articles from two specialty medical journals on fertility, and social science literature to inform my theory and draw comparisons.

### **Data Analysis**

Although there is no one set procedure involved in grounded theory (see also Fendt and Sachs 2009), it is suggested that the study concentrates on a process, "preferably one which can be expressed as a gerund: negotiating, encountering..." (Turner 1981: 347). Once a process is chosen

for analysis, it becomes the central concept and the researcher must examine it in full (Turner 1981). This study concentrates on the social process of fertility treatments.

After data collection, the first step in grounded theory is coding, which is an analytic method of categorizing and sorting data (Charmaz 1983; Fendt and Sachs 2009). One needs some parameters, limits, or lenses for sorting data, or else one will be swimming in a pool of data, or as Fendt and Sachs (2009) explain: "Scholars invariably find themselves gathering large amounts of exciting but unstructured data" (p.432), which make it difficult to generalize results. As Turner (1981) explains:

The researcher should be warned that when such an approach...is applied to a new area which the researcher is entering, a large number of categories are likely to be developed in the early stages. But, because the number of categories generated is a function of our interaction with the data, as we keep our particular zone of interest in mind, we find that, after a while, we begin to build up a vocabulary of basic categories or concepts which serves to express all that we feel is important and relevant about the area in question....(p. 240)

Coding is a two-step process and in the first step the researcher looks for trends and summarizes large amounts of information, making codes fit the data rather than forcing the data into established codes (Charmaz 1983; Turner 1981). For example, one such theme that I found was patient agency. Sometimes something is so relevant that begs analysis, even if researcher was not originally interested in or aware of the topic (Charmaz 1990). Such was the case for me with the idea of social isolation, which is one major theme in my treatment chapter.

After the categories have been established, the researcher needs to define categories to ease the placement of future examples into each category. After initial coding I checked, affirmed, and refined my developing ideas with further observations; in Glaser and Strauss's (1965) terms, initial analysis should be "vertical" and then subsequent analysis is "horizontal" as stories get compared with each other. In other words, more examples need to be accumulated to fit the categories for clarification and validation purposes (Charmaz 1983, 1990; Turner 1981). In my case, my interviews were spaced out over an 11 month period due to having to pursue multiple avenues to find subjects. Whereas this delayed my process greatly, it may not be a disadvantage for using grounded theory and the upside was that I began coding and analyzing before all the interviews were conducted. As Charmaz (1990) states, with- or after each interview the researcher must continually think critically, ask questions, and keep an open mind. Thus delaying sampling has some positive aspects in that it fosters gaining an in-depth understanding of the issues at hand.

If further examples do not exactly fit the extant framework, categories can be refined or new ones can be created (Charmaz 1983). Although each interview was unique, especially for lending some demographic differences, I did feel like I had reached a saturation point (see Glaser and Strauss 1967) for larger themes for my coding.

Memos are personal notes that are written at any time during the analysis and are basically a researcher's dialogue with oneself (Charmaz 1990). These can be useful for the researcher if s/he is engaged in another task and cannot devote full attention to a new idea. The researcher jots down the idea and comes back to contemplate it at a later time (Turner 1981). Memos allow the researcher to be exploratory, to try to make connections, to break down categories, and to find an integrated whole. Memos "tie together different pieces of data into a recognizable cluster, often to show that those data are instances of a general concept" (Miles and Huberman 1994: 72). This creativity can lead to new discoveries (Charmaz 1983).

I wrote memos while transcribing. I had one document window open for the transcription and another for my memos where I jotted down interesting points and started clustering themes as well. Memos allowed me to think about what the respondents were saying rather than "blindly" transcribing. And although I had hired students to do some transcribing halfway through the interviews, I already had some established codes that were helpful both as I read through the transcriptions and conducted further interviews.

The second step of coding requires theoretical reflection (Turner 1981) as one selects and develops concepts, or as Fendt and Sachs (2009) state, this step offers "a means of abstraction of such subjective experience into theoretical statements" (p.432). This is more concentrated and requires more

abstraction. I followed the guidelines of grounded theory (see Charmaz 1983, 1990) by developing categories at a deeper level rather than simply labeling them. I looked for “causes” and the conditions under which they operate as well as relationships between key concepts. For example, gendered ideas of motherhood were causes for women’s feelings of failure and motivations to pursue fertility treatments. Exposure to adoption was one condition for how far one was willing to go in the fertility treatment process.

In this second coding step one also explains how participant ideologies reflect those in larger society, or as Braun & Clark (2006) state, qualitative methodology “examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society” (p.81). In my study I found that people mirrored larger medical and scientific views on the power of genetics as well as cultural ideals of the heteronormative family as well as gender and class ideologies on reproductive choice and patient agency.

The second step of coding also requires contrasting and comparing data based on different interviewee demographics. Whereas I was able to do this to some extent, such as find differences in approach to physician authority based on socioeconomic status, this was also difficult due to the relative homogeneity of my sample. For one, many respondents revealed similar behaviors and thought processes. Secondly, if there were differences



in their ideologies and behaviors, it was sometimes difficult to pinpoint exactly why.

Existing theory can be integrated into the further analysis (see Lee 2008). It is often useful to look at macro theories as a means of comparison or to augment one's own theory. However, literature should not be used to force new research into so-called substantiated interpretations (Charmaz 1983; Turner 1981), as one of grounded theory's central objectives is theory building and not theory testing (Fendt and Sachs 2009). Glaser & Strauss (1967) suggest reading theory only after the data collection yet Charmaz (1990) does not think that reading theory first necessarily "ruins" the research. As she says, the researcher has a cache of sociological concepts (e.g. power) that lead to asking certain kinds of questions and analyzing the data from certain perspectives (e.g. feminist). This means that there is a delicate balance between a grounding in a discipline and pushing it further to view concepts in novel ways because some events and ideas need a fresh look. To me, Glaser and Strauss (1967) and Charmaz's (1990) suggestions need not be seen as either/or. I read general theories in the sociology of families and medical sociology literature as well as works on reproductive technologies prior to my data collection. As certain themes in my own analysis emerged, I read more specific literature related to these topics, such as patient activism.

Last, Charmaz (1983, 1990) also recommends that in this second and final coding step the researcher should also address the consequences of the phenomena; much of my analysis focuses on the physical, emotional, and financial consequences of fertility treatments, the medicalization of women's bodies, the reification of the normative family and women's roles as mothers, and the larger economic inequality perpetuated by a for-profit industry.

Throughout the qualitative process, or any scientific study, from the outset of selecting a research question until the last data are coded and analyzed, it is impossible to completely omit researcher bias. Although complete neutrality may be an ideal for some, it is not a realistic expectation (Fendt and Sachs 2009). Striving for pure objectivity is futile in that it is questionable in all methods and sciences (Harding 1998) yet researcher subjectivity need not be devalued as unscientific (Collins 1991; Fonow and Cook 1991). Although the researcher has chosen what questions to ask, and his/her own training and values are part of that decision, subjectivity in the selection and focus of a topic does not mean that it is poor research if it follows rigorous methodology and is theoretically sound (Fonow and Cook 1991; Peshkin 1985). Grounded theory should not be used to test hypothesis about reality, but to reflect how actors interpret reality (Fendt and Sachs 2009).

Essentially one follows his/her own interests, leads, and hunches in early stages (Charmaz 1990:1162) and some researchers see a certain

amount of subjectivity as an asset as it lends a particular degree of creativity and uniqueness held by the researcher (Fonow and Cook 1991; Peshkin 1985). For example, as seen in feminist studies, researchers come to the field with a unique perspective that can challenge conventional, male social theory, (Fonow and Cook 1991) such as my claim that the polycystic ovarian syndrome diagnosis is a new case of the (bio)medicalization of women's bodies. Being critical need not be viewed negatively due to the possibility it lends to consciousness raising (for both researcher and different types of readers) and change (Fonow and Cook 1991).

As Thorne (1995) and Kram (1985) recommend, self-understanding is a prerequisite as the researcher must constantly keep her/himself in check. One must look at the data and see if anything or anyone is being given more or less attention. In my case I made sure to read all respondent transcripts several times over as I worked on each of the major themes in my chapters. As Glesner & Peshkin (1992) recommend, I wrote many drafts in the process of my analysis in order to flesh out concepts and to investigate my own subjectivity and assumptions. Several times this process led me to see that I was making assumptions about physician intent that was more based on medical sociology literature rather than my data so I omitted those statements.

A suggestion for bias reduction during the interview is for the researcher to make an effort to not interpret events using his/her biases. This

can be accomplished only by making a conscious effort to recognize and acknowledge personal biases before going into the field (Ely et al. 1991; Thorne 1995). I thought about my personal bias before I began interviewing. I thought that although I did not know for sure what decisions I would have made had I been with infertility, I thought that I would adopt rather than go through very much physical, emotional, and financial cost related to fertility treatments. I was a little worried about this bias but what I found was that I got very involved in people's stories and was just in the moment. I was right there with them in their journey. I often teared up when they cried, became happy with their success stories, and even briefly became angry when a woman told me about finding out that her husband had been having an affair for the year that they had been doing in-vitro fertilization.

## Chapter Four: Conceiving Parenthood and the Importance of Biology

### Introduction

Although American families have experienced significant transformations in recent decades, one constant has been the wish for most women and men to become parents. Why this is the case has been a significant debate in feminist circles, mostly when pondering if society places too much pressure on women to become mothers and if becoming a mother then limits women's potentials to engage in other, important endeavors.

Many believe that children are the inevitable, desirable, and socially acceptable consequences of marriage, yet some research has suggested that most people are unable to explain exactly why they want to become parents (McMahon 1995). This might be one reason why this specific question remains relatively unexplored in sociology literature even though people all over the world become parents every day. Parenthood has become so normative in our culture that it goes fairly unquestioned. As sociologists attempt to uncover the meaningful in the everyday, one major research question this chapter addresses is *why do people want to have children?* Whereas most in the general population take this for granted, I explore this question directly with a group of people who have had to make concerted efforts to try to have children through the use of fertility treatments.

Reproductive technologies are expensive, time consuming, and physically and emotionally draining to say the least. Thus, the second, and possibly more interesting question I explore is: *why do people want biological offspring?* In other words, in a world where there are other alternatives, why is using fertility treatments the best option for some? I find that most men attribute the primacy of biological children to innate desires. Whereas in the past people may have used terms such as “blood relations,” my respondents are armed with rhetoric from the medical/scientific communities, discussing a primordial desire for children linked to a *genetic* code. Further, both men and women want a “normative” family as defined by society as biologically related (Demo and Cox 2000; Pyke 2000). Third, both women and men are aware that medical and legal institutions privilege the “ownership” of biological children. Last, both women and men feel that a biological link gives them a genetic advantage to have some control over a child’s personality, physical, and health traits.

### **Why Do People Want Biological Children?**

I opened all of my interviews with questions about why the respondents wanted children. More than half of my respondents feel like they have always known they wanted kids; as one respondent said, “I think I knew I wanted to be a mom forever, forever.” But they had to take this thinking a step further when becoming pregnant became a difficult process. As one

respondent says “I’ve thought a lot about why I want to be a parent... why it’s so important to me, when it’s so hard, when trying is producing so many negative consequences, like the fertility treatments were.”

One answer that I got from most men as to why they wanted children actually became the answer to why they wanted *biological* children. Although some men also gave some social reasons (as will be seen later in this chapter), almost all of the men pointed to an innate desire to have children, which goes against the bulk of the sociology of families literature. A few women also emphasized biology, but they were less likely to do so than men.

### **Instinctual/Innate Desires**

Do people believe their desire to have children is biologically or instinctually driven? No women gave a strictly biological rationale; a quarter (n=4) gave both biological and social reasons and the other three-fourths (n=16) only gave social reasons. The four who gave both biological and social reasons did not conceive naturally. One of these women is Ada, who at the last minute opted out of her insemination appointment due to a disgust with how her physician was pushing the secrecy of using donor sperm. Instead, she adopted her son and says that she does not feel less of a bond to him but thinks about how he bonds to his biological daughter:

And I wonder for him, the only person that he’s genetically related to is his daughter, I wonder what that’s like. You know that the only person that you can look at and you can actually see your own features.

There's no cousins, no aunts and uncles. I don't know what that's like. But you live your life, nothing's perfect.

Mai is another woman who gives mixed messages. She and her partner only knew each other for two days before they decided to get married, and have been married now for eleven years. Neither she nor her partner think that their desire to have children is biologically-driven (they adopted a child) yet Mai thinks that they are outliers compared to society in general and especially men, who have a genetic code that gives them a skewed notion of the power of genetics:

That DNA thing that tells us that we have to procreate. I see that attitude mostly in males. A lot of the women that I know who have gone through fertility treatments have done it because they were pushed. Their husbands had to have their children. They must have their sons, their seeds to continue on. I don't understand it. It must be something deeply genetic with men.

That being said, Mai is unable to explain why she did try to have a biological child and plans to try again in the future.

Mai's assessment of men privileging a genetic link is also reinforced by other women in the study who talk about the importance of both parents having an equal genetic connection with a child, especially the women whose partners have the fertility issue and thus are faced with the idea of not being genetically related to their children. For example, Ella doesn't like the idea of donor sperm because her partner has personal issues he is dealing with and she fears that he does not have the emotional stability needed to parent a child that is not his own biologically:



The non-stable one would not be the one that you would want to take out of the relationship. He lacks security. He would think I was doing it to have a child with somebody else. At least, that's how I would take it.

Erin also talks about thinking that they would not have used donor sperm because going through fertility treatments and infertility is stressful enough and feeling like the child was not completely biologically related to the parents would have been too much to handle.

Robin also discusses some mixed emotions about having only one genetic parent through the use of donor sperm:

I felt like if it couldn't be his child, then I would rather adopt. Then we could go through that together, instead of me having a child that wasn't his. Part of the reason was that you meet someone, you fall in love, get married. I thought, 'Gosh, I wonder what kind of kids we'll have.'

She even compares such use with infidelity when a bit later she said to her husband, "It would have felt like I had cheated on you." And although Robin's husband, Kirk, admits that he would have been bothered by having a child that was not genetically his, he is a very practical person and says his first preference would be adoption, then donor sperm, and last IVF with his own sperm because he thinks it is both cheaper and the likelihood of actually getting a child is more guaranteed.

My findings are also confirmed in other research; for example, Mundy (2007) finds psychological issues where only one parent is genetically connected to the child(ren). "Parents sometimes fear the power of genetic connection so acutely that...they try to deny it or try to assert their own fictional status as genetic parent." Further, the non-genetically related parent

fears being loved less than the other, genetic parent (p.99,100). I too find similar thoughts among some of my respondents,

The importance of genetics and/or genetic bonding to children was acknowledged by six of the eight men in this study. As Peter, a research biology professor at a large midwestern university, writes in his journal, “Is this a biological imperative lurking in the background?” In our interview he compares human and non-human behavior in discussing why it is important for him to have his own biological children:

In Africa when a new male lion takes over a pride of lions, first thing he does is kill all the cubs to bring the females into heat so his genetic material, not that of his predecessor, gets passed on.

Yet when Peter’s option to have a biological child required the use of a donor egg he says that both he and his partner shifted away from the nature over nurture argument as they ultimately used donor egg. In our interview he even downplays the importance of the egg:

She donated raw material. It’s like a blood donorship to me. There was no guarantee that what she donated would ever develop into kids. One way I mentally put it to myself, I do woodworking, you can take a piece of cherry, or an oak log, and you can either turn it into firewood or turn it into furniture. What you start out with is one thing but what you do with it ultimately determines where it ends up.

Further, Peter and all others who used donor ova split the eggs from the same cycle from the same donor with other couples for financial reasons. As such, they are sharing biological heritage with other, non-family members as their children have half-biologically related siblings in the world.

Perhaps this shows other, non-genetic, influences, that factor into wanting a child, or perhaps it was easier for Peter to accept a donor egg because it was not *his* genetic material being taken out of the equation. And although another respondent stated his strong preference for the child to be biologically related to both himself and his partner, he is still in the treatment process and thus it is uncertain if failure to conceive, such as in Peter's case, could change his mind.

Edward, a social worker who is married to Ellen, a sociology professor, provides another example of the tendency for men to lean toward biological explanations. Facing infertility had led Edward to give a lot of thought to exactly why he wants to have a child. He says that he used to give social reasons in the past but feels like they were justifications, that really "it's a biological desire. It's just having a family, that's where I come from, that's where we all come from, it's just natural to want to continue that." Because he believes it is such a natural desire, he thinks that people actually need conscious reasons *not* to have kids." This being said, when the fertility treatments were unsuccessful, Edward happily adopted a child.

The status of "father" has often referred to the siring, rather than raising, of children (Miall and March 2003). As will be seen, some of my respondents are similar to men in other studies where they feel that they need a genetic bond in order to be a "real" father (see Crowe 1985; (Miall and March 2003; Webb and Daniluk 1999). For example, one of my respondents

did not feel strongly about the actual parenting of the child. He talks about not getting involved in programs that help kids because, "I am not the most reliable guy, so I would worry that I would let the kid down. If the kid lived in the house, I would maybe be more active." Perhaps his attitude is related more to where in the family creation process he is (i.e. trying to get pregnant) and this attitude could change if he actually became a father.

Miall & March (2003) interview people from the general population and find that male (and female) respondents think that mothers and fathers have the same feelings for adoptive children and biological children. This differs from both the IVF husbands in Crowe's (1985) study who preferred no children over adoption, fearing not bonding with someone else's child(ren) and several of the men in my study who state their preference for a genetic child in direct opposition to adoption. Perhaps, then, men in general do not have such strong feelings about innate desires, and those who do are more prone to use fertility treatments; thus the men's views on fatherhood in my study may not reflect the views of men in the larger population. For example, one of the men in my study states: "Frankly it would take some degree of mental wrangling" to accept the idea of adoption. "It's tough to do when the door is still open [to having a biological child]."

The preference for personal DNA was reflected in Kevin Marley as well. Kevin has had some college and his wife, Julie, has a Bachelor's degree. Kevin feels so strongly about having their DNA that he says that he

would try to use a surrogate before adoption (and says nothing about which is easier on Julie) because “it’s our stuff, I’ll feel more happy that it is part of me. I want my deuce.” This is interesting because Julie herself was adopted into a loving family; so again, fatherhood is about genes and not social context and behaviors.

Reece similarly talks about her (now ex-) husband wanting a genetic child:

He has not had many experiences with kids. He has a small family and I have all those kids on my side. So I don’t know if he understands the idea completely that you can love any child as your own. I think he would go toward surrogacy before he would go to adoption.

This also reflects men’s double-standard of reproductive technologies and intervention. Throsby and Gill (2004) find that the infertile husbands see IVF as “natural.” The authors conclude that the men see IVF as natural and compare IVF to unnatural cloning, since IVF is lower-tech and more familiar. I, on the other hand, see it as more of a reflection of accepting technology that maintains their masculinity. I am saying this at a time where I have several female friends whose husbands refuse to get vasectomies, and have no problem accepting female contraceptive technologies, even more invasive ones like the IUD.

Returning to the idea of siring, we see that biologically fathering a child is tied into feelings of masculinity. The infertile men in Webb and Daniluk’s (1999) study felt emasculated and one of the women in my study talks about a conversation she had with her husband that also reinforces this link. Jaime

is a young woman in her late 20s who is currently pursuing her Bachelor's degree. Her partner got a vasectomy after having a child in his first marriage. He is similar to Kevin in that he said that he would do IVF before donor sperm (again, much harder on the woman's body). When discussing it with Jaime he said, "It's going to be your kid, not mine." His reluctance is not only about genetic relatedness but is also tied to cultural ideas of masculinity because he later comes around to the idea of adoption and even donor sperm saying, "I went and got the vasectomy, because it wouldn't make me any less of a man," thus disconnecting ideas of masculinity and the ability to produce offspring.

Although sperm banks rely heavily on clientele who do not use their own sperm, they are also capitalizing on the idea of male factor biological relatedness by marketing sperm banking to men who may become infertile through chemotherapy and/or radiation. The military also promotes banking sperm to soldiers before they are sent on active duty and both single and married soldiers have banked their sperm (Moore 2007).

Given this data, why do men place such emphasis on their biological ties to their children? Many men are alienated from the pregnancy, birth, and even infant/child care processes so perhaps they place greater importance on the contribution of genetic material (see O'Brien 1981). Taking a historical and cultural perspective, what constitutes a "legitimate heir" was wrapped into concepts of property, inheritance, and the control of female sexuality

(Francoeur et al 2004). As Grob and Rothman (2005) state, the current general societal reliance on genetic relatedness of family is based in a patriarchal notion of the importance of sperm that historically comes from the United States' patriarchal focus on "the seed" as the source of being. They think that science now acknowledges the egg as well but extends to women the patriarchal notion that kinship is based on genetic ties rather than relationships. Thus, several feminists have posited that assisted reproductive technologies such as IVF reflect a patriarchal ideology of conception, reproduction, and family (Crowe 1985; Grob and Rothman 2005). And the Marxist feminist critique that the New Reproductive Technologies industry is indicative of men using women's bodies to produce and control the product (Davis-Floyd & Dumit 1998; Saxton 1998; Whitbeck 1988) may be applicable here as well.

Grob and Rothman's (2005) argument, however, is nuanced, saying that this genetic ideology undervalues the importance of the in-utero relationship between child and mother, which is valued in matrilineal societies. If this is the case, I question whether IVF strictly reflects a patriarchal notion because it allows for a woman to be pregnant, even with a baby not made from her own egg. This should not be overlooked because a quarter of the respondents in my study, mostly women, discuss a bonding and/or curiosity about all or some combination of pregnancy, childbirth, and breastfeeding. This is consistent with the findings which have also been

reported in other studies (see Fisher 1992; Miall & March 2003; Parry 2005). Thus, the importance of the bond is biological, but not necessarily genetic, as this rhetoric was also heard among my egg donor recipients.

Although bonding with a child in utero and the experience of pregnancy, childbirth, and breastfeeding are all based in biology and can perhaps be explained by sociobiology as mechanisms to procreate or ensuring that mothers take care of their offspring; they are also socially constructed concepts. First, two men in my study discuss bonding with their unborn children through ultrasounds and hearing the heartbeat--how does scientific intervention play into men bonding with their unborn children? Second, norms of pregnancy, childbirth, and breastfeeding have changed over the years, making them more or less culturally important. For example, over the past 50 years social norms and thus openness to and rates of breastfeeding have changed. Currently the medical community is promoting breastfeeding and the 2005-2006 data from the Center for Disease Control show the highest breastfeeding rates since the onset of data collection in the 1950s. The idea of birth has also changed in the past 100 years in the US. The shift to hospital births in the early 1900s created a medicalized atmosphere, including a period of time where women were fully sedated during birth. This was fought by women's health groups so now we have more emphasis on pleasant births and mother involvement through the use of



such things as birth centers, birthing rooms (Starr 1982; Weisman 1998) and birth plans.

Further, 75% of my respondents did *not* mention pregnancy, childbirth, and breastfeeding as important. In fact, Ada discusses how these things are not important for bonding with a child when she talks about losing her first adopted baby:

The basic love, when my first baby was dying, if God would have said to me he could live but you have to die, I would have said, 'Kill me.' That's called being a parent. You don't have to breastfeed or give birth. In the womb...they don't have to hear your voice. Here's a person you love unconditionally, you love them more than you love yourself and you would do anything for them.

Why, then, were so many people invested in having a biological child? For some women it seemed to be because their husband's wanted biological children, others were not able to adopt due to a multitude of factors, and for many there were other social reasons to have biological children, as will be seen in the next section.

### **Social Influences in Wanting a (Biological) Family**

Whereas the previous section outlined some respondent's reasons for wanting children based on biological and/or genetic urges, the section outlines the social expectations that influence people's desires to have families, and more specifically, biological families. In this section I briefly discuss some social influences in respondent's desires to have families more generally, and then delve into why they prefer biological kinship.

## Wanting a Family

As far as social pressure specifically directed to men to become fathers is concerned, one man notes that more pressure is put on men to keep their last names alive. "It is only me and my brother. I don't see him having kids any time soon, so it is up to me to populate the name." For Kirk Vick it was not only being done with his college degree but also fitting into a "family man" role of breadwinner, not necessarily out of necessity because his partner had a decent paying, stable job: "Once I started working and had income, I think I was ready."

Feminists have especially explored the social and cultural meaning of motherhood, and many have tried to show the unequal, gendered expectations linked to a pronatalist ideology where women's social value is linked to instinctual, biological procreation (Bartholet 1994; Crowe 1985; Fisher 1992; Miall & March 2003; Ulrich & Weatherall 2000; Williams 1990). Some have argued that society polarizes mothers and childless women, placing pressure on women to have children and stigmatizes those who do not (Fisher 1992; Greil et al 1988; hooks 1984; Rich 1980) whereas men's roles are more fluid and those who break the male norm through involvement in childcare may not experience strong stigma because their fathering behavior is supposed to be based on learning and not biological essentialism (Miall & March 2003).

Similar to other studies with fertility treatment recipients (see Crowe 1985; Fisher 1992), many of my respondents discuss a major gender role for women wrapped into motherhood. This norm got internalized by some of the women in my study. One woman who struggled for six years with fertility treatments until she had her son: "I finally did something right, I feel like a woman." Most of the men in the study also mention the added expectations on women. For example, one man states that according to society, having kids is "the number one thing you do...I think a little bit more for women than men," which is an interesting comment from him since he is the one in his relationship who wants kids, not his partner. Another man also talks about women reinforcing this norm even when it is directed to men; when he was a student, female classmates would see his wedding ring and automatically ask about kids.

Similar to findings in other studies (see Fisher 1992; Webb and Daniluk 1999), my male and female respondents talk of [possibly unintentional] pressures from parents, in-laws, or other relatives. When Robin's sister was done having kids her mom said to her, "So, you're getting older. When are you going to have kids?" Her relationship was also being strained from pressure on her partner, Kirk, as well. His parents were telling him, "We'd like to have grandkids. We're saving our crib. We're saving this toy," which is one reason why Robin and Kirk did not tell his parents that they were trying to have kids until they started the fertility treatments.

More general societal pressures are also mentioned. One woman could not pinpoint why she wants kids, just that “You grow up wanting to have kids. It’s just what we did.” Similar comments came from men such as “it was like an expectation you were gonna have children” and “It really is the main personal experience of your life. It just seems like culturally, that is the number one thing you do.”

As Fisher (1992) states, our cultural understanding equates kids with full and meaningful lives and some of my respondents were addressing existential questions even though they were otherwise satisfied with their current lives. As one woman said, there is “something more fulfilling to life to have children, than not,” and another woman openly admitted that she likes to be needed and for people to depend on her. Ellen wondered what else there was to her life. Although she had a solid relationship, career track, and strong ties to her parents, brother, and his kids, she thought that a child would give her life more meaning. Other reasons of self-fulfillment were wanting to see a child grow and learn, the ability “to give a kid a life you can offer and share that with them,” “tossing a ball, stuff like that,” enjoying being a grandparent, and seeing “the look on their faces when Santa came.”

Other people also mention personal family modeling experiences influencing their decisions to start a family (that incidentally also include “non-normative” family formations). For example, one man felt that the long marriages of his parents and both his partner’s father’s second marriage

provided good role models for them. One woman talks about her sister sheltering her from a withdrawn, alcoholic father that made her want to have kids and her sister not want to have kids. She also mentions her partner's big, pro-child family, which included many foster children, developing his love for babies. Other people also discuss exposure to children in their extended families. A few mention stepchildren from their spouses' first marriages. Tonia appreciates her partner's level of involvement with the kids from his first marriage and it also comforted her to know that as a first time parent she would be raising kids with someone who had experience. Along the same vein, Robin and Cassandra think that their partners were initially not so interested in having kids because they were never around babies much, yet neither were some of the other men in this study who wanted kids.

### Wanting a Biological Family

"We wanted the child to be our kid like everybody else, almost everybody else."

Although the postmodern family is more fluid biologically due to divorce and remarriage, adoption, gay parenting, and reproductive technologies with donor egg, donor sperm, donor embryo, and surrogate motherhood, there seems to be cultural lag in general societal conceptions of a "normal" or "regular" family. Further, the connections between womanhood and motherhood still hold strong within culture despite the diversity of family forms

and significant changes in women's other roles (see Arendell 2000; McDaniel 1988; Miall & March 2003). I too have found this to be the case where the goal of my respondents was to create a heteronormative, biologically related family. Yet, as both Parry (2005) and I find, failure to produce a biologically related family shifts people's ideas of what constitutes a "normal" family and the importance of biological ties between parents and children. I argue that, despite changing technologies and family forms, the desire to create a heteronormative family remains strong, even among the lesbian couples in my study.

As a social issue, reinforcing norms of a "normal" family makes it harder for those with or from other family forms who are under attack for being the perpetrators of social decay (Coontz 2000). It also fuels the fertility industry that puts women (and men) through grueling physical and emotional processes and makes access to one's own biological children an advantage available to those who have the monetary resources to pursue it. It also diverts millions of health care dollars from other health issues into this industry, lines the pocket books of physicians and the pharmaceutical and biotechnology giants. This further widens the gap between the rich and the poor, incurs costs on society due to having more children with birth defects, and neglects children who need to be adopted into good homes.

Many in society, including many of my respondents, construct an ideal, heteronormative family, defined briefly as a biologically connected,

heterosexual, nuclear family, which continues to be the gold standard.

Whereas sociologists point to parenthood as a socially constructed, ongoing activity that is given cultural meaning, for the general population the ideal parent is, among other things, biologically connected to her/his children (Demo 2000; Pyke 2000). For example, several in my study thought that an adopted child would complicate their families too much.

The biological ideal is a social norm yet sociobiologists could argue that it is rooted in biological desires and reflected through social norms and institutions. My respondents discuss social/cultural influences reinforced by institutions such as the legal and medical systems and even one's own family.

Many respondents are aware of social pressures and influences. Rationally Marita knows that she would feel the same love for an adopted child yet guiltily admits that she is swayed by the societal idea that biological "is better and that's the way it should be. But neither of us believes it's true...we just buy into it." One respondent pointed out the power of childbearing stories:

It is hard to let go of the fact that you're gonna have that story. None of our peer group have the adoption story. I have lots of friends with stories of getting pregnant, being pregnant and giving birth. That's a story that you can tell that's culturally familiar and it's also familiar in my family. My mom has this story of going into labor with me and how it was when she was pregnant with me. Her mom had that same story to tell her and her grandmother...you know. My whole family generations back has had this certain kind of story to tell their children and ours is going to be really different.<sup>1</sup>

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<sup>1</sup> She does state, however, that an adoption story is equally special.

The primacy of a biological family is also reinforced by the medical industry. One can see this just in the existence of the booming fertility industry. As one woman points out, ARTs give people the option to try and create a normative family, “Now the technology is there and can give you your dream.” She explains that “we didn’t want to adopt and look back and say, ‘gosh, when I was the right age we should have tried that.’” Williams’ (1990) IVF recipients also felt like they had to do everything possible to resolve the infertility issue. Further, as will be seen further in depth later in the chapter, medical professionals suggest that donor genetic material match physical characteristics of the parent(s), indicating a shroud of secrecy involved in the use of donor material.

The fertility industry and the legal system also reflect a heteronormative ideology in several ways (Mundy 2007). For example, one of my lesbian respondents said that she was denied care by several fertility specialists because “she was not married.” She felt that this was a way to deny lesbians and perhaps this is the case; as Mundy (2007) notes, physicians in the US can be charged with discrimination against gays but no such legally protected category exists for single women.

I believe my respondents are trying to make a biological family in order to fit into a *heteronormative* model, perhaps even Patty and Jalila, the two lesbians in this study. Although Grob and Rothman (2005) talk about

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<sup>2</sup> Fearing regret is not an uncommon feeling, even Fisher’s (1992) childless women worry about regretting their decision.



literature that shows that lesbian and gay families with children talk about the families that they “choose,” breaking the idea of genetic connectedness of family, I see both this break plus a re-creation of a heteronormative, genetic family in the two lesbians in the study. Patty talks about how her partner feels like a man trapped in a woman’s body, which was one reason that Patty carried the pregnancy.

The same was true for Jalila, who is already in a very non-conventional family, an Arab-American woman partnered with a Mexican-American woman, yet she talks about somewhat fitting into a male/female family model: “Being pregnant, giving birth, all that is motherhood. I wanted that, my partner and I sort of identify with butch/femme dynamics and that complemented this idea.” Thus both lesbians used fertility treatments to reinforce a mother and father model by not only choosing who will be pregnant but also by matching sperm donor characteristics to the parent who was not contributing the egg.

### **(Re)Creating a “Normal” Family with Donor Genetic Material**

One might question how donor genetic material fits into people’s view of a biologically related family. Although Peter, whose wife had non-viable ova due to her age and a medical condition, says that using donor egg “completely scrambled the traditional model of motherhood. You can have a genetic mother, a legal mother, a surrogate mother, then a step-mother,” he is

still creating a normative family, just with other genetic material, as the fact that donor egg was used is being kept secret until his children are adults.

Interestingly, using donor genetic material creates new biological ties and forces many people to be more flexible in their ideas of family. Iris, a former marketing manager turned homemaker, who used a donor egg, is curious about both the biological mother and the other couple who shared the other ova the donor produced. She says that if someday her son wants to search for his biological half-siblings they could possibly have a “great relationship and a lifelong friendship, or it could turn out badly.” Iris is not the only one with openness to this type of family as many mothers who have used the same sperm donor seek each other out on a website that connects people via anonymous sperm donor identification numbers (Harmon 2006). Thus, people are open to different family forms, yet still base ideas of family on biological connectedness.

The Hollanders downplayed the idea of biological relatedness as they had initially been open to adoption, yet could not adopt due to their older ages. Although Christine really wanted to be pregnant, she just thought they had no other options due to Bob's vasectomy. Ultimately they used both donor egg and donor sperm and thus were somewhat more flexible with their idea of biological connectedness between parent and child. Yet they did not completely let go of the importance of blood connections because they used the same donor egg and donor sperm for both of their children, hoping that

the kids would feel a stronger connection to each other due to their biological relatedness. As Bob says, "If something were to happen to us, then they are really going to be blood brothers." Christine feels the same way, "To be related to each other, we'd like to think that it would create a little more closeness...the blood and genetics brings them closer." Further, they say that because they have many social and biological relationships with other family members; they see the genetic relatedness between their sons as a way "that they can actually be brothers. This is a separate family." Yet the biological connection they want is only to be between their two children as they talk about having no interest in going to reunions set up for kids from the same sperm donor. In this way they are still drawing on past family norms of biological relatedness to create a new family form. They were even comfortable with the possibility that their sons could be fraternal twins yet spaced a few years apart due to trying to use a frozen embryo from their first round of treatments.

Jalila and Iris also talk about the bond between their children.

Whereas the Hollanders think that a genetic connection will help their sons bond to each other, Jalila and Iris add a social element to the discussion. Jalila is planning on getting pregnant again soon and cannot use the same donor (she could not afford to buy two vials of the same sperm at one time and the donor is not available anymore) plus she does not want to define family strictly by biology. What she worries about is if the kids want to find

their donors and get different responses from their biological fathers, will one child resent the other one who found her/his “father?” Iris also seems to talk about the social implications. Her first child is from an egg donor and then she got pregnant naturally a few months after the birth. “The only thing I worry about with the second one, I hope it will never be an issue between the two of them.”

The importance of sibling bonding is not something other sociological studies have touched upon yet it seems to be an important social issue for some of my respondents. There is a website that matches family members by sperm donor identification numbers, meaning that children conceived from the same sperm donor can locate one another. Biology does matter to siblings as there are over a thousand matches between half-siblings. As journalist Amy Harmon (2005) reports, several siblings who have met talk about a “sense of familiarity that seems largely irrational, given the absence of a father, unrelated mothers and often divergent interests” (p.2). One mother thinks that this bonding helps her son feel connected to an abstract concept of his genetic father.

I see the use of sperm and/or egg donors both perpetuating the idea of biological connectedness yet also simultaneously requiring more flexibility in ideas of biological relatedness to children and ideas of family, albeit a middle-class family. Harmon (2005) also describes the half-siblings finding each other on the anonymous sperm donor registry as “building a new definition of

family that both rests on biology and transcends it” (p.3). In some respects, then, the postmodern family form does create some shift in ideas on family and this reflects the postmodern condition of fluid boundaries.

### **“Ownership” of Biological Children**

The legal system and public policy are other social influences for wanting biological children. Obviously no parent wants to lose her/his child and the legal system and public policy see biology as the primary indicator of family relationships (Grob and Rothman 2005). Egg and sperm donors understand these “rules” as well and thus prefer to remain anonymous. Thus the fertility industry prefers anonymous donors in order to maintain business; other countries saw a drop in the rate of sperm donors when they changed their disclosure laws (see Harmon 2006).

My respondents who purchased and used donor genetic material all opted for anonymous donation, some discussing a fear of a known donor’s legal rights. Iris thought about using her sister in-law’s egg but talks about the response she got from her fertility clinic: “They recommend not to do that, there can be problems down the road. I wanted it to be anonymous.” There were also the two lesbians who used anonymous donor sperm instead of asking a friend or relative. As one explained: “It’s partly about a level of fear how the culture would still give him ownership of our child” because the legal system both puts primacy on biological connectedness and often does not

rule in favor of gay parents. The other woman expresses similar fears that she and her partner have:

We want to be sole parents. It sounds selfish now when I say it out loud. We didn't want someone acting as that third parent or coming back a few years down the road not wanting to give up parental rights.

Peter and Iris both used donor egg and feared that with adoption the birth parent could come back and try to take the child away. Iris had a friend who was two weeks away from adoption when the birth mother changed her mind and Peter mentions a particular case he read about in the newspaper, "Rare cases, obviously, but it does go through your head when you're thinking about this sort of stuff." And although he says it does not worry him, since the legal issues with donor egg and sperm are so new and have not been entirely resolved, he has thought about the egg donor coming back someday to see or claim his kids.

Both the biomedical and legal rhetoric is couched in what Bell hooks (1984) says is a general view in society that children are personal property. Although this was not the case historically, currently the larger community is rarely expected or welcome to weigh in on family matters that are now considered private (Demos 1986). Now this idea can be analyzed at the "pre-child" level of genetic material, something so far largely absent in the infertility literature.

The ideas about ownership of one's own genetic material is reflected in several of my respondents. Although she did not have in vitro fertilization, Robin

theorizes about the fears of having to share or donate frozen embryos: “It was really scary to think about giving them to someone else. Even though it would be their child, it would still be our child in a way. I just knew that I couldn’t do that.”

Because people felt like personal DNA is private property, they did not feel like they had to exclusively own *another* person’s genetic material. All of my interviewees who used donor egg split the eggs with other couples for financial reasons. Harmon (2005) also reports a similar ideology in women who send leftover vials of sperm to other women who want to have a second child with the same sperm and found there was none left to buy.

### **Controlling Personal Characteristics**

In the previous section we saw the idea of biology as a means to [somewhat] control family formation. Parents also favor having biological children because they feel like they have some control over the personal characteristics of their children. How important this was for people ranged from quite important to an “added benefit” of using known genetic material (either their own or a donor’s). The level of importance seems to depend on where in the fertility process one is situated. When discussing initial attempts to have a biological child, people discussed a desire for their children to look and be like themselves and their partners. After several unsuccessful attempts, however, many then talk about feeling “desperate” and being less

“picky” about wanting control over their children’s traits-they just wanted a child! Finally, if people had to move on to donor material (or being with it for the lesbians) they were presented with a multitude of personal characteristic opinions based on donor profiles. So again, they became more involved in wanting to control the selection of personal characteristics.

Using one’s own genetic material was a comfort to many as they felt like they knew what traits were being passed on to their children. This is not to say that parents only rely on biology; as Edward, who adopted a child, and Peter, who used donor egg, note, respectively:

The impact you have on a child is probably the...most direct...strongest influence you have in your life. So it’s natural...to want to leave a positive impact in the world, so you can feel like you’ve done something...productive in your life.

I’ll be egotistical. I think we’re a little smarter, a little more liberal and a little more ecologically minded than half the country and I just wanted to bring more good people into the world.

Yet similar to the respondents in other studies (see Parry 2005), the general societal dependence on genes as explanatory factors for physical features, personality, and health was reflected by many of my interviewees as they relied on genes to try to control some of their children’s traits. Whereas none of my respondents talk about the possibility of adversely influencing health, such as the increased chances for birth defects through the use of ARTs (see Mundy 2007), they talk about controlling fetal health through pregnancy and breastfeeding. Most discussion of control however, is at at the DNA level. For several, they felt like they knew their own DNA through an



intimate knowledge of their own observable traits. “What you see is what you get.” For example, Peter wanted a child that was related to both he and his partner: “knowing what you are getting...for better or for worse.” Cary also says, “We have our own genetic problems. At least I know what those are.” He had an “all or nothing” attitude toward “personal” DNA versus donor material:

It is very much akin to adoption. It’s not ours. It’s not combining our DNA. It’s something different than that. The donor egg thing doesn’t really appeal to me in that sense. If something wasn’t working, the risk would not be worth the actual reward, unless [Leslie] wanted the actual childbirth.

Adoption, then, was seen by many as giving up all control of what a child will be like. This lack of control is frightening and conjures up bad scenarios in some people’s minds. They like themselves and mostly focus on their positive features. As Peter writes in his journal, “Naturally, I think we have superior genes, and I want them passed along.” Even people’s own less-than-desirable traits are not as mysterious; they know what they are and for the most part how to live with their more negative attributes. All of my respondents have managed to be relatively successful in life.

Further, the fear of the unknown seems to come into play as some also imagine that a stranger has worse problems than they do, or just problems that they are unfamiliar with. For example, some view parents who put their kids up for adoption as less fortunate and thus create children with health and/or emotional problems. In his journal Peter explains that he is more

comfortable with donor egg than adoption due to more genetic control: “Who puts their kids up for adoption? Not the smart, well-educated, intelligent types. It’s the idiotic white-trash losers who can’t stop dropping litters of brats.”

This being said, the lack of control over an adopted child is not only genetic. As Cary states, “I worry some with adoption about problems that the kid would have, either from a genetic perspective or early environment perspective.”

Control was also seen as an important theme among those who used donor material. They noted the advantage of having a child that is still half-biologically related to them. They were also sold on the idea that they have some choice over the physical, personality, and health characteristics of their children through the selection of certain genetic material; that selecting specific donor material was a way to regain some of the control lost by not having their one partner’s DNA represented in the genetic mix.

Although several of these people specifically said that they were not trying to get “designer children,” they still had some control over the selection of their children’s traits simply due to the options given to them by the fertility industry. Some scholars argue that having control over what is considered a “positive” trait is an exertion of power and privilege, or what I might term “positive eugenics.” For example, sperm banks reinforce certain ideas of masculinity (Schmidt and Moore 1998) by discouraging semen from gay,

short (below 5' 10"), high school drop out, ill, and disabled men. There is also probably not a large demand for men that fit those categories and as such both banks and consumers co-produce the "perfect" man (Moore 2007).

Whereas using one's own DNA is preferable, when this is no longer an option people shift their ideas and focus on the possible, more positive, aspects of using someone else's DNA. They cannot worry about passing on their health (or other) problems and assume that the donor has better DNA due to a "rigorous" screening process and "full" disclosure on donor profiles. The donor profile, then, takes on a life of its own as it represents a "super-human," or someone only with positive traits. For example, in my study, Patty tells me of one advantage to not using sperm from a friend or relative, "There's always going to be something about someone that you're like, 'I don't know about that so much. There's this crazy tic thing that he does.'" And one of the single mothers who journalist Harmon (2005) interviewed sees her donor as "some consolation for not getting to fall in love with someone who would most likely have been more flawed" (p.2). And other single woman report's seeing friends divorce or in unhappy marriages say they are not willing to settle for "Mr. Almost Right" (p.3).

Thus, some who used donor material talk about having *more* control than if they used their own DNA. This may be a case of "biomedical enhancement" that some medical sociologists have written about coming in the near future (see Conrad 2005); perhaps the future is here with fertility

treatments. The idea of control is sold to users through the presentation of a multitude of options of minute details to choose from (in the following sections I give examples of this rhetoric of consumer choice) if one is willing to pay for it. For example, one can pay extra for a multitude of health or genetic screenings of the semen to get what Moore (2007) calls “technosemen” (p.107).

Given this idea of controlling traits through DNA, combined with the dawning of consumer genetics where one can buy their own genetic profile where the cost keeps decreasing and currently ranges from \$400-\$100,000 depending on how complete a profile one purchases (Pinker 2009), perhaps the next step in ARTs will be screening personal DNA and then deciding whether one wants to use their own, or another person’s DNA, to create the type of children they want.

My respondents do note, however, that with so many options for physical, health, and personality characteristics, one cannot find the perfect combination of the multitude of traits to reflect themselves, their partner, or the combination of the two (or perhaps some wishful thinking of an ideal child?) although Moore (2007) says that they can fanaticize about it given the new, interactive sperm bank websites where people can list their most desired traits and try to find matches.

When my respondents talk about picking traits, they often view the passing of genetic material in a binary fashion; they usually mention the child

being like one parent or the other rather than a combination of the two, or other ancestors. They also do not note the possibility of “unseen” traits from recessive genes or other genetic attributes that may emerge only under certain environmental conditions. Current scientific research has noted that only a few traits are linked to a single gene and most often genes operate together and/or have environmental interactions (Conrad 1999; Gibbon 2006) yet we often hear the watered down version in the popular media where scientist are looking for, or have found *the* gene for a particular trait.

### Health

Health concerns were brought up several times. Many think that knowing personal health history, irrespective of environment, is important, reflecting the current trend of the medical establishment to look for genetic causes of both poor and good health. As Conrad (1999) states, genetics is at the forefront of medical and public discourse about illness and health. For example, one respondent discusses the advantage of having a biological child by talking of a friend who was adopted through a closed adoption and does not know her health history and now has some illnesses. Yet this woman does not discuss her diagnosis of polycystic ovarian syndrome and the possibility that she could have passed that along to her biological children.

For those who used donor genetic material, they think that having the health histories from the egg and/or sperm donors is very important

information, and some have a deeper understanding of genetic interactions and/or health. For example, some used the health histories to avoid certain illnesses that run in their families to reduce the chances of inheriting the diseases. One woman picked a sperm donor without a history of diabetes because it runs in her family. The Hollanders are also more impressed with the health histories of their sperm and egg donors than their own, stating: “Our children, other than environment, have a greater chance of being healthy.”

All, however, expected getting what they paid for. In other words, they were not prepared for traits to emerge that were *not* listed in donor profiles. Patty paid an extra fee to get the medical history of her sperm donor, which ended up being to no avail because her son has a genetic disorder. Both Patty and the anonymous sperm donor are recessive carriers for a rare genetic disorder that occurs in 1 in 40,000 live births. It is so rare that neither was tested and thus Patty unknowingly gave her son this disorder that now requires extremely careful monitoring of his protein intake, so careful that she was not allowed to breastfeed.

Knowing one’s health history has its advantages, as there are some genetic connections to some health conditions. Another, rarer case is mentioned by the Hollanders who state that insurance companies cannot hold their health histories over their children’s heads since they used an egg and a sperm donor. Still, one still cannot completely avoid or alleviate illnesses or

genetic disorders with this information. First, knowing one's health history at the time of donation is incomplete knowledge as people develop health problems as they age. Further, there are those rare disorders that do not get tested, and as seen in Patty's case, one cannot fully escape the odds. Yet last, and possibly most importantly, one can insert a more general medical sociology critique of a reliance on genes as explanatory factors for health and illness that omits influencing factors in our direct and larger environments. This sense of randomness is reflected by Mai, who adopted: "It's just biology. Most people have some pretty messed up genetics anyway."

#### Physical traits

One factor parents want to control for is physical resemblance (also see Grace 2008). Or as Mundy (2007) states, parents want their children to look like them, to "'embody' their love for each other (p.117)." Cameron: "This is going to sound goofy, I wanted to see what my kids would look like I realized my partner would be reflected too." Marita enjoys saying, "oh he has your eyes or he pouts just like you." When talking about using donor egg, one woman states, "You get to decide a little if your child should look like you." Some want to see a combination of themselves and/or their partners.

From a symbolic interactionist standpoint, resemblance is an outward marker, or a symbolic representation, of our normative construction of biological family. The symbols get reinforced as a talking point in social circles or even among strangers, who, for example, will comment in the

grocery store on children looking like parents. As such, physical resemblance is somewhat socially constructed and people see what they want to see. This occurs through “reinforcing” comments, such as an example from my partner, who was adopted yet growing up people would say he looked like his dad. Others question why family members *do not* look alike. Drawing on my own personal experience, my partner also has one adopted sister and one sister who is the biological offspring of their parents. A new neighbor once curiously commented on the difference between the two sisters’ hair. My respondents who used donor material state that they now try to avoid making comments on resemblance and Mundy (2007) notes that comments such as “s/he does/n't look like you” reminds parents who used donor material of their infertility and worries them that it will upset the children.

For those respondents who used donor genetic material, all chose physical characteristics that somewhat matched themselves and/or their partners. For those using egg donors, this is done with both a written description of the donor’s physical characteristics and a photo of the donor, either or both as a child and an adult. Sperm donor descriptions only rely on written descriptions, yet these can be quite detailed, especially if one pays extra money for additional information. Interestingly, the sexism inherent in society that places more importance on physical attractiveness for women is also seen in the fertility industry—one can get a picture of an egg donor, but not a sperm donor.



The selection of egg donor traits can be done individually by going through a private company online or by medical staff at the fertility clinic. Upon staff recommendation, egg donors are matched to recipients on physical characteristics. Sperm banks list “phenotypes” as their first, and key factor (Moore 2007) although both fertility clinics and sperm banks also collect information on personality and health traits. In essence the fertility industry is maintaining the ideology of the normative family, or at least the reflection of the normative family.

These fertility clinic staff match available donors to couples who have been on the waiting list the longest so exact matches are never possible. Although couples can reject a selected donor, this extends their waiting time so all of my respondents accepted all selected donors. This, to some extent, makes some recipients more flexible with the idea of resemblance. For example, Christine talks about using a donor egg:

There were some physical characteristics that were similar to mine. At this point, we didn't really care. They didn't really give us any choices. 'This woman is available. She has lots of eggs. You want to get pregnant.'

Peter also reflects on getting the first available donor egg from their clinic who roughly matched their characteristics: “You get a little less exclusive. Let me just have the kid, who cares what it looks like.” He did, however, talk about not wanting an someone *too* different, “If you have really short parents and they give birth to a 6'6” basketball player, people are going to go, ‘Where'd the tall one come from?’” He did not, however, want to go so

far as choose very specific characteristics of a donor through an on-line service: "...the meat market. They literally have pictures of the girls on there and I'm really uncomfortable with the thought of designer children." On the other hand, Peter writes in his journal: "I do kinda like the fact that they potentially can weed out some of the less prime embryos before implantation."

None of my respondents used on-line egg donors and although they did select preferred traits for their egg donors, as stated earlier, they accepted all donor invitations. Apparently some people are finicky, one of my respondents said that the woman who does the donor matching at her clinic told her that some "reject profile after profile looking for the perfect person."

The selection of sperm donors, on the other hand, is done by individuals. There are only a few large sperm donor companies in the US. The most widely used are the commercial enterprises although there is one nonprofit that will deliver sperm directly to a woman rather than to her physician (Moore 2007), which Christine Hollander used.

Patty tried to match the sperm donor with her partner and describes the physical profile:

How big are his eyes? How wide-set are his eyes? How big is his nose? Is it wide? Is it flat? Does it have a hook in it? How wide are his lips? How big are his lips? Does he have a big forehead? Are his ear lobes connected? Are they disconnected? If I were a police sketch artist, I could probably draw you a sketch of what this guy looks like. It is that detailed.

All of these attempts at matching, however, were trumped by the inability to truly control genetic characteristics. Patty used her egg with donor sperm with similar characteristics to her partner; she has a son that looks like her. Iris also has a son who looks like her even though she has no genetic connection to him; she used her partner's sperm and a donor egg.

Sperm profiles also include the ethnicity of the donors, seemingly to match physical characteristics yet this meant more for the Hollanders. One way that parents create bonds within their families is by transmitting ethnicity. Whereas sociologists view ethnicity and its maintenance in social norms and practices, Christine and Bob Hollander, a music and biology teacher respectively, wanted to pass ethnicity on at the genetic level. Their Scandinavian and Eastern European heritages are important to them so they looked for these backgrounds in their donors. Many people choose donor genetic material based on race and/or physical features that are similar to themselves but Christine stressed the ethnicity factor. She said that she would feel like she was "lying" to her sons, implying that one cannot truly engage in ethnic practices and feel ethnic bonds without the proper genes. The Hollanders could not find an exact ethnic match but found a donor who had heritage from neighboring European countries and thought that genetically it was "close enough," again showing that ethnicity is genetic and not socially constructed (i.e. based on specific language, customs, foods, etc).

There are a few non-white sperm donors and Jalila and her partner chose Latino sperm with the correct brownish shade because of their pride in their Saudi Arabian and Mexican heritages. This, however, is bittersweet as Jalila also talks about this bringing up the emotional stress of discrimination of their family as a whole and issues that her child will have to face:

It was also a really strange time to be going through all of this. The man/women marriage debate was all amping up in particular ways and the way Arabs were viewed I think also gave a feverish pitch. So then it was all complemented by the view of Mexicans, illegal immigrants. I felt like the political machines used fear and hatred of Arabs, Mexicans, and queers. That was the pretty package of our last election presidential election. Here we were trying to create a family because we love all those things in a political context we were to be most hated and feared.

### Personality

When choosing an egg donor Iris' partner put athletic ability on his list of preferences yet education was most important for them as they see talent and intelligence as partially genetically determined. This raises the question of whether athleticism is a personality trait or a physical endowment. (Is this an attempt to live vicariously through your child, picking designer babies that reflect your ideal and does not necessarily reflect your own genetic features?)

Patty paid an extra fee to get the online personality profiles of sperm donors:

You can find out the most minute details of this person's life: their favorite color is purple, their favorite rock band was AC/DC, their favorite movie was *Cocktail*. This is what they got on their SAT. This

is their GPA in high school. This is the group they belonged to, etc., etc., etc., and on, and on, and on.

Whereas there is a short profile description for every sperm donor, Moore (2007) calls them "teasers" (p.100) to entice recipients to buy the longer profiles. Perhaps it was good marketing, but Patty was also willing to spend the money and time on these profiles because she believes that personality is nature over nurture. Here she describes her son's similarities to her partner due to matching the sperm:

The donor we selected for James is an industrial engineer, and his - I wanna call it the Keirsey scale – he was right on with Renee. When I look at James and some of the things he does, I mean, it's Renee. It's absolutely Renee. Now that could be because Renee's raising him, but I think a lot of it is because he has those industrial engineer personality traits that were already in him from the donor. But the two of them act a lot alike. He may look like me, but he acts like Renee.

This is an example of dichotomous genetic arguments: looks like her egg but acts like the sperm donor.

None of my interviewees mention thinking about traits that were *not* listed in donor profiles. A whole person cannot be displayed in a few paragraphs. Further, they do not discuss that there is a selective process, by the for-profit agency or the donor who gets paid, about what gets included and/or omitted. Whereas the list of personality traits (that one can pay extra for) seems endless and somewhat descriptive, it cannot truly be endless. The sperm donor is not writing an autobiography and they are selling themselves so most of their profile should be positive. Using a symbolic interactionist

approach, one can also point out that many personality traits are created contextually. Even bioevolutionary theorists believe that certain traits lie dormant and others emerge depending on the environment (see Buss 2003).

Those who adopted, such as Mai, however, do not feel so strongly about biology, "It's just DNA. To me, it doesn't tell you who you are. It's not going to build your personality. My husband is more like his adopted sister than his biological sister." Those who adopted do not have the same feelings of control. Ada talks about adoption and being willing to take kids with problems, she says maybe there is less of a chance of having a biological child with problems but still:

You don't know what's going to happen, I guess the fear is the same with giving birth, are you going to find yourself in a situation you can't handle because the child has needs you can't meet? A lot of people have this idea that if you adopt a kid it's gonna be damaged or weird or something and well your own kid, you know you give birth, who knows what's gonna happen.

Mai even goes to the polar opposite. Her partner's family adopted kids so both she and her partner have very positive attitudes toward adoption. She thinks that one can have *more* control over the selection of a child if one adopts. She talks about a good friend of hers who had a great pregnancy, a perfect sonogram, and has a son with "all of these problems, a chromosomal misfire, he is autistic. That scares me." On the other hand, she says with adoption that:

...you can show up at the hospital and say no. You can walk away. You may feel bad, but you can say no. They can come home with you

for a couple weeks, and if it doesn't work out, you can say no. If you have your own child, you have to keep it.

Interestingly, Iris used donor egg but reflects Mai's idea of control to some extent when she describes matching the recipient couple to the egg donor: "we went in there and filled out our profile, which is sort of like an adoption thing where you say what you want, what you're looking for."

### **Family-Building Alternatives**

Although my respondents are using reproductive technologies with the hope of fulfilling the heteronormative dream, this attitude can shift once they decide to stop treatments. After initial attempts to create a normative family are unsuccessful, people are faced with several options—move to other and other higher tech procedures, be without children, or pursue other avenues to create family. Parry's (2005) unsuccessful IVF respondents became open to other family forms and I find this in my study as well, even among those who decided not to move on to IVF. For example, Edward and his partner decided that high-impact procedures were too invasive and time consuming and have adopted a baby. Although Edward had wanted a biological child he was always open to the idea of adoption. To him family can take multiple forms and connection is about shared history. He states that he feels like family with his in-laws, that they have "adopted me as an adult." Yet he also ponders the genetic connection:

I suppose I've thought about a biological child reflecting the genetic material of my parents and they're no longer here. That's all pretty abstract. I don't think about it that much, a little, and I think 'yeah, that'd be cool' but it's not a huge thing.

I did point out that his child will reflect how his parents raised him, and he said, "Exactly, it will reflect that even more I think."

Further, because Edward's parents have passed away and he has only one biological sibling he is excited about having a connection with the birth parent. "I have room in my life for more family, or semi-family members. Sometimes I think 'it can't work out well all the time' but it seems to work out well most of the time." He also thinks it is great that his child will have another set of grandparents beyond Ellen's parents.

Cassandra, a PhD student in music, is also open to creating a non-normative family, but it should not be similar to her initial ideal family. After tapping out financial resources on low-tech fertility treatments that were unsuccessful, in addition to some bad experiences with the medical establishment, she and her partner looked into adoption. They wanted to adopt an older child, not an infant, in large part because they felt uncomfortable with having the birth parent in the picture:

Talk about intrusion of other people into your life. When you adopt an older child, you are basically adopting a family. An older child will continue to have some contact often with other siblings, aunts and uncles, with grandparents – generally not with birth parents because they are being adopted out by the state for a reason. You are letting a lot of people into your life. I guess I saw a distinction somehow between trying to create the perfect family with your own little infant and 2 parents versus trying to create a totally different kind of family. Adopting an infant felt to me like trying to create the perfect little



family, and these birth parents are not supposed to be there. They're intruding on the idea of the family that we're trying to create, that we would have done ourselves if we could have.

Another alternative to having one's own biological children mentioned by both Parry's (2005) respondents as well as some of mine is reaching out to other people's children, such as nieces and nephews.

Cultural behaviors are driven more by options given than an unyielding set of values. This is akin to Swidler's (1986) tool kit analogy where there are several ideological options available and people pick the one(s) that are best suited for their current situation. Or as social/cultural family theories point out, as circumstances change, so do people's ideas of parenthood. As such, people may have various reasons to have biological children but many are ultimately willing to shift their own ideological frameworks. This could be justified by sociobiologists as the interaction of the biological and the social spheres in people's lives or it can discount sociobiology by showing the trumping of social conditions over biological desires.

## **Conclusion**

This chapter sets the background to why my respondents wanted children, and more specifically, biological children. In the next chapter I follow these individuals as they attempt to have children naturally, decide that there is a problem, and seek out a medical diagnosis.

## **Chapter Five: Standing on Nonfertile Ground: the Infertility Diagnosis**

### **Introduction**

In the previous chapter we followed 28 individuals in their decisions and pursuits to have biological children. We now follow them through the next steps in their journeys—what influences the decision to start trying to get pregnant? How do couples and physicians decide that getting pregnant is not working and that there are real indicators of infertility? Why are women's bodies the focus of (in)fertility problems and how does one make sense of a diagnosis of infertility? How does this diagnosis affect women's views of their bodies?

In this chapter we begin with these individuals' quests to try to have children. Whether or not my respondents had "always wanted children," or whether they evolved into the decision, all followed the traditional, cultural script and started trying to have children after they were married and in stable occupational and geographic positions. Aside from a few women who had medical issues, most respondents did not suspect that there would be infertility issues and were thus confronted with the decision of knowing the right time to seek medical help. Many waited the standard year length of time defined by the medical industry, but a few others were more "impatient" and only waited several months.

Women were the first to initiate contact with the medical community and most physicians also responded with gendered lenses—women were always the first, and sometimes the only ones to get tested, and some women were under- or over-treated based on an “aging egg” theory that was applied too universally. As such, the infertility diagnosis was almost always attached to the woman’s body (sometimes incorrectly), especially polycystic ovarian syndrome, which encompasses a variety of symptoms yet seems to be a new case of the medicalization of women’s bodies.

Women’s responses to the diagnoses were varied. Whereas there is relief in finally discovering a problem that can be followed up with a treatment plan, the diagnosis evoked feelings of disappointment, guilt, and anger in not having a “normal” female body and not being able to fulfill goals and/or expectations.

### **The Time is Right to Get Pregnant**

Although my respondents gave biological and social reasons for wanting biological children (as seen in the last chapter), social and contextual reasons were given for *when* to have children. Beyond general feelings of wanting children, context mattered; specific situations made a certain time the right time to start trying and these situations followed the traditional, cultural script. For example, for most, starting to have a family was a natural progression after settling down into a certain lifestyle in terms of jobs,

educational degrees, geographic location, and being in stable relationships. One woman is a bit uncomfortable with this justification, “You hate to be so trite about it and say it was the next logical thing,” but others are comfortable with the convergence of a constellation of life events:

We had moved from here to there, and we both worked high-energy, stressful jobs in the corporate world. We decided to move back here, so that we could take over a family business and buy a house. I guess, having a kid just became the next step. I always thought I wanted to have a child. I guess it just worked out at that time.

Parenthood has long been a socially defined vital role for married couples (Crowe 1985; Fisher 1992). Some of Ulrich and Weatherall’s (2000) respondents, as well as half of my respondents, especially focus on partnerships being important indicators to both themselves and others that children should be an addition to their families. Couples, and especially women, who had been recently married, or married for a few years, felt pressure to have children. In Marita’s case, although she was only 26 years old when she got married, her gynecologist suggested that she start trying to have kids due to her history of irregular periods. Perhaps the change in physician attitude was due to having a new doctor, but Marita attributes it to her new marital status:

My very first gynecologist appointment after we got married...the conversation was very different with her, which is funny how they change their tune, how it becomes socially acceptable to start talking about are you ready to start having children. She asked and I said we want children and I don’t know if we’re ready right this second. Then she went into the ‘well looking at your history I’m concerned about fertility.’ I went home and told my brand new husband.

One woman even talks about practical strangers asking about having kids:

...talking to someone's mom at the baby shower, and they would be so excited about being a grandmother. They'd say, 'Oh, when are you going to have kids?' Oh, that was the worst.

For another woman, embracing her new status as a married woman was instantaneous. She had not wanted kids and then as soon as she got married she was "desperate" for them: "it's just a little switch went on." And of course, it is not only being married that is important, but being married to the right person. One woman and her partner had both been previously married and had wanted children but did not find their first spouses fit for parenthood.

Jalila notes her use of the word "natural" to describe the coupling of two lesbian ethnic minorities: "I think that it was just a natural progression into our relationship. Not to use the word 'natural,' you know, imperfect language." Jalila's personal politics had also changed from a radical feminist eschewal of children; she no longer felt that childbearing represented patriarchal control over women's bodies. Further, for both Jalila and Patty, the other lesbian in the study, getting serious about trying meant getting their finances in order, perhaps because they are in dual-female income households.

Although many said that they "have always known" that they wanted kids, others evolved into the idea based on social and contextual reasons. Some even felt strongly about *not* having kids before the change in attitude. Cassandra explains:

No, I didn't always want kids, and I didn't always want to be married. I could envision my life alone without a traditional family and be happy that way, even since I was a child. I know that's not typical. I think my parents were a little flummoxed by that. They have 4 kids, and they think, 'Wow, she doesn't want to be married and have kids. What's her experience been like in this family that we have created? There must be a reason that's driving her away from wanting to have a family.' They took it kinda personally. I think they got used to who I was, and I think that they figured that I would change as I grew older. And I did. So, I got married, and I still wasn't sure which route we would take – if we would have children, and when.

Cassandra and her partner had just moved to a new city and she had not yet started graduate school so she felt like it was time to add to the new chapter in their lives. She was also surrounded by family-focused primary groups of her family and the Mormon Church.

Mai has a similar journey:

When I was in college I was on a professional track. I thought I was gonna have a grand, glorious career that was gonna keep me busy on multiple continents speaking several languages. Getting married and having kids was never in the picture.

Meeting her husband, who came from a child-focused family, was what changed Mai.

There was also Peter, who talks about when he was in his 20s in graduate school and “terrified of kids” until he met his wife. He found someone that he loved and admired and wanted to experience a new “frontier” with her. In describing his want for parenthood he states, “You can only see it but you can't experience it. We were kind of curious to explore that.” They would have accepted childlessness but they did want to give having kids “their best shot.”

For Patty, the traumatic event of her father-in-law's death caused her philosophical existentialism. She had grown up in a family that was not close but she had built a comfortable life with her partner of many years and a job as a corporate art director. The loss of her partner's father made her reevaluate the idea of family as she saw how family came together. She wanted a family now so they could take care of each other and also enjoy good times together. "It really changed my ideas about how I wanted the last half of my life to be. I wanted there to be this family unit instead of just me and Renee."

Several men and women also mention getting older weighing in on their decisions to start a family; anywhere from 30 years old and up although 30 seemed to be the magic number for many women. As one respondent describes: "I won't be a young mom, but a younger mom. When my kid is 20 I'll be 50. I'll still be considered young."

### **Suspecting Infertility**

"Teenagers can get pregnant, how hard can it be for us?"

The majority of couples in this study assumed getting pregnant would be easy because of the larger societal idea that women's bodies are made to have babies. We grow up with the idea that pregnancy is the natural result of sexual contact if precautions are not taken and even get information to scare us into being sexually responsible. As one man says, "The thing that shocks

me the most is this isn't the story we got in high school. There was the idea that if you walked near a girl, she was gonna get pregnant." As such, most of the people I talked to had spent periods of their lives trying to avoid pregnancy and several point out the irony of trying not to get pregnant for so long only to find out it is a problem: "You spend those first years trying not to get knocked up. Then you try and the joke is on you." One woman even talks about the pregnancy scares: "a lot of worry that I could have gone without. Not to get personal but all the irregular cycles through our premarriage, there was always that 'oh no.'"

Whereas infertility was a non-issue fifty years ago because little was known about it scientifically and it was not discussed socially (Balasch 2000), today infertility finds its way into the media, discussion in social circles, and a fertility industry that nets 3 billion dollars annually (Sabourin 2006). As such, when pregnancy is not working, an obvious next step is to seek medical advice. First, because greater help for infertility is available to couples today than a few decades ago, and because more people are aware of this help (Balasch 2000), turning to the medical community seemed to be the next logical step.

As Webb and Daniluck (1999) and Silva and Machado (2008) report, the male partners in their studies did not think that there could be a fertility problem, which also seems to be the case for many of my male respondents.



Ultimately this leads to women doing more of the worrying and “emotion work” (see Hochschild 2003) at this stage of the infertility process.

### **Initiating Contact with the Medical Community**

What is the next step after a fertility problem is suspected? In this section I discuss why women initiate contact with the medical community, when they decide to do so, and what medical professional they seek out first.

Women in this study overwhelmingly took the lead in pursuing medical treatment for infertility, as has been found in other studies (see Jordan & Revenson 1999; Meerabeau 1991). Why women initiated this contact may reflect the fact that motherhood is an integral part of a woman’s status and the belief that the problem resides in her body. For the women in Greil’s (1988) study, infertility became an issue of loss of control over their lives and role failure. And although infertility is role failure for men as well, men seem to want to avoid this stigma by avoiding diagnosis (see Webb and Daniluk 1999) whereas for women going to the doctor is a way to gain some control over the situation (although as will be seen in following paragraphs diagnosis also increases the reality of the problem as illness gets socially constructed). Others also suggest that women’s responsibilities accord more with the sick role (see Roberts 1985). Further, women are more accustomed to consulting doctors about reproduction, plus most people assume that the fertility problem

lies within the woman's body (see Stanway 1980), perhaps even some physicians who are socialized in the same society as everyone else.

All respondents started with allopathic doctors to get a diagnosis. Although Winnick (2005) reports that many Americans go directly to complementary and alternative medicine (CAM) practitioners, it seems as if CAM has not made a name for itself in infertility diagnosis and treatments yet.

For those without "symptoms," how does one know when it is time to seek out a diagnosis of infertility? Defining infertility is an important issue, since a diagnosis is a signal for a need for medical treatment which leads to major life changes. Further, the medical literature contends that finding the right time to test for infertility (and thus administer therapies) avoids both under- and overtreatment (see Brosens et al 2004).

Defining the existence and legitimacy of any medical condition can become contested terrain. There are some competing medical definitions for infertility, which highlight the tensions between the desire to produce a more 'accurate' diagnosis and the capacities of current diagnostic tests and treatments (Gleicher and Barad 2006). Although the World Health Organization defines infertility as a child is not conceived after two years of unprotected sexual intercourse with the same partner, some believe that the availability of (for profit) fertility treatments has cut that time to one year, or even six months, in the medical community (Sabourin 2006).

Fertility specialists contend that six months is an appropriate time period because diagnostic tests are becoming less invasive and more accurate and because new studies show that people are “more fertile than has previously been estimated.” Based on these accounts, 80-90% of couples get pregnant within six months. Thus the conclusion is that “most couples are likely to conceive early, and the question of subfertility can be raised after 6 months” (see Brosens et al 2004:1689,1690).

On the other hand, the National Collaborating Centre for Women's and Children's Health (2004) has data that, while not contradictory, can lead to the conclusion that couples and physicians should wait longer than six months to begin fertility diagnostics and therapies. Their data show that under normal conditions, about 84% of couples in the general population will conceive within one year if they do not use contraception. Of those who do not conceive in the first year, half will do so in the second year. Moreover, 94% of women over 35 and 77% of those over 38 will conceive after three years of trying. Some believe that if a waiting period of two years of unprotected sex was required before turning to assisted reproductive technologies, many people would be spared the strong emotional involvement in and financial stress of a physically demanding process that often poses health risks and that has a very debatable success rate (see Sabourin 2006).

About one-third of the women in my study used the medical definition of normalcy and waited approximately the standard year length of time before

going to the doctor; some got pregnant and miscarried within this time, some did not get pregnant at all. Three women only waited about half a year before going to a doctor. Only waiting a few months could be due partially to our “fast” and impatient culture (Mundy 2007). For Cameron, a marketing manager, it was “impatience” coupled with the idea of pregnancy as a normal, easy, and natural process for women:

We had no problems, we had a healthy sex life. He had never impregnated anyone, I had never been pregnant, but you go your whole life expecting it to be okay so I was really impatient.

One-fifth of the women sought medical attention when their bodies did not act “normally,” such as having multiple miscarriages or a combination of several factors, such as in the case of Peter’s wife who had two miscarriages, a history of endometriosis, and was “racing the clock” at 37 years of age.

After the decision to seek help is made couples are faced with the decision of *who* to see as there are a variety of physicians who provide fertility treatments (Glatstein et al 1997). There is a hierarchy of medical expertise, starting with family practitioners, moving on to obstetrician/gynecologists, and finally specialists, mostly known as REs (Reproductive Endocrinologists).

Does it matter who one sees? A few people started with family practitioners in part due to the idea of pregnancy as an easy, natural process. They also went in order to begin with less invasive treatments such as drug therapies, for cost, insurance and/or referral purposes, or in Ellen’s case, just being able to see someone. Ellen had gotten on a long waiting list at a fertility

clinic so after several months she went to her family practitioner and got referred to an endocrinologist, where she was placed on yet another waiting list. Thus, a few months later she went to a gynecologist who started the treatment process.

Most women, however, started with their OB/GYNs in hopes of having some specialization or expertise in the area of pregnancy and of resolving the problem(s) with less invasive and costly treatments. Further, getting in to an OB/GYN has a shorter waiting period than many fertility clinics. Yet similar to other people with chronic conditions (see Lonardi 2007), several people went to multiple doctors in search of a diagnosis when they were not satisfied with the answers or results that they received during their initial contact.

Whereas women were the first to initiate contact with the medical community, by the time a specialist was seen most male partners came to most visits, or at least as much as they could given time conflicts with work. This was not found in Meerabeau's British (1991) study where 70% of men went to the first specialist appointment but many did not attend other visits, in part due to the clinic atmosphere that was not as open to partners. Although I did not observe clinic atmosphere it seems as if clinics and/or men in my US study seem more open to their involvement, at least in an encouraging role.

## **Physician Responses to the Possibility of Infertility**

How do physicians respond to the possibility that their patients are infertile? Other sociological studies on fertility treatment recipients do not discuss differences between types of physicians because they focus on higher impact treatments that require a medical specialist. Because my recipients used both lower and higher impact treatments, my data gave me a snapshot of some different trends based on the type of physician seen. This section shows that generalists and specialists responded differently in terms of how quickly they acted, and their different views of a “normal” female body and what is considered “old.”

Based on my findings, it seems that whereas fertility doctors do not make the assumption that women can easily get pregnant, more generalists and OB/GYNs do, and this view of the naturalization of pregnancy is something that many women’s health advocates promote for the medical profession (Weisman 1998). Yet for those who are infertile, they complain that this slows the diagnostic process. For fertility specialists, they state that waiting too long favors “underconsumption” of ART (see Brosens et al 2004:1689).

Marita laments about gynecologists she had as a younger woman who assumed that she would have no problems getting pregnant (she does not think stereotypes about Latinas was one of the reasons her doctors assumed she could have kids) despite her irregular menstrual cycles. Marita is in her

early 30's and only now her current gynecologist found out that she has low progesterone. In the past few years she got the book, *Taking Control of Your Fertility*, which explains in detail how to detect different hormonal cycles through menstrual charting and now thinks that she could have figured her problem out herself, much earlier. Although it does not seem realistic that teachers would provide this reading material to pre-teens, she makes her point:

I really do feel cheated. That book did not have rocket science in it. When they split up the men and women in eighth grade they should just hand the girls this book. There's all this information and I felt like it was this big secret that somebody kept from me. Why don't you just tell what is normal and natural, that's what this is doing.

Sociologists have found that physicians' views and practices differ based on their stereotypes and values (see Mitchell and Georges 1998), including sexism (see Bouchard et al 1995) and I too found this to be the case. The idea of the naturalness of getting pregnant was accepted to such an extent that some doctors' actions and words verged on sexism. Some physicians reportedly thought that their female clients were overly concerned with trying to get pregnant, hypochondriacs, or mentally unstable. For example, one physician told Mai that her problems were "in her head" and prescribed an anti-depressant. Erin's first doctor said it was stress plus dismissed her vaginal pain issue during intercourse with a misogynistic comment about it needing to be painful for the man to enjoy himself.

Reece is a radiologist yet her physicians did not seem to respect her concerns coming from both her medical and personal knowledge of her body. She feels like her gynecologist thought she was too nervous about reproductive issues even though she was bleeding every two weeks. He told her to try for a year then come back. When she started bleeding most of the month she went to another gynecologist who discovered a hyperthyroid condition. He treated her for this but she still felt like he was not treating the infertility seriously. When Reece and her partner moved to another town she found a gynecologist who was more proactive; through a simple physical exam he found a huge cyst on her ovary. Yet Reece had to be assertive once again and after doing her own research asked the doctor if it could be endometriosis. The doctor doubted her self-diagnosis but confirmed it after performing surgery to remove the growth. Two surgeries later she remains with a functioning right fallopian tube unmatched to her one left ovary. In the end a fertility specialist got really aggressive because he thought that she eventually needed a hysterectomy.

Like Reece, several respondents experienced the frustration of having their expertise and opinions ignored by doctors. Hillary's nursing degree also gives her medical knowledge yet her OB/GYN told her to "try harder," meaning try to plan when to have intercourse instead of just seeing what happens, and they "tried harder" for another year. Hillary, like Reece, eventually had to take more initiative.



A few women took some of the diagnostic process into their own hands both before and during their medical diagnostic processes, which again, was not readily accepted by physicians. Sasha learned how to chart body temperature and cervical mucus. Her charting led her to believe that she had a certain hormonal imbalance and she felt empowered with this knowledge, felt in control, and felt like this information could be turned into action. “But my fertility doctor didn’t believe in charts. He was like, ‘Whatever, that doesn’t tell me anything.’” Other respondents also talk about their physicians’ technological imperative that discounts grounded, or non-allopathic knowledge as “unscientific.”

As Davis-Floyd & Dumit (1998) state, “biomedicine is accepted as best because it is expert, technological, scientific, and new, as opposed to wise, intersubjective, traditional, and time-tested” (p.2). The reliance on technology, then, takes patient agency out of the diagnostic (and treatment) process. The postmodern critique would be that these practices turn women into docile bodies, subjugated into objects of rationalist, medical knowledge (see Cartwright 1998; Franklin 1993; Mitchell & Georges 1998) that takes precedence over “embodied knowledge.”

By looking at the medical literature, it does seem like mucus quality was not given much attention in the past. In the last five years, however, a few studies have come out, showing that observations of mucus are highly effective for showing a six day fertile window, even for “subfertile” couples

(their window is three days). The conclusions are that “intercourse should occur on the days with optimal mucus quality...regardless of the exact timing relative to ovulation” and that “mucus observation is likely to become an essential part in the conservative management of patients attempting pregnancy.” They are saying, then, that mucus charting should be done first, and if this is not successful after six months a medical infertility investigation should be done (see Bronsens et al 2004:1690).

Sasha expected a negative response to her charting much from a western medicine doctor and did not push the issue but in retrospect thinks she could have forgone some of the other testing and possibly just done acupuncture and Chinese herbs because she saw results from these treatments on her charts. Subsequent sonograms and tests at the doctor’s office showed that in fact she had the hormonal imbalance that she had suspected based on her charts. Sasha said the only reason she continued with the specialist was because she had insurance and might as well exhaust all options.

The physician rejection of alternative medical practices has recently been reproached in major medical journals, stating that physicians should present a non-judgmental stance toward alternative medical practices in order to encourage patients to confide in them (Winnick 2005). Perhaps some of the physicians my interviewees talk about should also heed this advice as several of my subjects switched medical professionals. For example,

Cassandra switched OBs several times because she was not willing to work with an OB who was not open to her charting. This could be a good strategy for patients, however, because physician-patient relationships have an effect on health outcome (Arora 2003).

One of the problems with physicians not taking women's issues seriously is that it slows the diagnostic process. Mai is a real go-getter, earning an MBA, becoming a project manager, and bringing her baby to work with her every day. She was also pro-active in trying to figure out why she was feeling so bad generally and fertility issues were secondary. After seeing about six different doctors over a five year period she was finally sent to an RE who looked at her chart for "a minute and a half" and diagnosed her with polycystic ovarian syndrome. Erin also went to several doctors who did some tests, put her on fertility drugs, then finally diagnosed her with polycystic ovarian syndrome:

The doctor said it should have been more obvious, because I had been telling them that I had never had regular cycles. It made me mad at that point. They didn't seem to listen. The medication, we were buying ovulation kits and pregnancy tests – we thought, "Gosh, we've spent all this money. It takes them this long to come up with a diagnosis?" We finally went to an RE.

An exception to slow treatment is if generalists saw "real" indicators of major fertility problems based on a disease model. This information, however, needs to be communicated properly. Ella was having multiple miscarriages and her OB was running some tests; when he found a problem from one of her miscarried fetuses Ella said they "didn't communicate that

appropriately with me. So I had information but I didn't know what it was.”

The nurse practitioner read her the word for word medical terminology.

(Other medical sociology studies on cancer patients have also found that physicians often use medical terms that patients may not understand (Arora 2003)). Ella also mentions that the internet was not to the point where it is now where she could have easily researched it so it took her two years to figure out what exactly the doctors did know and then several more years to have a viable pregnancy, with more miscarriages and heartache in the process. Ella laments that her husband is over forty and she's almost there, “It was just unfortunate that we waited so long to get the level of testing that we did.”

Marita's gynecologist was also working under the assumption that her window of fertility was closing. Marita was the only one to note, not necessarily complain about, her gynecologist's aggressive treatments that made her try to get pregnant sooner than she would have on her own accord. She was young and only due to her history of irregular menstrual cycles did her gynecologist recommend trying to get pregnant right after she got married. It took the maximum 6 cycle allotment of Clomid, an ovulatory drug, to get pregnant and when Marita was done nursing her child she got some symptoms and was diagnosed with polycystic ovarian syndrome. At this time her gynecologist was aggressive once more with another recommendation to

start Clomid again as soon as possible if they want any more children because polycystic ovarian syndrome only gets worse.

An aging egg is also accepted as a sure sign of becoming less fertile. There is no “aging sperm” counterpart theory (see Fausto-Sterling 1992). This can work against women if they have fertility issues yet are not taken seriously because they are still considered young. For example, one woman is frustrated that she went through several years without pro-active physicians: “They felt like I was young, I was in my thirties and just to kind of wait.” There is no standard age that is considered “old,” although the line is usually drawn at 35. For example, Sasha’s gynecologist ran preliminary tests after two miscarriages but sent her to a fertility specialist right after the second. Sasha thought the urgency was not due to her miscarriages but due to her age. She was already 35, but maybe her gynecologist was attuned fertility treatments because Sasha mentioned that the doctor herself had triplets! But since Sasha was not attached to her gynecologist and had insurance she did not mind going to a specialist.

For specialists, however, many treat women in their early thirties, although some will treat even younger women; the national data show that 12% of ART cycles (not drug therapies) were on women under 30 years old. Jaime may be a casualty of being too young even for fertility specialists. She thinks that her initial specialist was too slow and perhaps this was because she is only in her late 20s. He almost seems reluctant to treat her:

He didn't do any testing on us or anything. Every time there was some sort of testing, he would say what we could do but that it was my choice. I would ask if he recommended it. He said it was up to me, that it was 50/50.

Women under 35 years old are by far the largest group of women using high impact fertility treatments; they represented 40% of all ART cycles carried out in 2005 (CDC 2008). As for my sample, eight women used ARTs, three women were in their late 30s/early 40s when they began seeking medical help, and five others were under the age of 35 but still got aggressive ART treatments.

It seems like these women are part of what Balasch (2000), an obstetrician, calls a "prognosis-oriented approach" where women are recommended to proceed to ARTs following an often incomplete diagnostic work-up (p. 2251). One of my respondents had an unknown diagnosis, four were diagnosed with polycystic ovarian syndrome, two had endometriosis, and one woman has one fallopian tube and ovary (both on the same side). These diagnoses by themselves do not necessarily call for high-impact ARTs. These women had all been started on drugs but were moved to IVF, some relatively quickly. Balasch (2000) believes that the liberal use of ARTs (and IVF more specifically) is due to the move away from diagnostic to prognostic fertility treatments and the progress in the success rates of IVF, which he says may be due to selecting younger patients rather than an improvement in the actual treatment.

“Old” eggs were definitely focused on more by generalists, and of course, specialists. This can be an advantage, or disadvantage for women, depending on whether the eggs really are the problem. In Ella’s case, one reason her physician focused on her body for so many years was because she was aging yet in the end they found that her husband has a chromosomal disorder. On the other hand, Peter’s wife was sped through the medical process. She was in her later 30s and had had two miscarriages. She was started right away on an advanced form of IVF where a fine needle directly injects the sperm into the egg. After several unsuccessful attempts she moved on to donor egg and became pregnant. (This is not to say that there is no patient agency, but there must also be the willingness of the couple to endure and pay for these high tech treatments).

The quick treatment for the aging Hollanders (she was in her mid 40s and he was in his later 50s) was due to both the aging body and the abundant use of high impact treatments (see Balasch 2000). Their specialist moved quickly; the motto being you try twice, then you move on to the next step (or stay at the highest level for awhile!). The Hollanders did two intra-uterine inseminations with donor sperm without success, then tried two IVFs with his sperm and donor egg, which resulted in one miscarriage and no pregnancy the second time. This led the doctor to the assumption that the sperm was not viable despite the fact that there had been a recent pregnancy. As a

result, the Hollanders moved on to both donor egg and donor sperm for 3 rounds of IVF until they had a successful pregnancy.

## **The Diagnostic Process**

As seen in the previous section, women's bodies are the focus of an infertility diagnostic work-up. The first part of this section discusses the gendered nature of focusing on women's bodies in order to diagnose infertility. Further, what do these tests tell us? Beyond age, what are the signs and symptoms for infertility? This is widely debated in the medical field. The second part of this section discusses the disagreement and lack of standardization in the medical field regarding diagnostic tests for infertility.

### Focus on Women's Bodies

#### Is Sperm Important?

Medical sociology literature finds that technology for fertility and procreation focuses on women's bodies (see Davis-Floyd & Dumit 1998; Saxton 1998; Whitbeck 1988) and this was the case in my study as many women physicians assumed that the problem must lie within the woman's body. In my sample all of the women got tested, and some were the only ones who got tested, such as Cameron and Sasha. Cameron explains that she "just took on the responsibility and assumed it was me" when she went to her OB/GYN. Both Sasha and Cameron used drug therapies for a short



period of time in order to get pregnant. Had they needed to go to the next steps their partners might have gotten tested. Although Sasha worked with a specialist who did not test her partner's semen, most specialists in my study did perform semen analyses, which has also been reported in the medical literature (see Glatstein et al 1997).

The medical literature, however, does note that there is variation in how physicians evaluate semen analyses and what they consider to be normal cutoff values (see Glatstein et al 1998). This was a problem for some couples in my study who worried about abnormal sperm values until another doctor assured them that the values were fine, and other men had to give more than one semen sample when they switched physicians in order to accommodate the testing practices of the new clinic. I also find a lack of standardization of care; for some, sperm analyses were done early in the diagnostic process, some later in the process after drug therapies on women had not been successful, and for others there never was a semen analysis.

The men in my study who did submit sperm samples talked about the professionalism of the staff, which did not make them feel awkward. This is contrary to Silva and Machado's (2008) Portuguese men who describe the process as "horrible" and "awkward" and Webb and Daniluk's (1999) Canadian respondents who use the terms "humiliating" and "awkward" (p. 13). Is there a cultural difference in men's perceptions or in medical practices? Is there a difference in presentation or perception of masculinity

based on levels of education since my sample is highly educated and can afford fertility treatments, which is not necessarily the case in countries with national health care?

Not testing men reinforces the idea that procreation is solely a woman's burden and simultaneously reinforces the idea of male virility. Or as one woman points out, testing can also reinforce a masculine pride of virility if test results come back positive. Her husband "had to go through all the fun testing and he was fine. They told him he had super swimmers and then he held onto that like that was his million dollar ticket."

Not running or delaying sperm analysis leads to a focus on women's bodies, which has its consequences. For one, it leads to women having the brunt of processing and negotiating medical information, and spending more time during the day en route and in doctor's offices. First, some of the testing can be invasive, or as one woman who "only" went through low impact procedures puts it, "you've been poked and prodded in so many ways that you feel like a farm animal." These tests can also be quite painful, such as a scan where dye is injected into the fallopian tubes. The logical consequence of this medicalization of women's bodies leads to more interventions and thus women take the brunt of the health risks.

Ignoring the possibility of a sperm issue also prolongs a painful and expensive diagnostic (and treatment) process. Ella was the only one to be tested during her multiple miscarriages until years later when they found a

chromosome issue with the sperm. All had assumed that the sperm was adequate because Ella's partner had fathered a child in his first marriage and had already fathered one child with Ella in their current marriage. Yet if anyone had dug any deeper they would have discovered that his first wife had also had miscarriages.

So does it really matter if a sperm issue is the cause for a couple's infertility? Some physicians say yes, because "superficially normal semen analyses can affect fertilization and...fertility potentials" (Gleicher and Barad 2006:1952). But what does this mean? For treatment purposes, it might be useful to know if there is a major sperm problem if donor sperm or genetic sperm sorting are recommended. For example, similar to Ella, after Erin kept miscarrying, finally a chromosomal problem was found with her partner's sperm, which ended up being both the larger problem and the one that required out of state medical travel for her husband for specialized genetic testing of the embryo which included combining embryonic cells with mouse cells and the sorting and selection of suitable sperm before being able to do IVF.

This focus on women shows a single-problem approach that many physicians in my study seemed to take, regardless of warnings in the medical literature. As Gleicher and Barad (2006) write, "initial diagnostic workups always encompass both partners, even if one partner presents with an obvious infertility problem" (p. 1952).

In other cases, a known sperm issue does not really matter because most treatment follows the same routine: treat the woman's body regardless if there is a sperm issue or not. Ellen talks about women she knows at her infertility support group:

They decided the problem lies with the husbands and they still put those women on fertility drugs, which just blows my mind. There was one whose husband's sperm count was low and she was going to do the IUI and they put her on 2 pills of Clomid for 5 days, which is not even what I started out at, they put her on both of the shots, and the progesterone suppositories. And I just can't believe that they are putting a healthy woman on all of those drugs. So that is really disappointing. That it's always the woman's problem even if it's not the woman's problem.

Ellen's story mirrors some of the cases of the women in this study. Although both Robin and Jaime's partners have low sperm motility, is the women are the ones taking drugs to get their cycles "perfectly" timed for sonograms and then inseminations. Their doctors are not being sexist or veering away from standard medical practice, rather, are reflecting the larger industry that has done more testing on women's bodies and thus has produced interventions for women's bodies, even if they are healthy bodies.

Women's bodies are also the focus if there is an unknown diagnosis. Six years and many IVFs later Iris has no clear diagnosis (maybe ovarian resistance) and wonders if there could be a sperm issue that current sperm analysis cannot detect. Erin's specialist also put her on fertility drugs even though there was no specific diagnosis. Eventually she was diagnosed with polycystic ovarian syndrome, which led the direction for fertility treatments until they found out that the larger issue was with her husband's sperm.

## Polycystic Ovarian Syndrome

Although other infertility studies have not specifically addressed ovarian syndrome (PCOS), the data in my study suggest that special attention needs to be paid to this diagnosis. PCOS is a hormonal imbalance and one of the most common endocrine disorders of women in the reproductive age group, with a prevalence of 4-12%. The medical literature states that a “subset of women with PCOS are infertile” and that “most women with PCOS ovulate intermittently thus conception may take longer than in other women” (Emedicine 2008). One-third of the women in my study received the PCOS diagnosis, which makes sense in that the women with PCOS who have fertility issues would be overrepresented.

Among women with the PCOS diagnosis in my study, one never got pregnant, three had difficulty getting pregnant even with fertility drugs, two got pregnant after a few months of drug therapy, and two got pregnant “accidentally.” Although there is a range in the severity of polycystic ovarian syndrome, as an outsider looking in it seems like this may be another case of the medicalization of women’s bodies. What is a severe enough case of PCOS to become labeled as infertile and in need of medical intervention?

Although there are specific criteria for having the disease that are found in blood tests and ultrasounds, I wonder if “healthy” women also have some of these symptoms that do not get found because they do not have

much trouble getting pregnant. Similar to OBs who do not see natural births and thus have a very medicalized concept of birth, do fertility physicians not see the range of normalcy in PCOS? Are fertility doctors more interested in treating patients than letting people take longer to conceive if PCOS is the only issue in their fertility? This being said, I am not implying that PCOS should be completely overlooked as a diagnosis as it is linked to long-term health problems. What I am saying, however, is that physicians may be too quick to link PCOS to infertility and may be too quick to prescribe Clomid, an ovulatory drug which has serious side effects.

In the above paragraph I implicate physicians as one of the prime movers of medicalization, not only as professional claims-makers but as profiteers in a for-profit industry. Yet, health insurance companies also benefit in this diagnosis. One of my respondents sees sexism in the system, saying that the PCOS diagnosis made her insurance go up, something she said, would not have necessarily happened if her partner had gotten diagnosed with fertility problems. Further, the pharmaceutical company may also be a major player as Clomid is was prescribed to all the women with PCOS in my study (and to other women with unknown diagnoses).

Thus we see a shift in medicalization, or what Clarke et al (2003) call biomedicalization, which they contend started with technoscientific innovations around 1985, which is also the timeframe when ARTs started emerging. As Conrad (2005) states, most social science writing about

medicalization since the 1970s has focused on the medical profession, organizations, social movements, and interest groups as the prime movers of medicalization. He contends that changes in medicine in the past two decades have altered the medicalization process such that biotechnology (especially the pharmaceutical industry and genetics), consumers, and managed care are now driving medicalization. In other words, medicalization is now more driven by commercial and market interests than by professional claims-makers (p.3) where patients are consumers or potential markets (p.4). One can perhaps see this as the pharmaceutical companies make \$3 billion a year on fertility drugs and devices (Mundy 2007).

Thus we need to look at medicalization from both social constructionist and political economic lenses. Conrad (2005) targets the pharmaceutical industry's advertising to both physicians and the general public, which is the case in the fertility industry where one finds advertisements for ordering medications on-line. As Conrad (2005) states, medicalization is still both "exploiting and reinforcing gender boundaries" (p.11).

### What Tests To Use?

A variety of diagnostic tests were mentioned by my respondents, which coincides with the medical literature that admits that despite a basic diagnostic workup outlined by the American Fertility Society and the World Health Organization, a lack of agreement exists among fertility specialists with

regard to how to interpret diagnostic tests, which diagnostic tests to perform, what their prognostic utility is, and what should be judged as “normal” (see Balasch 2000; Glatstein et al 1997; Gleicher and Barad 2006; Siristatidis and Bhattacharya 2007). Glatstein et al (1997) also find that there is variability in what tests get run based on the type of practice (larger, private practices versus smaller or university-based practices), physician age, and physician gender. All of these variables differed for my respondents, which could partially explain why their diagnostic experiences differed.

Perhaps such a large discrepancy exists because (in)fertility is a relatively new field, and recently the medical dialogue has been asking if it matters that there is such a variation in infertility testing. Some physicians say yes, since the diagnosis reached is dependent on what tests are performed. For example, many physicians note that “unexplained infertility” is often a result of an overlooked, and thus misdiagnosed, condition such as endometriosis. Thus, some physicians are pushing for a more accurate diagnostic process (see Gleicher and Barad 2006) whereas others say that in the end, it might not matter that much if a completely accurate diagnosis gets made given that there are only a few therapies that get used for the multitude of diagnoses (see Siristatidis and Bhattacharya 2007).

The question not asked in the medical literature (or the medical sociology literature on infertility for that matter) is if getting an accurate diagnosis matters to the patient. In the following section I outline some of the



positive and negative effects that receiving, or not receiving, a diagnosis had on my respondents.

### **Getting a Diagnosis: The Good, the Bad, and the Uncertain**

Diagnosing a specific problem, as well as treating it for that matter, can become a guessing game, perhaps more so with non-fertility specialists, but with specialists as well. Despite the fact that medical control is supposed to reduce uncertainty (see Miles 1991; Rice 1992; Schmidt & Moore 1998; Watson et al 1991; Wertz and Fletcher 1993), “unexplained infertility” describes the absence of a specific diagnostic finding (see Gleicher and Barad 2006). Unexplained infertility is attributed to 30-40% of couples (Smith et al 2003), which is the most frequently made diagnosis, or non-diagnosis so to speak (Gleicher and Barad 2006). There are no universally accepted methods for diagnosing unexplained infertility (Siristatidis and Bhattacharya 2007), because as the previous section outlined, there is no standardization of which diagnostic tests should be used. This upsets one woman in my study: “they are not even going to diagnose the problem, just try to fix it with medicine.”

The uncertainty of a diagnosis, however, is not necessarily always negative. In the short term, some of my respondents preferred uncertainty. For example, one woman talks about delaying genetic testing because she

and her husband interpreted it as “finger pointing” although eventually they wanted answers and did the testing.

Uncertainty can also allow for optimism. Julie might be a case like the fibromyalgia patients in Madden and Sim’s (2006) study where uncertainty provides for hope (yet too much uncertainty is not good either). She stayed positive and felt more stressed by other events in her life such as closing on a house:

I think I am doing pretty well for the one ovary I have. I can produce. I am trying to stay positive about it. What can you do? It is either going to happen or it’s not. We are doing everything we can to make it happen. Maybe we just aren’t meant to have kids.

Julie also looks at the bright side of having more IVF chances:

We haven’t really had major disappointment. We have 2 more rounds. I think once we get to the third round – if we have to do the third round – then that’s when it will maybe take a toll. I am not ready to get distressed and emotional until we have exhausted them all.

On the other hand, uncertainty can be frightening so some welcomed a diagnosis as they were relieved to finally have symptoms make sense, or what Madden & Sim (2006) call “reinterpretation,” where the diagnosis fits the illness experience. As one woman describes, “I was scared that I would be told, ‘There’s nothing wrong with you. You’re in terrible pain, but we don’t find a source or cause.’” This is not to say that people were not scared of getting a diagnosis. The uncertainty was too frustrating for Mai so she underwent countless tests, which she describes as an “emotional rollercoaster. Every

day the phone rings with a different lab result, and I wondered if that was the day I was going to find out that I had six months to live.”

In the symbolic interactionist medical sociology literature there are references to receiving help as one possible positive effect of labeling (see Anderson & Bury 1988; Bury 1988; Jobling 1988; Parsons 1952) and in my study we see that a somewhat positive aspect of receiving a diagnosis is that it can lead to a plan of action. As one respondent explains, “It’s hard to accept that we had a problem, but at the same time it was liberating” because they could seek specific help. A concrete example is Erin Garcia. After she lost her second pregnancy the doctor did genetic testing on the fetus, found a chromosomal translocation and recommended that the Garcias do genetic testing. They were apprehensive at first, not wanting to know who had genetic problems (plus it was expensive) but they went through with it and found out Ramon has the genetic condition. Now they had the option of genetic sperm sorting. They were also no longer in the uncertainty limbo, as they said, “We know couples where neither of them were diagnosed with anything. At least we have some answers.”

Whereas there are some positive aspects in receiving a diagnosis, Pinder (1992) explains that dealing with a diagnosis is “a crucial turning point for many patients” (p.1) and for many chronically ill, diagnosis is “often a life crisis” (p.12). Although it is debatable whether to call infertility a chronic

illness, for many of my respondents the infertility diagnosis was life altering, as seen in the next section.

### **Diagnosis, the Flawed Female Body, and Women's Burdens**

Unlike the infertile men that Webb and Daniluk (1999) interviewed who went through a stage of denial, the women in my study (and other studies) immediately accepted their diagnoses and many felt disappointment. One respondent sums it up: "Sometimes I want to scream at my body." These feelings are brought about in relation to a concept of an ideal female body that has babies easily. As one respondent says, "The epitome of being a woman is being pregnant and having a child. I mean, they [men] can't do that." The use of fertility treatments and idea of infertility have the potential to change the idea of the naturalization of pregnancy, as biomedicine is the mediator between women and motherhood (see Padamsee 2004), yet many women do not question this assumption as they (and their physicians) still believe that their bodies can have babies, just with a little help; their bodies are at fault and the naturalization assumption is not flawed.

As Ulrich and Weatherall (2000) state, faulting the body is inherent in some medical terminology that describes female infertility, such as "incompetent cervix." This leads to some women's rejection of their bodies. Reece says her body is rebelling against her due to the auto immune

diseases plus feels less feminine without a fully functional reproductive system. Cassandra also has some strong feelings:

I internalized. I have to say that after 12 or 13 years of reproductive pain by that point, I hated my reproductive organs. I wanted them out. It affected my perception of myself. Rejecting a part of yourself is never a healthy thing to do, I felt like it had betrayed me from the very beginning, and it was useless.

Hillary thinks the negative feelings about her body compounded other feelings of self-image as a woman who is aging. She wanted to still feel attractive, which became more acute when she and her partner had to schedule intercourse where arousal was not spontaneous but a conscious effort.

The three women in my study who labeled themselves as feminists in the interview do take issue with the naturalization of pregnancy idea. For example, Ellen addresses the issue of what bodies are supposed to do:

Being diagnosed with polycystic ovarian syndrome and learning what that does, what that is, made me feel unhealthy. Having to go through fertility treatments made me feel even more unhealthy. Because I've always thought of being pregnant and having a child as this really natural process. And it's like, if I have to work this hard to make my body do a natural process, and it may not even work, how messed up is my body that I have to take all these pills and shots and do all these things just to ovulate, which is this totally normal bodily process for a lot of women, or is supposed to be, so I think it just made me feel like I wasn't healthy. And I've always considered myself to be a healthy person so that was hard.

Jalila also addresses that feeling "broken" is not healthy, which bothered her on an ideological level as well when thinking about gendered norms:

I felt like I was losing myself in some way because I don't believe a woman's worth is determined on whether she can produce children. I felt like 'have I internalized these shitty values that I completely disagree with' and what does that mean as a feminist?

Guilt/blame is also a common theme among the women in my study (and Ulrich and Weatherall's (2000)) for not performing up to their role expectations. One source of guilt is family. Erin talks about her parents, who are traditional and conservative, putting the blame on her even though Ramon has the major medical issue. She feels like her family faulted her because she is career-oriented. This thought is not uncommon, when thinking of infertility many in the general public conjure up an image of the working woman who places priority on her career and waits to have kids until it is too late; in actuality this is not the case in the majority of infertility cases (Mundy 2007).

Blame can also come from other areas. We have already seen that blaming women is tacit in the functioning of the medical system as it is set up to automatically pinpoint the woman as the problem when sperm testing is either not done, done after the woman is tested, or in conjunction with the woman. And last, Webb and Daniluk (1999) find that male partners tacitly lay blame on their wives as they are reluctant to admit responsibility for infertility and often send their wives in for repeated testing. Sharing blame/responsibility for infertility is not a two-way street. Of all the women in my study who were diagnosed with an infertility problem, none of their male partners wanted to share the responsibility (also see Throsby and Gill 2004).

Even if most of the fertility problem is the man's, women still take on the burden of the responsibility and even more than their share of the guilt and blame (also seen in Greil 1988; Jordan and Revenson 1999; Throsby and Gill 2004; Webb and Daniluk 1999). Of the three men who were diagnosed with infertility issues, two of their partners were willing to accept some blame. Of these three couples, one woman was also diagnosed with PCOS yet her partner has a serious chromosomal issue that cannot be overlooked, the other did not have 28 day cycles (but have regular cycles and knew when she was ovulating!) so the real issue was her partner's low sperm motility, and the last woman is young and has no "problems" and thus does not share the blame.

, Perhaps women take on more than their share of the blame because a woman's identity is often more intricately linked to a parenthood status than is a man's. Further, their partners *allow* them to take some of the blame. As also found in other studies (see Throsby and Gill 2004 and Webb and Daniluk1999), infertile men often blame their female partners as a way to avoid their own culpability, as infertility is emasculating. This means that their partners, then, are also complicit in upholding gendered ideologies when they accept blame for male infertility. Although Erin was diagnosed with polycystic ovarian syndrome, finding out that Ramon has a chromosomal problem was comforting to some extent and Ramon seconds that: "I was glad that I had

something. She was blaming herself more than anything else.” Yet Erin does not focus on Ramon having the more serious issue:

We’ve been able to get pregnant, it was pure luck the doctor got the few [sperm] that have a normal balance. I wonder why we couldn’t just get that on our own. I’m not mad at him, he can’t control it, it’s not his fault. We both have issues, it’s not like it’s just one of us.

And Ramon feels the same way, “Right, where the other partner would feel like it’s their partner’s fault. We both have something that can hinder us.” At the same time Ramon also blames himself for both having the medical condition and for not trying to have kids sooner in their marriage.

Before Kirk joined us for the interview, his wife, Robin, told me that Kirk finds it hard to admit that he has the larger medical issue. The doctor “identified right away that our problem was totally on [Kirk’s] side. Kirk might not feel that way, he won’t admit that.” She says this was “hard for [Kirk]. Guys don’t like to hear that. He was a trooper, he was willing to go and do what needed to be done.” Yet when Kirk came in to the interview he talks about it pragmatically:

In the beginning, I was glad it was a problem with me. My brain was thinking that it was easier to treat me than her. I don’t know why. In reality it’s the opposite. It’s harder to treat men. Part of it was my own stress. I can deal with it. I don’t want her to have to deal with the stress of feeling that something is wrong with her. I don’t know. Looking back, I say, ‘Maybe it would have been better if it was her. Then it would have been easier to treat.’

Yet during our joint interview Robin responds to Kirk’s statement by taking her share of the blame: “We were both model reproductive people [for the doctors]. It made it easier, because we both have issues to deal with. I



got my problem. You got your problem.” And then she adds, “When I talk about it I say we both have some issues.” And Kirk does not “correct” her, even though her “problem” is not having a 28 day cycle, which is questionable if this can even be labeled a “problem,” especially since Robin does have a regular cycle and knows when she is ovulating.

Both Ramon and Kirk wonder if their conditions are inherited (again, as seen in the previous chapter, respondents use genetic rhetoric and think about health conditions at the genetic level) yet cannot talk at great lengths about these issues with family due to its taboo nature or perhaps as Gibbon (2006) finds with her breast cancer advocates, there could be hidden stories that do not want to get stirred up. Aujoulat et al (2008) view situating one’s illness in family history as a tactic of self-empowerment as people make sense of illness and accept that they cannot have full control over their bodies and must integrate illness into their identities. I think the hereditary link makes Ramon and Kirk feel more vindicated and less guilty, yet these men accept more responsibility than others in other studies who either blame their female partners or keep their own infertility a secret from others. Perhaps this is due to the fact that they are past the fertility treatment process; Webb and Daniluk (1999) find that the infertile men in their study were initially in denial and only came to terms with their infertility when they had some sense of closure.

This suggests, then, that men who are still in the diagnostic and/or treatment process are less likely to admit their culpability in fertility problems. This is backed up by Meerabeau's (1991) study of couples in the treatment process where the men are not quite willing to admit that they have a low count or that having a low count is problematic for impregnation. This also sounds like someone in my study. In Jaime's case, the sole issue lies with her partner so she cannot blame herself. Her partner, however, is having a hard time facing the issue of low sperm motility: "He tries to ignore it, turn his head. If I say something, he thinks it is good, even though the doctors will say...He tries to look at it in a different way than me."

Ramon and Kirk's admissions of at least some responsibility (versus men in other studies), however, could also possibly be due to a cultural difference, as the current studies on infertile men (see Throsby and Gill 2004 and Webb and Daniluk 1999) are not done in the United States. This is to say that although the idea of gender differences is still strong and widely upheld in the United States, we are also seeing more flexibility in conceptions and presentations of gender; the infertile men in my study may be a representation of this change, perhaps also due to educational or class differences as my sample is skewed to the more educated.

And last, as in other cases of chronic illness (see Lonardi 2007; Madden & Sim 2006), some people in this study want answers for why they have this illness. Some women seek spiritual or social reasons in their pasts

for answers to their guilt and blame. Erin explains her thoughts and notes the gendered element as well:

You blame yourself for things you did in your past, if that had any effect on it. I know it's different for guys and girls to go through. You did something stupid when you were young, which can be true if you had a very sexually active life. Some of the sexually transmitted diseases can cause infertility. We've used so many chemicals, we pollute. Is it because you're a non-believer? You have these horrible thoughts. You just start questioning everything.

### **Beyond Pregnancy**

The effects of the infertility diagnosis go beyond the act of getting pregnant for some. A little over one-third of women in the study were diagnosed with polycystic ovarian syndrome and several other women had other diseases that have life-long effects as well. This affected many of their perceptions of their bodies and their identities; adding a new identity, in some cases even a master status, and changed their lifestyles. A symbolic interactionist interpretation seems apt here as the illness label becomes one of the primary identities that is attached to, internalized, and reconstructed as a person copes with the social implications (Freidson 1988; Kelleher 1988). This is especially of interest in the literature on the management of a constant yet changing chronic illness (see Anderson & Bury 1988; Morgan 1988; Pinder 1988; Robinson 1988), which is difficult; we see Cassandra struggling for some time with her endometriosis:

I think it was 18 months to 2 years when we just didn't worry about it. I think I was still believing that my body would find a way to right itself,

that surgery would take effect, that after the surgery my body might normalize in some sense. I don't know. Maybe I was fantasizing.

And after acceptance of a diseased body, many women have altered their perceptions of their bodies. Cameron thinks she only has a mild case of polycystic ovarian syndrome yet still worries about it to the extent that she feels the need to educate her daughters about the condition in case it gets passed on to them. She also says that she feels silly about being more aware of, or as she says, "hypersensitive to," her bodily processes: "Every pain, strange feeling, or my cycle is funky, or breastfeeding. Almost like I'm trying to find something wrong and I shouldn't be." She thinks this is due to knowing that she has a "syndrome" and finding out that one of the fertility drugs she took has a link to heart problems.

Several other respondents are also worried about future conditions related to polycystic ovarian syndrome such as diabetes and heart disease.

Ellen explains:

It's a little bit scary, not the infertility itself but the underlying problems causing the infertility, how is that going to affect me the rest of my life? If your body isn't working right that must mean you're unhealthy. You can trick your body, you can take artificial hormones but there's a chronic problem that's not going to go away.

As someone who teaches radiology, Reece's diagnosis affected her work:

It was a conversation more in terms of cancer patients really trying to understand what that diagnosis means. The grieving process and they have to do all these other things. You can expect that they will have a breakdown during treatment but certainly it has broadened me a lot more. I share that with students.

## **Conclusion**

This chapter outlines the beginning of the infertility journey as my respondents find out that they are infertile and what this means to them. The following chapter moves beyond the diagnosis to the actual treatment process.

## **Chapter Six: (Re)Producing Pain: The Trials and Tribulations of Fertility Treatments**

### **Introduction**

After receiving a diagnosis of infertility, couples are faced with the decision of how to proceed. All of those in my study decided to pursue some form of traditional medical treatment, which ranged from “only” taking drugs, to drugs and inseminations, with or without donor sperm, to IVF or advanced IVF, with or without donor sperm and egg. One couple used the rare gamete intrafallopitan transfer. Although the treatment options are varied, the “usual suspects” are ovulatory drugs, Clomid in particular, insemination, and/or IVF. These are standard treatments despite the wide variety of causes of infertility. In actuality, then, these are not “treatments” in the sense of treating the causes of infertility. Rather, they are attempts to circumvent infertility.

This chapter discusses different reasons why my respondents decided for or against certain treatments. In this chapter I analyze respondents’ rationales for pursuing medical treatment within the context of larger structural factors such as the role of the physician, their financial abilities and health insurance, and their attitudes about alternative methods of becoming parents, particularly adoption. In assessing the role of the physician, my respondents repeatedly indicated that their doctor’s attitude about reproductive technologies, especially their optimism, was an important factor in their decision to pursue treatment. This physician optimism stands in contrast to

the actual 30-40% success rates (see CDC 2008). Further, I find that personal contact with adoption greatly affects people's views of adoption, negatively or positively based on the adoption story. And last, for others the simple fact of the costliness of fertility treatments made the decision for them. I also offer a rich description of how these treatments affected them emotionally, physically, and financially. We see that treatment greatly disrupts daily life, has severe side effects, and creates stress between couples as well as social isolation from other family members, friends, and co-workers.

### **Why Pursue Medical Treatment?**

Why do couples decide to pursue medical treatment to resolve infertility? Of course, as seen in chapter four, there are several reasons for wanting a biological child, and Donovan (2008) contends that because fertility treatments do not treat the problem, but only by-pass it, they are not treating the body, but rather the desire for women to have children. Beyond the desire for children, this analysis identifies three major influences in the decision to pursue treatments: optimistic physician prognoses, the level of openness to the adoption alternative, and how much time and money couples are willing and able to spend. Although some radical feminists critique Assisted Reproductive Technologies as an exertion of male, medical control (see Throsby and Gill 2004), here we see that there is also patient agency in

the decision to use treatments. And although this section looks at the “rational” answers given by respondents, I must note that these decisions are also laden with feelings of guilt, grief, anger, and loss.

This section looks at the social dynamics of decision-making processes, which might be an interesting starting point for a comparison to those in the population who I did not interview—the ones who decided *not* to pursue fertility treatments.

### **Physician Recommendations**

When discussing why they eventually sought medical treatment for infertility, every respondent discussed physician optimism about success rates. While doctors may believe showing optimism enhances their relationships with their patients, research shows that prognostic uncertainty is not necessarily a disadvantage for physicians because it does not negatively affect patient-physician interactions (Calnan 1984). Gibbon’s (2006) study of genetic breast cancer testing finds that sometimes physicians even address uncertainty in genetic knowledge in order to counter patients’ high expectations. In my study, however, all diagnoses and treatment plans were paired with the optimism of a medical solution, perhaps because this is a for-profit industry. In addition, a good attitude is better for doctor/patient interactions for any ailment and may help treatment success because stress does not help any illness, or in this case trying to get pregnant. Some of this



optimism, however, may unfounded due in part to doctors not really knowing the possible outcomes of such a new and unexplored field (not that older medical practices are 100% predictable). In fact, physicians must be aware of the relatively low success rates of fertility treatments.

Those of my respondents whose pain and financial burdens were minimized and had positive outcomes in a short amount of time appreciate this optimism. One woman said that her physician was “really great about ‘let’s try this and not talk about anything else until we know it isn’t going to work’” and one man comments that “they would be very honest, I felt. They tended to very upbeat. The nurses were always excited and happy to see you.”

Critics state that the idea of medical control gives a false sense of security (Blank 2003; Davis-Floyd 1992; Laudsman 2000; Mentor 1998). Whereas my respondents always began treatments optimistically with trust in the physician and medicine more generally, this feeling can wane as treatments fail and/or the process becomes prolonged. Strained patient confidence in physicians and/or the medical process could be problematic for the treatment process (Mechanic 1998), or as will be seen in the following chapter, lead to a loss of clientele.

Ellen did not get pregnant through drug therapies and due to her academic pursuits in the sociology of medicine, science, and knowledge, she has less faith in science so she somewhat expected “failure.” Her partner,

Edward, however, does not appreciate what he views as false optimism that doctors expressed. He looks back at the year of fertility treatments and is upset that the physicians made it seem so possible. He and Ellen were open to adoption and for him the fertility treatment process postponed the adoption process. He speculates on why their doctors seemed so hopeful:

There's an assumption that if they can make you feel better about it then you're gonna be more likely to conceive. Maybe they think the best thing to do is tell you, 'Oh yeah this will be just fine' rather than be realistic with you. Which is interesting, because, if people would have been more realistic up front there's a very good chance we might have actually dealt with the whole thing better and not felt so disappointed.

Another male respondent, Terry, also blames doctors for being overly optimistic about the success of gamete intrafallopian transfer. His wife did not get pregnant and he is upset that the doctors made it seem so guaranteed, not only for monetary reasons but he thinks that having his partner be so heartbroken, feel like a failure, and get into a depression ultimately led to their divorce. In another part of the interview, however, Terry admitted that his wife was too ashamed to talk about the problem and he, as a male, was not good at open communication. Although Terry did not explicitly link this fact to the divorce, I assume that the lack of communication did not help the relationship.

Cory and his wife Leslie experienced several failures with drug therapies and then moved on to IVF, which also resulted in failure. Cory talks about the time where Leslie was in the intensive care unit with side effects after the IVF:

I felt a little bit bad, because we were pregnant. She should have been happy. She wasn't doing well at all. There was always sort of a specter of the previous pregnancy. Until we got past that point, it was difficult to have any optimism about what could happen.

After this pregnancy also resulted in a miscarriage Leslie becomes critical of what optimism means with medical specialties that have such narrow foci.

She talks about her subsequent consultation with her fertility specialist:

He said I was pregnant twice, and that was very hopeful. It was weird. There is not a sense that your body can't get pregnant, for him. I think success for him is the pregnancy part of it. Then, he wants to discharge you.

Leslie also becomes critical of the profit motive. As political economists point out, health relationships get mediated by economic relations through the biotechnology market, managed care and pharmaceutical companies. Leslie says that "their excitement that I saw at that point I read as real" but now thinks that really the physicians just want their money. This is bad news for medicine in general as her suspicion of her specialist's profit motive changed her view of *all* doctors. She talks about her visit to the intensive care unit from her ovarian hyperstimulation from her IVF:

It just looked like a big bill that was coming, you could never say that you didn't really want that test, that you didn't need that test. They insist in order to cover liability purposes, or whatever that might be. But it really wasn't for the health of me.

On the other hand Reece, who is in the medical field herself, is aware of the profit motive but does not let that shade her view of *all* doctors. When her physician optimistically said that he thought she still had a chance with IVF after two failed attempts, Reece believed him: "I don't think he would

have told me that just to collect another ten thousand dollars, which some may have done.”

### **Weighing their Options—a Comparison to Adoption**

Given the optimism of treatment success, treatments can be, or can seem, cheaper and faster than adoption due to the long waiting period for healthy, white babies. Initial levels of openness to adoption were due to several factors, the first being how strongly one feels about wanting a biological, or genetic, link to children, as seen in chapter four. Further, positive and negative exposure that people had to adoption stories weighed into the decisions of how far to go with treatments. Aside from one woman who really wanted the experience of pregnancy, those who had positive personal life experiences with adoption and were not very invested in the biological link moved to adoption when lower impact procedures were unsuccessful if they were not prohibited from doing so due to a variety of factors such as sexual orientation, age, health, and being too recently married. As such, I had three such cases where my respondents entered the adoption process after unsuccessful drug therapies. Even some who were successful with drug therapies yet still fit some of the above criteria discuss that they thought of adoption as their next step. For example, Robin was successfully pregnant with twins after a few rounds of drugs and inseminations but said she would not have done more:

The thought of spending \$16,000 on a procedure that wasn't even guaranteed versus spending \$16,000 to adopt a child and give that child a really good home and not have to deal with all the other issues. It would have been much easier emotionally on me to adopt a child than to go through that process.

Robin makes adoption seem so guaranteed, perhaps because she intimately knows the experiences of both the waiting and failures with treatments. On the other hand, Ada and Mai, who both adopted children, know the trials and uncertainties involved in adoption. Mai explains:

You go through the hell of medical procedures that may or may not be successful. Or the hell of adoption, which may or may not stick. Moms can change their mind. Children may not stick. They could get taken away.

The reasons that Mai and Ada adopted, then, were: Mai was a bit uncomfortable with spending large amounts of money on high tech procedures and Ada was opposed to the physical difficulties: "I mean you don't know if you're going to get it, you don't know if it's gonna be successful. But at least you're not putting your body through torture."

### **Weighing Their Options--Time and Money Factors**

Of the treatment history I got for 21 women (this includes Peter and Terry's stories of their wives, and omits Ada, who opted out of any treatment), 19 started with the more basic treatments of drugs and/or inseminations. The three respondents in my study who successfully used hormone therapies got pregnant between 1-6 months of trying. Overall, however, there was a range between using relatively inexpensive drug treatments for a month or two for a

two respondents to one woman trying for almost seven years, which included several rounds of IVF with donor egg. The average treatment length for all my respondents was almost four years.

What is considered “cheaper” or “faster” is somewhat arbitrary as there are ambiguous quantifiable boundaries between cheap/expensive or fast/slow. There is quite a range of cost depending on treatment, anywhere from \$1,000 to \$15,000 per intervention (Grob and Rothman 2005). For some of my respondents the boundaries were clear, such as tapping out all of their savings. Others took out loans or went into debt; in fact, fertility clinics offer their own low interest credit cards, financing plans, or some money back if not successful!

Beyond financial repercussions some respondents acknowledged a physical or psychological stopping point. Five respondents stopped after not being successful with drugs and/or inseminations and another five who were successful through these lower impact fertility treatments said that they would not have moved on if they had not been successful. They discuss discomfort with high tech ARTs, not wanting to go through the physical pain, and/or ethical reasons for not wanting the possibility of destroying embryos. For example, Ada thinks that she probably could have gotten pregnant if she had kept her artificial insemination appointment but decided to adopt instead. She talks about her emotional boundaries when she discusses fertility treatments and IVF more specifically:

And the repetition of failure, that's the thing that I just don't understand, that you put yourself through that over and over and over again over the years. It's not rational, even if they think it is.

Although those who moved on to IVF also hoped for quick success, they were willing to spend more time on getting pregnant. Seven of my respondents (11 interviews if I count their partners) tried IVF by itself or with donor egg and/or donor sperm. The reasons given for advancing to these procedures are multiple. For one, the further one goes in the treatment process the more invested s/he becomes and feels like success could happen at any moment. For example, Leslie felt that starting the adoption process anew would take longer than moving on to higher tech procedures: "It seemed like the closer thing, the thing that would get the kid to us sooner. We were on the doorstep." She elaborates:

I felt invested, I had taken the time to learn the ins and outs of the process. I knew the pain of this process, but adoption seemed like this whole other thing that I would have to learn the ins and outs of that pain. We had a couple of different friends who adopted with huge roadblocks and difficulties. That seemed like it could be even a worse pain to go through.

And Leslie's partner, Cary, follows up on the idea of having a professional to guide them:

Part of going along with that is that we had the guide. The doctor was going to tell us what to do. We just had to go along with him. With adoption, we would find somebody new. There was nobody that we trusted. We probably could have found somebody...(he trails off)

Further, Cary greatly preferred his own genetic child anyway, as did many male partners of women who underwent IVF and this influenced decisions to move to more invasive procedures.

In-vitro fertilization also allowed people more opportunities to fulfill a dream or goal as several respondents talk about wanting to “exhaust all possibilities.” Peter explains that his partner was feeling like a failure to the marriage and as a (potential) mother. Their IVF attempts had failed and they had to grapple with the idea of donor egg. Peter thinks that one reason for his partner’s eventual acceptance of donor egg was that she “could ultimately take on the maternal role.”

Yet this “mission” mentality of wanting to exhaust all possibilities also overtook several women who said that they were so invested in the process that they lost sight of the bigger picture of wanting to be a mom. Now in retrospect, one woman said she had tunnel vision. She felt like a failure, and she had never failed anything before so she was on a mission. Leslie describes her thought process after having to terminate her first non-viable pregnancy:

Immediately after the DNC, my mind went to trying to get this done. “When can I sign up again?” At the same time, I thought I was crazy thinking that while I was in the hospital. It was not a logical plan.

Cameron also discusses being “so consumed it was no longer a happy thing to wonder about pregnancy and motherhood. It was almost a job, like I have to cross it off my list.” She says that she probably would have



exhausted every physical option to get pregnant because she was so consumed by the idea. Now in retrospect she says “the most important thing is that I have my daughters, not necessarily that they’re mine from a biological standpoint.”

Of course those using IVF also had to have a degree of comfort with advanced medical technological interventions. For some it was a general faith in the medical field and for others the comfort came from a gradual adjustment from low to high tech procedures. As one respondent who ultimately used donor egg explains, it was “an evolution, classic putting a frog in water and turning on the kettle, we gradually became more and more comfortable with certain procedures as the process went on.”

### **Difficult Lifestyle Adjustments and Stressors**

Bury (1982) points to the immense impact disease can have on daily life, what he calls a “biographical disruption” as it interferes with work, social activities, individual identity, mood, and economics. These subsequently put strain on future prospects as well (see Aujoulat et al 2008; Kleinman 1988; Lonardi 2007). Although infertility cannot be neatly categorized into a chronic illness category, the treatment regimens that are given to my respondents have the same types of consequences. As such, the illness and treatment experience cannot be compartmentalized; it affects one’s whole lifestyle. This section outlines the immense impact infertility has on the totality of people’s

lives. As one interviewee said, “It was really paying a toll on all of my relationships and everything in my life.” The following section discusses interviewee issues with scheduling their lives around fertility treatments, treatment stress, relationship stress, and social isolation.

### **Scheduling and Disruptions of Daily Living**

Although other medical sociology literature talks about the disruption of daily schedules (see Kleinman 1988) this is mostly absent from the fertility treatment literature. Yet the issue of schedules/scheduling came up in almost every conversation I had, mostly for women because they were the ones undergoing treatments. Some women had to drastically reschedule major aspects of their lives. They needed the flexibility because of an inflexible fertility regimen where people had to be at clinics not only on certain days but specific times on these certain days. One woman explains calling in to her work: “I have to go in today and do this procedure. It can’t be after work or tomorrow, it can’t be this weekend.” Sometimes people even had to go in on weekends.

Further, treatments were often a daily occurrence. One woman had to go in to the doctor’s office downtown every day and try to get in early to be the first in line so she could get to work in the suburbs on time, “There was always that group, you could tell that we all needed to be somewhere so we all tried to beat each other getting there.” Others did not have to go in to the

doctor's office, they could give themselves the treatments, yet still had to stick to a rigid schedule, "I joke that it was like fertility boot camp. On this day, you do this. On this day, you do that."

People also had to think beyond the daily to the longer term. One respondent quit her PhD work and others quit or changed jobs in order to free up time. Others had the stress of attempting to get all their treatments in for the year because of the contingencies of their insurance. Many respondents talked about their plans only covering 3 inseminations per calendar year. Leslie had to terminate her non-viable pregnancy close to the end of the year and she and her partner, Cory, were unsure if they should go ahead and try again; they wondered if her body was ready and if they were emotionally ready. Further, her job takes her away for months at a time so they felt quite pressured about timing. Cory explains when they moved to IVF their clinic did not do it in the winter months:

because seasonal affective disorder, or whatever. They find that it is largely unsuccessful during those months. That's great unless you're pushing this deadline. She has these wildly irregular cycles.

The treatment schedule even interfered with their out of town trip. They were in Chicago when Leslie got her period so they had their physician call in a prescription to a pharmacy there, and they had to try to catch a cab and figure out where they were exactly. Similarly, Robin's work took her to a small town high school football game where she had to sit in her car in the parking lot to

inject herself, “I was terrified someone was going to walk by: ‘She’s shooting up!’”

The complexity of scheduling sometimes lasted for years as people were in treatment for those lengths of time. There was also quite a bit of frustrating rescheduling due to cancellations when women’s bodies (either my respondents or the egg donors they were counting on) were not ready at their scheduled times. One woman complained that the medication she took got her ova ready but the side effect was a thinning of her uterine lining so she could not have her treatment that month. This reflects a technological imperative that exists in medicine that Rothman (1989) describes as viewing the body in a mechanical way that attempts to break it down into component parts. In order to fix the machine/body, then, medicine must produce each part separately and figure out how to link the parts back together.

Whereas discussing scheduling may seem somewhat banal on the surface, the scheduling process is in some ways a way to try to control an otherwise uncontrollable situation. On the other hand, the long-term planning of the almost uncontrollable evokes quite a bit of anxiety about trying to obtain important, long-term goals.

## **Strained Interactions**

The infertility itself, and the treatments, caused strained relationships between my respondents and their partners, extended family, friends, and co-workers.

### **Relationship Stress**

“It can kill you, it can kill the marriage. It’s like having a second job.”

Whereas many of my respondents state that the whole infertility ordeal ultimately brought them closer together with their partners by having gone through hard times, it was very difficult during the process, especially if there were also other issues that the couple was dealing with. One respondent did get divorced due to this stress and Erin talks about a couple in her infertility support group who got divorced over it too, “It’s very stressful, because you’re not just dealing with a physical health crisis. You’re also dealing with emotions, your dreams, and finances.” Peter writes in his journal of finding out one weekend that none of their sixteen extracted eggs got fertilized and he and his wife wondered if that was their last try at having a child that was genetically related to both of them. There were, “tears, silences, ‘discussions,’ avoidance, confrontation, and a few slammed doors and squealed tires, more or less equally divided among us.” Guilt and blame were also among these emotions as Peter and his wife lamented that they should have started the pregnancy process sooner than in their late 30s. His wife

was sad and he was angry at her, stating that she "...had a conference instead of a child. Always wanting to be in control, too busy for this, that, always time for others and never any time for us."

Stress in a relationship is hard enough in and of itself, and for these couples the stress may be exacerbated as oftentimes someone's partner was the only one s/he could turn to for discussion and/or comfort. This probably also adds pressure, and thus more stress, on some relationships, perhaps especially for the non-treatment recipient as s/he is not going through as much physical pain and is expected to be strong and supportive.

Whereas the previous paragraphs outline the medical aspects of trying to reproduce, the actual act of intercourse also became a source of tension between heterosexual couples. Many talk about having to schedule sex and one woman said that she and her partner "hated our sex life. We didn't even want to have sex anymore." Erin admits that it was "stressful to have to get in the mood. It was like every other day." And although men are stereotyped as wanting sex all the time, her partner adds, "It was like a job." Hillary had to have intercourse and within a certain time frame go into the doctor's office so they could see if there were live sperm in her cervical mucus. She said this exact scheduling made her a "basket case." Kevin and Gillian were living with his parents, whose bedroom was down the hall and then his brother moved in to the room right next door which made timing and having sex a little more awkward.

Sexual intercourse gets taken out of the equation early on in fertility treatments (for heterosexual couples). If drugs on their own are not working the next step is inseminations and then IVF. Only five women only took medications, the other 23 interviewees had inseminations or IVF. Whereas couples can obviously still have sex, Peter laments about sex in his journal, or the lack thereof due to their depression and that there is “no longer any imperative to try to get pregnant by traditional means, and hence the loss of the sole motivating factor to have a little nookie.”

Some are also bothered by the disconnect between intercourse and conception. One woman talks about how strange it was to be holding her husband’s hand while she was laying on a table having a doctor insert her husband’s sperm through her cervix. Another woman’s religious convictions led her to decide that a lack of intercourse goes against God’s will and that she would not continue treatments if she could not conceive through intercourse.

### Social Isolation

As Lonardi (2007) writes, “When everyday life falls apart, a regressive choice leading to self-exclusion is easily made” (p.1623). There is literature on other chronic illness that discusses social isolation (see Goffman 1963) yet this extremely difficult lifestyle adjustment is largely absent from the medical sociology literature on fertility treatments. I was not looking for this theme but

it emerged very quickly after several interviews, and became apparent in subsequent interviews. One woman talks about her self-imposed isolation due to her depression:

I had to get up every single day for work. It was all I could do. I came home from work, I'd climb into bed and start crying. I wouldn't eat, wouldn't talk on the phone, wouldn't go out. [Renee's] trying to get me to go out, 'There's this Christmas party' or 'It's Fourth of July, there's gonna be fireworks.' I'd say I'm not doing any of those things.

Both women and men felt a range of emotions when being around people with kids such as sadness, anger, resentment, injustice, envy, and even hatred: "I hated pregnant women and mothers, especially the ones with young children." And if the step-parent/step-child relationship wasn't strained enough, another woman talks about her feelings toward her husband's grown daughter : "extreme jealousy, frustration, anger. She got pregnant first, we were trying first. We wanted it more, we wanted it longer."

Similar to the infertile men in Webb and Daniluk's (1999) study, my respondents protected themselves emotionally through avoidance of friends, relatives, or even strangers, by not going to certain functions such as birthdays or baby showers. Not only were these full of reminders of children, but people at these functions also made seemingly innocuous comments or asked questions based on the assumption that having babies is easy for everyone, such as "it's about time you guys have kids," which obviously adds to the stress and sadness.



Many also felt like they could not be good friends to their friends who were pregnant because it was hard to be happy. Iris says it was hard to even be on the phone with friends and hear their kids in the background. However, she says that now, after her almost seven-year treatment process was successful she is “back among” her friends.

A few people, however, found talking to people to be helpful. Although there were those who made insensitive comments, they also discovered that “the more you talk to people, the more you hear everybody else having similar issues.” Many, however, chose not to disclose their difficulties with others, perhaps some were “passing” and keeping their stigmatized illness invisible (see Goffman 1963), yet many mention reasons similar to those who are trying to get pregnant; there is (added) pressure from people waiting for the pregnancy announcement and the burden of explaining what happened if the pregnancy did not work.

Others had to stop talking to friends who could not “handle the two-way conversation and not hurt my feelings in the meantime.” Many talk about friends not knowing what to say or saying the wrong things, things that made one woman think: “What the hell are you thinking? How could you say something like that to me?” Another woman says, “Some of them would say what a great thing it is to not have to use birth control and not worry about getting pregnant. I wanted to hit them.” One respondent got, “Don’t think about it and it will happen” and then his wife adds, “It’s kind of hard not to

think about it, it's part of your life." Another person was told "God must not want you to have children."

Many respondents also heard some derivation of "just relax." Beyond being painful and insensitive, these comments negate the patient status. As one woman said, "that stuff used to make me so mad. I knew they found biological problems." This seems similar to complaints that people have about mental illness or less visible or hard to diagnose illnesses that are hard for others to acknowledge as real illness (Ussher 2000).

The workplace can also be a stressful environment. One man describes his partner having a negative pregnancy test in the morning and when he got to work someone announced that they were pregnant. Leslie had to explain her work absences due to IVF to a colleague and friend whose wife also happened to be pregnant because she knew the risks involved in what Goffman (1963) calls "passing." As she explains, "I hadn't wanted to tell him, but eventually did. I knew we were going to run into this weird deal where I would cry and he would wonder what was the matter." And perhaps it was good that Leslie told him because he later called inviting them to a baby shower and Leslie said she "immediately started crying on the phone" and told him that she could not come.

Whereas Leslie's co-worker was understanding, Jalila's was not. Jalila speculated that because this co-worker/friend had gone through fertility treatments herself, too many sensitive feelings were stirred up and thus

evoked a negative response. Jalila decided what others who suffer from chronic illness decide—to adopt different communication strategies with different people (see Lonardi 2007). In Jalila’s case she was silent at work and only shared with her family, which she said made her feel “schizophrenic” and was hard to do because she normally shares a lot.

Cassandra had to eventually withdraw from church friends who were once a strong network:

It was hard for me, because we would befriend a new couple. Then they would get pregnant. They would have a baby, and we would see their baby grow up. Then, they would have #2. Their life is moving. Our life seems to be stationary.

Another woman talks about being “hypersensitive” to all her surroundings while trying to get pregnant:

It felt like everything was mocking, it was just a theory of coincidence on what your psyche picks up on, all the commercials were about babies and everybody outside was pushing a stroller.

Similar to the infertile men in Webb and Daniluk’s (1999) study, others also talk about not wanting to watch television or listen to the news. As one respondent said, “Every celebrity was pregnant.” Many also talk about not wanting to hear the horror stories of mistreated children as they felt a strong sense of injustice. As one woman explains, “I was really committed to having a family. Then there were all these people who were wasting the opportunity.”

One respondent’s statements went a step further, reflecting a class bias that seems to be rooted in a larger societal stereotype of poor people

reproducing irresponsibly. Contraception has morphed from its beginnings from a right (although some scholars argue that classism was behind Margaret Sanger's activism to get birth control for white women) (Weisman 1998) to something that is now a moral responsibility such that conceiving an unwanted fetus, or having one that a woman cannot afford to take care of, is seen as lack of good judgment and self control (Grob and Rothman 2005). Peter's journal reflects several classist statements along these lines. In one segment he is describing a pharmaceutical company video that is explaining the process of IVF injections to a "dense couple who sure didn't look married, and sure looked like they probably shouldn't procreate in the first place." Yet he then explains that:

I don't think the stupid people are the ones going through IVF, it's the intelligent ones. Judging from my last trip to Wal-Mart, the dumb ones have no trouble at all breeding (we won't get into their personal hygiene, dress, or behavior, however).

On the other hand, Peter believes that the woman who donated her egg for his IVF did it for "altruistic" reasons and not for the \$3,000. Perhaps this is his way of justifying to himself that he is getting "good stock."

In many cases all this social isolation leads to people going through emotional turbulence, miscarriages, and hospital scares without many support networks. At one point when Leslie and Cary had good news about the pregnancy they were going to tell their families over Christmas. But right before Christmas the physician could not find the baby's heartbeat:

He said that we had to come back the next Wednesday. There is Friday to Wednesday. Then, there is Christmas in between. That was really, really, really crazy long. Mentally, just even to think about that was difficult.

### **Treatments: Physical and Emotional Stress**

Similar to patients in other studies (see Bury 1982), my respondents report quite a bit of treatment stress on their bodies, which is also emotionally stressful. This section outlines some of the explicit stories women shared about how treatments affected their bodies and minds. Some of stories are not for the “faint of heart,” and this information is definitely not seen in very much of the infertility literature.

Even more basic treatments were quite grueling for many women. One woman talks about giving herself shots: “To somebody who has never taken a shot, I don’t even take a regular vitamin a day, to give myself a shot was completely overwhelming.” Another woman who went through fertility treatments for a few years said that she was bored one day and “counted over 300 shots that I had had in my butt.” Ellen explains her process in some detail: “Five days of Clomid and 2 shots in the first 14 days of the cycle, plus all the ultrasounds. And then the IUI.” Even the insemination (IUI) is invasive as a small catheter is inserted through the cervix. And after the procedure: “I had to give myself progesterone suppositories. So I was doing two of those a day until a negative pregnancy test. So for not doing IVF it was still kind of a lot.”

## Treatment Side effects

Although some women were not very affected by their medications, like many people who are being treated for various medical issues, the majority of my respondents had to cope with a plethora of treatment side effects. It seems as if currently the medical and larger community does not consider pharmaceuticals to be as invasive as other medical interventions yet their less visible internal workings can create major bodily changes. “Minor” side effects included bruising and burning from injectable medications, oily discharge from vaginal suppositories, headaches, insomnia, nausea, feeling sore and/or swollen from having an abundance of oversized ova, or hot flashes. Sometimes these led to a cascade effect (see Deyo 2002) where new medications were needed to take care of the other medication side effects.

Side effects from the higher impact treatments can be quite grueling as well. For example, a few women got ovarian hyperstimulation after undergoing IVF. Erin had trouble breathing because fluid was compressing her lung, which had to be drained in the hospital. The same side effect made Leslie’s ovaries swell up to eight times their normal size and fifteen pounds of water had leached from her uterus into her stomach. She could hardly walk and had to sleep in a chair because she could not lie down. She explains what happened and again we see the physical side effects coupled with

difficult circumstances. We also see the re-emergence of feelings of guilt and hedging optimism:

I thought it was really bad and that I must have done something really, really wrong. I thought I ruined the whole thing, so I was really upset. We went into the doctor. I was crying. I felt bad, because there were all these hopeful women. They said that if I was that far bloated that I had to be pregnant. I just kept trying not to listen to that. I didn't want to get my hopes up and have that come crashing down. They admitted me to the hospital.

Unfortunately the hospital experience was very stressful as medications were mismanaged, which made Leslie's physical conditions worsen, gave her other side effects, and put her in the ICU for a week.

Further, the hospital stay worried Leslie about the small life inside of her that she was responsible for. She worried about her pregnancy and whether she should be taking all the drugs. Some other women also mention being worried about longer-term medication side effects from fertility treatments such as cancer for themselves and birth defects for babies.

Unfortunately miscarriage is a relatively common occurrence from pregnancies from both low and high tech procedures; for example, the CDC (2008) reports that 17% of pregnancies conceived from ARTs end in miscarriage, induced abortion, or stillbirth, but again this seems like something that doctors do not warn patients about. Leslie and Cory had a hard time: "We were old, but very naïve. We thought when you get pregnant, you get pregnant. I was very shocked." They were not going to have a DNC

but ultimately could not wait any longer for the miscarriage to happen naturally: “It kept bleeding. It was horrible. It kept doing it for 3 weeks.”

Another woman also struggled with her body trying to abort naturally: “I can’t believe I’m calling Suicide Hotline, it killed me to realize just how low I had gotten.” Cassandra was in Los Angeles for a conference and had to go through her miscarriage alone in a hotel room in a strange city in the middle of the night. She did not call her husband because she did not want to tell him over the phone:

I miscarried late Saturday night, it went on until 5 o’clock Sunday morning, the day I was coming home. I was alone. I didn’t want to go to an emergency room in L.A. at 3 in the morning. I waited it out by myself. Honestly, pain-wise, it wasn’t any worse than anything I had already experienced. After a few hours of bleeding, the embryo came out. It was blue. You could see the head. You couldn’t recognize anything else. The thing that really haunts me about that is that I left it there. I didn’t have a way to bring it with me. I couldn’t memorialize it in any sense. I always said it was a boy. I deserted him. That happened about 5 in the morning. The gift shop in the hotel opened at 6. I went down and bought a bunch of tampons. I put them in – 2 or 3, I think. I was bleeding heavily. I got to LAX. I got on the plane and went home.

The agony does not end when the miscarriage is complete. Here was Cassandra’s homecoming after her trauma in LA:

I go into my home, and it feels haunted. I left it pregnant, and I came home not. It was like it never happened. Then I hated that house, and I hated to be in it. It just felt like this unfulfilled place. Incidentally, we had just put our 12 year old dog to sleep 2 weeks before I miscarried. He was our baby. We got him shortly after we moved to Kansas City. We never dreamed that our infertility would outlive our dog. But it did. We were back where we started. Our dog was dead. Our baby was dead. I felt physically so sick.



Yet people are expected to move on with their lives as miscarriage is not necessarily considered to be a death in the family by organizational standards. The many women in my study who miscarried had to go back to school, work, being with others, and “normal” life even if one’s heart was not there. As one woman said, “You never get over it, you just learn to get through.”

#### Clomid: Major Depression and other Emotional Disorders

A major culprit in producing mental side effects was Clomid, a hormonal drug to induce ovulation that is often given as the first line of treatment (WebMD 2008). Writing on Clomid side effects is all but absent in both medical and medical sociology literature on fertility treatments, perhaps because the drug is relatively new. This is a huge omission given the severity of the symptoms this drug can create and its widespread usage, which is not likely to subside any time soon; the pharmaceutical industry makes \$3 billion a year on fertility drugs and devices (Mundy 2007). A closer look at Clomid, and other drugs for that matter, is also important as most feminist critique is centered on the use of high-tech fertility treatments at the expense of low-tech methods, which they say, women have more control over (see Throsby and Gill 2004). Yet what I find is that although women may have control over the actual application of the treatment (in this case taking a pill), they still feel controlled by the medication, especially emotionally. For example, Patty describes how Clomid caused her suicidal thoughts and other dark feelings:

I've got journals, I started them when my whole mental attitude started sliding downwards. I was talking with people about things that were inappropriate. I can't apologize for who I was. That wasn't me. I was on some major hormone-changing drugs. I was like, "Ya know, I was obviously not meant to be a mother. Why am I going through this?" Oh, it's because I bite my fingernails, I'm not supposed to be a mother. My mother used to do this, and the universe is afraid of that too, so, therefore, I'm not gonna be a good mom. There were all these things that were going through my head. I have pictures that I drew. There's this stick figure, and there's this big, empty circle where my uterus is supposed to be and it's scratched out. It's this big void in my body that doesn't function. You really start beating yourself up mentally. Almost physically. It was absolutely terrible. It was *the* worst thing I've ever been through....in my entire life.

Patty describes the cumulative effect of her consecutive, two-year regimen of Clomid, which is quite rare in and of itself because now Clomid is not recommended for more than a six month period due to links to cancer. Long-term usage, however, is not a prerequisite for side effects. Cameron felt severely depressed within 24 hours of taking Clomid. She only tried this for one cycle saying it was so bad that she decided that if that was the only option to get pregnant that she was not going to have children naturally; this coming from a woman who wanted to be pregnant so badly.

For others it took longer to connect the Clomid to the mood changes. Ellen talks about struggling for several months with the depression, which caused her to lose sleep, which made her tired and unproductive at work, which subsequently added to her depression. The mood changes did not help with coping with an already stressful situation:

First of all, you are going through a really emotional experience -- trying and failing to get pregnant. In our case we were starting to think about what it would mean to not be able to get pregnant, not have any

biological children, and that's really emotional. And the emotions you have don't *feel* like "side-effects," they feel like your real, true, honest-to-god emotions. And it's also the fact that even though you only take clomid for five days at the beginning of your cycle, the side-effects last the *whole month*, even through the first day of menstruation. It's really only because I had to take a month off here and there in the middle of the fertility treatments that I'm able to see this.

One woman said the "crazy woman juice" affected her ability to think clearly and Iris' story mirrors this thought:

One time I came home from work and I had a rational thought of taking every dish out of the kitchen cabinet and breaking them on the floor. It was like PMS on overdrive. It really messed with my emotions. It was pretty intense.

She also says being on "artificial hormonal changes" made her feel sorry for herself and like her husband couldn't understand.

Cassandra also explains how Clomid both made her feel crazy and socially isolated from others:

I felt anxiety. The second month I took it, I felt intense paranoia, I felt like I was being watched all the time. I could hear footsteps. I was constantly looking around. I felt like walls were closing in on me. I couldn't be in a crowd, because I was too paranoid. It was terrible. I felt like I was losing my mind. That's exactly how a couple of my other friends described it. We talked about it after the fact. They were so afraid, because when you seriously feel like you are going crazy – you don't want to tell a soul. You don't know what will happen to you.

Others were also afraid to talk about their feelings. Patty's partner was urging her to go to a therapist but for a long time she was too afraid to do so: "I can't tell somebody that I'm thinking about killing myself. They'll think I'm crazy, they'll lock me up."

Marita also talks about Clomid, “We started at the smallest dosage and I only went a little bit crazy.” Then on larger doses:

We did that for six months, I was nuts and I mean that in the nicest way. But it was like having PMS times a million every single day. I mean I could yell and the next moment I was laughing you know I was really certifiably not doing well.

Yet Marita kept on taking the Clomid for the maximum 6 month period for both of her pregnancies, which both were conceived during the sixth month of the Clomid treatment. She explains: “It just becomes a cycle. You’re in it and you’re surviving it. You’re probably not going to kill anyone so you might as well keep trying.”

Although we see the dark sides of Clomid that one woman describes as a process that was “gut wrenching and scary and upsetting,” there are also mixed emotions. Many talk of a “rollercoaster” cycle of hope and disappointments each month as they hoped for and then did not get pregnant.

Mai explains:

I don’t know if I was on an emotional rollercoaster just because I wasn’t feeling well or if I had so many hormones. It was probably the darkest days of the past few years. Everything was either pissing me off or making me cry.

Other hormone treatments create fluctuations as well. Christine talks about the hormones to get her and the egg donor’s cycle synchronized. She says they first turn her natural hormones off and she has no emotion, then put her on an artificial hormone cycle all the while dealing with her social reality:

Emotionally, you’re on a high, anyway, because you are ready and excited to get pregnant. Then you have the emotional letdown that it is

not going to happen, and then to stop all the hormones. Your body has to figure out where it is and what it is doing. Then you have to wait until you have gone through a cycle or 2 to get it back before they even do it again. It was tough.

Although the process is mostly harder on women because it is their bodies and they are facing stronger parenthood pressures, some men talk how hard it was to see the person they loved in so much pain and not be able to do anything about it. Terry talks about his ex-wife:

It was hard for me to see her face after every month when she would start [her period] because I just saw how disappointed she was and how she would go within herself into this little shell and not be a happy person, not be a good person, you know pissed off at the world.

### Ethical Decisions

The many ethical decisions that some are faced with serve as more stressors. To Thompson (2005), one model of science places moral responsibility in scientists who are policed by societal norms, but she believes that this cannot be the case for ARTs due to the multitude of ethical questions (p.12). Further, I posit that there are now new types of ethical questions that are raised, which makes taking a position difficult for physicians. For example, some critics state that the illness or disability that causes infertility may be nature's way of ensuring fit parenting. Sub-par sperm can be a result of a genetic problem or environmental factors. Now ARTs can bypass that process and thus scientific intervention is changing evolution. Women and men with fertility problems can now pass on diseases, one of those being infertility (which then creates the next generation of infertile patients for

doctors) (Mundy 2007). How do physicians feel about their potential role in changing the transmission of “normal” genetic makeup and essentially changing the gene pool?

Second, I wonder if this highly profitable industry wants to steer away from many ethical restrictions. Last, fertility doctors might also feel limited in this area because whereas medical literature in other areas such as prenatal testing discusses ethical issues (see Fletcher & Wertz 1992), I have not seen a similar discussion in the fertility medical literature. Thus, physicians have no standard of practice with some ethical questions.

As such, those who use fertility treatments are not given medical guidance, or cultural scripts for that matter, on how to make these tough, ethical decisions. Some of my respondents mention wanting to tell or worrying about their kids when they are older in case the disease got passed on to them yet none chose to deeply examine their infertility problems from the genetic-ethical perspective of passing on genes that contain some sort of potential disability. Kirk is a young man with a Bachelor’s in engineering. He was one of the men whose sperm was subpar and he and his partner, Robin, would rather be unsure about the hereditary possibility. Kirk says, “I haven’t thought about it a whole lot. But it has crossed my mind. I hope my poor kids don’t have to go through this.” Since the physician did not know if it was hereditary and did not really care to delve into the “why,” it makes Robin wonder if it “was more of a dietary thing since the supplement worked.” This

denial does not acknowledge that it still could be a genetic disposition even if the herbal supplements helped.

For that matter, Bob knows that he carries a recessive trait for dwarfism because one of his children from his first marriage is a little person. Although ultimately Bob and Christine moved to donor sperm (when the doctors thought the sperm was sub-par due to his vasectomy and/or age), Bob had no qualms about trying to have more children with his sperm, possibly because producing a little person is rare as it requires two recessive genes or possibly because Bob's son has a successful career and Bob does not speak of him as a disabled individual. He also does not mention doing any genetic testing just in case. In fact the topic of his son being a little person almost did not come up. Further, few mentioned the fact that children conceived through the use of fertility treatments have a higher rate of certain types of rare birth defects (Grady 2008; Mundy 2007).

ARTs can also bypass another natural process of infertility—age. Bioevolutionary scientists would say that infertility prevents possible birth defects and possibly ensures young, fit parenting. The two couples who were “too old” to have children naturally dismissed any concerns with bypassing the aging process by using donor ova from younger women. They even chose to naturalize the process in their explanations. Peter's aging wife had two miscarriages and then several unsuccessful IVF attempts. Peter is unfamiliar with or ignores the data that shows that eggs produced by women

in older age groups form embryos that are less likely to implant and more likely to spontaneously abort if they do implant (CDC 2008) and dodges the question of age by explaining that IVF is:

helping Mother Nature with a mechanical problem. Just because a woman has blocked fallopian tubes but is fit in all other respects, why should she be kept from having a kid? We took it a little step further by going with donor egg.

Bob Hollander also naturalizes the process, but through a historical comparison to concubines:

You had one guy that sired lots of different children with lots of different women. He may have been in his 40s, but all these women were 16, 17, 18. They just used youth instead of technology.

Although Leslie and Cory do not seem to be very religious, they talk about the dilemmas in destroying the “life” that one so purposefully created when they attempted to miscarry naturally rather than have a DNC:

Cory: That’s a tough question, too. If there is no chance of survival, do you let it run its course? Do you wait for it to die, or do you kill it?

L: The previous DNC really upset me afterwards. It happened really, really fast. On second thought, if I had waited, maybe the heartbeat would have gotten stronger. But it wouldn’t have.

C: We went from things being great, being pregnant to everything being done with a DNC within a week. Feeding into that was right before the DNC the doctor asked if we were sure we wanted to do it. We didn’t know there were options!

L: We had the IV in, and we were ready to go. For the next year, I thought about it.

C: Did we jump the gun on it? Were we hasty? I don’t think we were, but .....



L: On the second DNC, just to cover him, he said the exact same words. I think he feels like he has to say that. It made me feel better about the first one.

IVF raises questions of how many eggs to implant and does one take the risk of birth defects with multiples or what about selective reduction of fetuses? What does one do with the frozen embryos? Peter and his partner have several frozen embryos that they are storing for \$300/year. Peter explains that they do not want to have more kids:

Do you let them defrost? Do you give them to someone else to use? Do you hand them over for research? I guess we'll keep them on ice until we figure it out or forget about it. There's no guarantee that they'll turn into people if implanted. On the other hand, they are embryos. There's an unresolved issue for society to deal with, which it probably won't.

Only one of my respondents addressed an ethical issue of even larger scope; the fact that new technologies often get tested on poorer populations (especially nonwhite women) and then used on more privileged classes (Ratcliff 2002). Although Jalila veered away from some of her past radical lesbian feminist politics she still espouses Marxist feminism (my label) as she talks of greater concerns with the fertility industry:

Testing fertility drugs on vulnerable third world women who have little access to information or money. I was really upset when there were all kinds of fertility industry magazines in the waiting room telling me if I purchase their product that this is my path to motherhood. At the same time we poured money into that industry.

## **Treatment Results**

As far as how representative my respondents' treatment success and failure rates are to the general population, I can somewhat compare my rates to annual data from the CDC but not in a direct quantifiable manner because I have data that span over more than one year of their treatment processes. In 1992 Congress passed The Fertility Clinic Success Rate and Certification Act of 1992 [FCSRCA], Section 2 [a] of P.L. 102-493 [42 U.S.C. 263 (a) -1]), which requires all clinics performing ART (this includes IVF, GIFT, and ZIFT, the first two were used by my respondents) in the United States to annually report their success rate data to CDC.

Birth rates for ARTs can get close to 40% for women up to 30 years old and then taper off dramatically as age goes up, 16% by the age of 40, and less than 1% by 45 years old (CDC 2008). None of the women in my study younger than 35 were able to get pregnant within one year of ART cycles. A few women had eventual success with more attempts as they aged; of the nine women in my study who tried IVF, five (56%) were successful.

In all of these pregnancy attempts there were many miscarriages and induced abortions of non-viable fetuses. Of the 6 women who got pregnant from their many ART attempts, 5 had at least one pregnancy that ended in miscarriage or induced abortion. The CDC also reports high numbers for their annual data, 82% of the pregnancies resulted in a live birth and 17% resulted in an adverse outcome of miscarriage, induced abortion, or stillbirth;

1% was unreported. My numbers are probably higher because as people have more and more attempts the number of fetal losses also becomes higher.

Further, the CDC reports that in 2004, 11.3% of pregnancies from ARTs resulted in a multiple-fetus pregnancy. I had a higher rate over my longer period of time, out of six pregnancies, two resulted in twins. Clomid is also associated with a 10% increase in the chance of having twins yet of the pregnancies among my respondents who used ovulatory drugs the rate was less than 2%, which is the same rate as naturally occurring twins.

National success rates for Clomid are around 30% (Webmd 2008) within a few month period because most women do not take Clomid for more than a six month period due to increased chance of cancer. As such, it is easier for me to compare my respondent rates to the national averages because I am working with the same timeframe. I found slightly higher rates among my respondents if "success" is measured as a viable pregnancy and not as the ability to get pregnant. Out of the twelve women in my study who used Clomid, eight (67%) got pregnant and five women (42%) had viable pregnancies. When I look at the fifteen women who used Clomid or a similar ovulatory drug, eleven (73%) got pregnant and six women (40%) had viable pregnancies. My higher than national rates seems reasonable due to self-selection of respondents.

Information from an article in the medical literature that came out right around the time that many of my respondents were going through infertility testing may reveal one reason for relatively low success rates. Glatstein et al (1997) state that there is a dearth of data from “rigorous, controlled, clinical trials evaluating the efficacy of infertility screening tests in relation to clinical outcome, namely the establishment of pregnancies” (p.443). In essence, there is no standardization in diagnostic measures, plus there are only a handful of therapies that get used despite the multitude of factors that may cause infertility. Thus, fertility treatments are somewhat of a gamble. This may reflect a more general trend in the medical industry that Blank (1993) critiques, stating that the increasing demand for medical fixes creates a fine line between experimentation and therapy (p.10).

### Success and Failure: Lifestyle Impact

Treatment failure is stressful in many ways and an important component in the whole fertility treatment process, whether one eventually becomes successful or not. Most infertility literature looks at the *end* result, and interviews people about the end result. From a symbolic interactionist perspective, looking at the larger process not only looks at the broader picture and explains the process in more detail, but also explains the newfound sensitivity that all who have gone through the process have for anyone struggling to have children. Although many themes emerged in my

study related to the treatment process, the one of focus here is failure, or repeated failure.

Although one of the men in my study says that the first time the insemination did not work “was the biggest failure I had ever failed,” as discussed in the diagnostic section, failure to become a parent is often equated with gender role failure, especially for women. Whereas the infertile men in Webb and Daniluk’s (1999) study tried to compensate for their feelings of inadequacy by taking on other masculine roles such as “acting like a super jock,” having an affair, or devoting more time and energy into their careers (p. 15), being a mother is such a primary status, or master status, for women, that my respondents do not discuss re-directing their gendered roles.

“My goal had been by the time I was 40, I would be pregnant. I was thinking that I had to get that job done.” Becoming a parent is a major goal in many people’s lives so not being able to fulfill this is quite devastating. Iris tells me about getting the phone call from her doctor’s office with test results and an “I’m so sorry’, like there had been a death,” and it was a death in a sense as she put her aspirations to rest. She said, “I knew that meant I wasn’t going to have children...that was a day where everything came crashing down.” Iris’ sense of loss and grief is similar to respondents in other studies that reveal a sense of loss and grief in not being able to fulfill hopes of producing a child (see Webb and Daniluk 1999).

Another woman talks about the treatment failure affecting all portions of her life so she felt like she was an overall failure, “I’m failing at my job, I’m failing at my personal relationships...” And this is in addition to what another woman calls the stress of “playing all the mind games” while wondering about a multitude of circumstances that could have been the reason for the treatment failure.

As one can surmise, more failure leads to more stress. Many talk about increasing levels of “desperation” with each unsuccessful try. One woman said she was feeling worse and worse because she “had a running loop of fantasy of driving up to Iowa where most of my family is and getting to tell everyone that I was pregnant.”

A great deal of anxiety also surrounded the more ambiguous areas in between the success and failure polarity. For example, the uncertainty in waiting to see if treatments are successful is quite difficult. One woman who went through several rounds of IVF with donor egg says that “The emotional side of this is 90% of the process. The not knowing and no control.” Peter eloquently writes of his wife during an IVF procedure: “The Valium has relaxed her, and she sleeps, face at peace, a long and dreamy distance from the tears and emotion of the night before and the morning of.”

With IVF there is daily anxiety for five days after the eggs are removed and fertilized in a dish; couples get daily updates on how well the eggs are fertilizing. Then there is an anxious two weeks between IVF implantation and

knowing if the fertilized eggs will actually develop. Here is one man's agonizing description:

That feeling became intensely acute after the eggs were harvested, fertilized and implanted and we were waiting to hear if they had taken. By then we were \$15,000 into that round, [Sandra] was now in a painful round of shots, and this was the last roll of the dice. The psychological investment is getting really high too. You're going insane, sitting there looking at a time bomb. You don't know whether it's going to go off or not. Either we were going to become parents, or we weren't.

There are also bittersweet feelings of treatments having counteracting effects, being successful in one aspect but causing other problems that lead to failure. As one respondent notes: "You have given me this medication that will regularize me, but at the same time, you have taken away my ability to make an egg to implant. What are you doing to me?"

There are also multiple stories of treatment success (or failure) being in transitory states and fluctuating with each doctor visit, which can be days apart. Cassandra excitedly found out she was pregnant but in the next sentence was told her that her hormone levels were low. She went in every 3 days to test her levels and during the third check her levels were great. She eventually miscarried. Another woman also describes pregnancy scares that finally ended with a sonogram: "What do you mean there's no heartbeat? Three days ago there was."

Leslie went in for a sonogram that revealed twins. "But one's heartbeat is not doing well. The other one's heartbeat is doing fine. That was good and bad news." During her next visit they could not find the heartbeat of

the viable twin. When Leslie miscarried the viable twin they had another rollercoaster:

The doctor had always said that the little twin was not ever going to make it. The nurse who examined us was kind of hopeful. The doctor didn't come in after Christmas. She told us to come back so we could look at the little guy again. We waited from Monday to the next Sunday. We started to get hopeful again. When we went back in on Sunday, the doctor was there. He said he knew what the nurse said, but that there was nothing that was organized life in there.

## **Conclusion**

This chapter followed the many financial, emotional, and physical costs of fertility treatments. Yet despite all the hardships that these women and men endured, when I asked them if they would recommend these procedures to others in similar situations, they all said “yes.” For those who were successful and had children, the pain was worth it. For the others, they still feel that trying was the right decision for them at the time and despite the hardships may have provided them with some positive feelings of hope and agency. Throsby and Gill (2004) also find that their unsuccessful recipients continued to regard IVF with appreciation, which they read as adhering to a perspective (i.e. liberal, not radical) that views medical technology as politically neutral. Yet this is not necessarily the case for my respondents. In the following chapter I explore respondent experiences with the medical community and their various strategies in maneuvering within, or outside of, this system.



## **Chapter Seven: Sterile Situations: Experiences with Doctors and Patient Reactions**

### **Introduction**

Are patient-physician interactions important aspects of the treatment process? Do positive and/or negative interactions affect patient agency? Whereas we saw some patient experiences with their doctors related to the diagnostic process in a previous chapter, this chapter delves into various experiences my respondents had with physicians during the treatment process. The doctor-patient relationship has been a major area of study in medical sociology for decades, and especially the relationship between doctors and female patients (Lorber 1997). Studies have found that the quality of the doctor-patient relationship is related to medical compliance and satisfaction with health care (Winnick 2005). The literature shows that satisfaction with physicians reduces patient uncertainty about their illness, gives them a greater sense of control, and improves health outcomes (Arora 2003). This type of analysis is not only important for the larger medical sociology literature, but as Charmaz (1990) says, grounded theory can provide physicians with alternative understandings beyond what was provided in their medical training of patient's beliefs and actions outside of clinical settings, which can improve communication (p.1161).

Symbolic interactionism lends me the understanding that physician-patient communication is dependent on both the practitioner's and the patient's communication styles. Symbolic interactionism focuses on micro-level communication, especially the ability of actors to use symbols, assign meaning, and take the role of others. The theory has focused less on power differentials, but most empirical studies find that doctors assume a dominant role in dealing with patients, and that their communication styles are shaped by their assessment of such factors as patients' education, gender, and race (Lorber 1997). Because my sample is relatively homogenous, patient problems with physicians tend to focus more on issues related to medical training that does not stress a good "bedside manner" or listening to the individual, as well as a profit motive that creates an almost assembly-line effect. Perhaps one reason physicians did not pay much attention to the quality of their interactions with patients because they know that the demand is there; my interviewees talk about how full the clinics were.

In my study, five respondents were very pleased with the quality of care and the warm and personal staff; all of these people were able to get pregnant, either quickly or after several years. Ten respondents had a few bad experiences but also had at least one physician that they were quite pleased with; of this group there are those who got pregnant and those who did not. The other 13 had some good medical experiences here and there but had such bad experiences that this overwhelmed their views of their

treatments and physicians; of this group only a quarter were able to get pregnant. They had a variety of complaints such as impersonal treatment, ineffective communication, a lack of sensitivity, and heterosexist ideology. Some thought that their physicians moved too quickly, others too slowly. In general, however, infertility treatments tend to be quite interventionist, which might increase opportunities for patient dissatisfaction. Further, long-term doctor-patient relationships based on goal oriented treatment may be subject to more frustrations.

The first section of this chapter outlines how patient-physician interactions were crucial elements of the fertility treatment process for the respondents as they affected decisions about whether to stay with certain physicians and also affected them psychologically, either positively or negatively.

For the remainder of the chapter I discuss several types of patient response to the medical industry. To what extent are women and men who seek fertility treatment satisfied with their relationship with the doctor and the care they receive? Does the social class background of this mostly middle-class sample affect how they respond to physician recommendations? What are different types of patient agency?

## **Types of Patient Response**

Researchers have examined the doctor-patient relationship in terms of patient activity versus passivity in terms of how closely they follow the doctor's orders (Winnick 2005) as these relationships are very important to patient satisfaction and even treatment success rates (Winnick 2005). In my study the first type of response is deference to physician authority, which is more apparent with respondents with lower SES (in my sample the lower-middle class or no college education) or those who work in the biological sciences. The second type of patient response is personal agency within the medical model or turning to complementary and alternative medicine (CAM). Working within the medical model some patients took it upon themselves to monitor their communication styles with physicians so they did not come off as "bad" patients, some went to support groups and/or switched health care providers, others did their own internet research. Quite a few respondents also turned to CAM, either due to their personal backgrounds that were open to CAM, due to physician recommendations, or their eventual deep disappointment with western medicine. Patient activism was the last type of response whereby some turned their anger and/or disappointment with their treatment into personal activism with trying to change what health insurance covers or being vocal about dispelling some of the gendered myths behind ideas of fertility.

## **Patient Complaints of Medical Treatment**

### **Impersonal Treatment**

One respondent thinks that they had caring professionals who treated his wife “like a patient, not a piece of meat,” which is important because when the patient is treated as a “person” there is better adjustment to illness, successful information exchange, and collaborative decision-making (Arora 2003:792). Half of my respondents, however, complain of impersonal treatment by itself or paired with lack of communication. Edward calls the process he went through “dehumanizing” and explains:

‘This is what we do’ and you’re going through what they do rather than think about ‘this is who you are, let’s focus on you.’ They will test everything if they have the ability and technology, regardless of whether it is indicated or not.

Impersonal treatment that ignored the family’s medical history was common. For example, Cassandra is very critical of not being treated on an individual basis both because of her experiences with trying to get diagnosed and treated for fertility issues and family history:

They relied on blood work and the numbers. I can give you an example from my family where we tend to have iron-rich blood. When my mother began to have problems with anemia and early menopause, because of excessive bleeding. Her levels, although they were at the point just bottom of normal, were so low for her that she was very sick. So, I really think that numbers need to be placed in the context of a person’s history and background. I was not pleased with the doctor who would not look at the patterns in my ovulation charts and really see me as an individual instead of one member of this larger population.

Patty also comments that her first specialist was treating her “like one of a million”:

The consultation was a little disappointing. She barely looked up from her desk. She didn't even realize that [Renee] was at the appointment with me. She was constantly looking around for prescription pads. They were pre-printed already with prescriptions, and all she had to do was put my name in them. They already had the dosage, and the medicine, and signatures. I thought, 'Is this really gonna work?'

Both Patty and Cassandra's stories reflect a disconnect that postmodernists see between the medical model and actual bodies that fall anywhere from being similar to, to being different from the ideal type at different times in a person's life.

#### Lack of Open Communication

##### Not Listening to the Patient

Other complaints of impersonality revolved around medical personnel not listening well to their clients, which in some cases prolonged the treatment process. One respondent told her physician that she is sensitive to medications yet she was given several medications at too high of doses, which gave her bad side effects and caused her to delay a treatment cycle. Julie, and especially Kevin, are a bit upset that when the physician put Julie on Clomid he would not listen when she said she was a late ovulator so “he would always stop too soon or check too late.” Kevin chimes in about the doctor, “His timing from his experience, you have to do it this way. But your body was saying to do it that way.”

Medical sociologists note that people who experience medical symptoms are likely to turn first to lay consultations, but doctors may be dismissive of such knowledge (Meininger 1986). Jalila had a history of irregular periods and consulted with her woman friends first, which led her to suspect that she had polycystic ovarian syndrome. Then she went to her gynecologist who is “dismissive of polycystic ovarian syndrome as a diagnosis at all.” Given her medical issues and because she has a sister who had a hard time maintaining a pregnancy, she quickly went to a fertility clinic that her family practitioner recommended plus she had heard from friends that they accept “single” women. The clinic tried to help her get pregnant but Jalila complains that the doctor did not listen to her concerns about polycystic ovarian syndrome. She was frustrated because she felt that treatments were not working due to a misdiagnosis because her specialist did not listen to her. She felt like this led to wasted time, which she said is not only expensive but she also felt like her fertility was “eroding” in the meantime:

Things weren't working, why are we messing around? I felt like the clinic did not do a good job of listening. In our initial consultation with the doctor I said 'I think I have polycystic ovarian syndrome, I don't have any kind of diagnosis but here are seven reasons why.' She said 'oh that's fine, we have Clomid that will fix whatever we find.' After we tried getting pregnant without anything we tried on Clomid and nothing was happening. She called us into a consultation and wanted to tell us about this thing called polycystic ovarian syndrome and I said “really, really, really.” She talked to me about not eating sugar and I said 'I don't even eat fucking carrots.' Like clearly you have not heard anything I have said and why have we just wasted the last few months? It felt like they have a system and they feed into the system. They wait for the system to tell them about you. I frequently felt that way.

After all of the stories of the emotional effects of Clomid outlined in the previous chapter, one would think that physicians both know about and forewarn their patients, but data from my interviews suggest neither seem to be the case. Yet perhaps this is not surprising because there is a history of the medical establishment not paying attention to women's side effects from contraceptive technologies (see van Kammen and Oudshoorn 2002). Further, we know that economic incentives of pharmaceutical companies affect clinical trials, research and publication, (Sismondo 2008) as well as the assessment of drug safety and health risk (Abraham 1994).

In my study many women thought physicians either had insufficient information about Clomid side effects and did not care to learn more. One probable reason for this is because currently Clomid is the "best" drug on the market as it has replaced a previous drug that had harmful physical side effects (although one might question if Clomid's side effects are overly harmful plus Clomid cannot be taken more than 6 months at a time due to an increased risk of cancer). This made Cassandra very angry because she felt "misled by multiple doctors about the side effects of this drug." She and three other friends who also had negative experiences with Clomid said that their specialists told them that they "would not have severe side effects and that severe side effects were very uncommon." One of my respondents said that she felt that her comments were dismissed when a nurse said, "That is very unusual, we will note it in your chart." Another angry respondent thinks that



doctors should try to set up a screening mechanism to make sure that patients are emotionally stable before prescribing Clomid and tell them about various resources such as support groups.

### Inadequate Explanations

Some respondents also complain that their physicians did not explain treatments or their side effects properly. Studies have consistently reported that patients want to know detailed information on prognosis, treatment options, side effects, risks, benefits, etc, and that physicians under-estimate patient desires for information and over-estimate their own informativeness (Arora 2003:793). One woman complains that her physician's lack of explanations were due to impersonal treatment, where he treated her on a "need-to-know basis, I didn't need to know much. They made it difficult."

Another woman's physician even (mis)communicated via mail:

They would send you prescriptions for new drugs for your next cycle with a form letter saying "we hope you don't need these but here's the prescription if you do." Before I had talked to a doctor they sent me prescriptions. One month they sent me prescriptions for the Clomid, for the 2 shots, the progesterone suppositories, and a bunch of needles. And nobody had told me why I was getting the prescription, or how and where to give myself shots. They hadn't consulted with me about the risks, the benefits, about anything so I was really upset about that.

Others complain that doctors did not relay important information.

Luckily Hillary is a nurse and noticed the ambiguity of the medical language that could have led to an overdose:

They just gave me a shot to inject. They said 'here's the powder, here's the liquid, mix them, give yourself a dose.' So when I read the directions on the bottle a dose was a fourth of the vial, not the whole thing. That's what I did and I tried to call them after hours and they didn't have anybody that was on call. So I didn't do the whole shot. I am a nurse but no one gave me or there were no written instructions. I was afraid to overdose myself by giving myself that whole bottle even though that's what the whole prescription would have been. I felt like it was a real rushed process and not very personal.

One of Mai's doctors also omitted some important information that could have cost her life:

He said I would feel better in six weeks, and we would talk about getting pregnant. Two trips to the ER, a brain hemorrhage later, I was not feeling better. He neglected to tell me that the Metformin has adverse effects in 10% of women. 1% has severely negative effects. I'm that 1%.

The physicians at the ER the first time also did not know that the Metformin was causing the side effects and sent her home, which is why she was in the ER again a week later. When she came in the second time the ER doctor figured it out and tried to get her specialist on the phone but Mai says he "would not come off the golf course to answer questions." The ER physician told her that the dosage was too much too soon and to stop taking it.

Jaime was very upset that her physician did not tell her what her miscarriage would be like:

I was passing balls of.....I didn't know what it was. I had to take it into my doctor. "Is it the sac the fetus was in?" He said, "I don't know what it is." It was the size of a tennis ball. You don't know what all this stuff is. But it is gross. They don't tell you that you are going to be bleeding for a while, that you are going to be passing a lot of stuff; it might take a couple days.

Cary wonders if their specialist had strong suspicions that their pregnancy was not viable but did not want to tell them right before Christmas:

The only thing for me is that I'm not sure that the RE didn't lie to us. Not lying in a sense that he saw something, but it just seems to me that there was a reason for him to be upset about what was happening. He didn't give us any information at all. I just wonder if he had a really good feeling, but he didn't know. He didn't want to tell us two days before Christmas that we had lost the child, or he wasn't sure. But other than that, he has been very honest with us, even in the situations where it has been bad news.

Ada also uses the language of "lying." She was one of my pilot interviewees and talks about how thirty years ago her doctor recommended that they do an insemination with donor sperm (her husband had had a vasectomy). The physicians were very secretive about fertility treatments and did not want children to know that they were not genetically related to a parent so Ada explains what the gynecologist recommended:

They'd say things like 'go home, and go fuck, maybe your husband has some sperm and maybe it'll be his kid.' You know, like, 'hello?' it was not straightforward. The guy was laying these layers of lies on it and I was just really uncomfortable with it.

This discomfort caused Ada to opt out of the insemination and she adopted instead, which she felt was easy to be open about with her child.

### Improper Communication Between Health Care Providers

Lack of coordinated care between physicians was also a problem, what some medical sociologists say is a consequence of several physicians with specialized (and thus limited) knowledge trying to work on the same body

(Weisz 2006). In my study, however, the problems with health care staff communication with each other seems to be due to being too busy to put the time into proper verbal communication or organization. Ella explains using physicians from two different states:

They didn't communicate as much as I would have liked. The doctor in St. Louis just kinda told me things, and I would tell the Topeka doctor what they told me or what test needed to be run. They would fax things back and forth, but to me it's like, "Could y'all get on the phone." But I think...it was so new to me, but they both knew what to do. It worked, so I guess....I was just like, "Alrighty."

Hillary also thinks there was a lack of communication between staff members at the same clinic. One day they told her that they had to do a test that they had recently done, and another time they called in a prescription to the pharmacist who did not want to fill it because the dosage was too high. So Hillary called her doctor's office and "they pulled my chart and decided that I didn't need to be taking it."

### Insensitivity

Responding to patients' emotions is a very difficult task, but one that my respondents would have liked to have seen in the medical treatment that they received from both physicians and staff. They complain of impersonal treatment, coupled with a lack of sensitivity to the emotional aspects of trying, and failing, to get pregnant. For example, one woman thinks that her nurse did not want to listen to her: "The one time I started to cry in an appointment,

she basically became very upbeat like this was good news, I think so she could scoot me out before I really started to sob.”

Jalila also feels like her impersonal treatment was paired with insensitivity. She relays a story of being upset that her treatments were not working because she knew that she was not going to move on to higher tech treatments:

They were understaffed, there was a tech who was not normally there and she was really rough. It hurt me when she was inside of me and then said my body wasn't responding to the injectables and I began to sob. She pulled the sonogram out of me and turned the lights on and left the room. At that point I felt like 'okay I am just one more vagina and I know she sees vaginas all day long'.

These are not isolated cases in a specific medical setting, many researchers suggest that physicians should show more caring to patients, especially when it involves breaking bad news (Arora 2003). Jalila continues, however, to say that a kind nurse then pulled her aside to another room and was very empathetic.

Jalila's incident also shows a lack of sensitivity to some sexual trauma issues that get stirred up in women when they have vaginal exams and procedures. In his journal Peter writes about his wife emerging from a procedure “tight-lipped” and made it to the car “before she let it out”. He explains that “she can steel herself against nearly any pain elsewhere, but pain in the genital region strikes dangerously close to some deep-seated negative emotional memories.”

There are also accounts of (sometimes unintentional) insensitivity that are not necessarily connected to impersonality. One respondent did not mind her physician having a “terrible bedside manner, no warm fuzzies...but we preferred that, just tell us what’s going to work.” Others, however, were more bothered, as one respondent said, “We have had some cold people.” One respondent learned that she had miscarried from a single sentence, “There is no heartbeat.” She also thought their subsequent instructions were insensitive: “Just stick everything in a butter container and bring it in.”

Cassandra had a similar experience when her ultrasound at 6 weeks pregnant revealed that the fetus was not measuring right and the nurse told her that she had a 5-10% chance of miscarrying:

I was talking about how devastated I would be if that happened. She said, ‘Well, at least you had a chance to get pregnant. A lot of women never get that far.’ I thought, ‘This is my experience. I’m not comparing my experience with what other women have done’. If I did that, my God, I could look at my mother and say, ‘She never had to go through anything that I went through, and she has 4 children.’

She also talks about going in to the clinic after she miscarried to make sure that the miscarriage was complete. The personnel started talking about her options of fertility treatments or just waiting for a bit:

There is really no empathy on their part. I guess that is to protect themselves from riding the ups and downs of every patient that they see. On the other hand, it was pretty upsetting to have someone sit there and tell you in very clinical terms that this one didn’t work out but that I could try again, and all these different things. I was pretty numb and just didn’t hear anything. What really upset me was that they never offered me any counseling or suggested it to me.

The critiques go beyond medical staff for fertility issues, they include other health providers who also do not handle fertility issues well. For example, one woman describes going to a women's health clinic for a separate issue when the health practitioner saw from her file that she was going through fertility treatments:

She just said all the wrong things. She said that she had 3 boys and something to the effect of 'you're lucky there's a lot of days where I wish I didn't have kids.' And I was thinking, 'you don't mean that, I'll take your children if you seriously mean that, but you don't.' And I think she saw that what she had said upset me so then she tried to make it better by saying, 'But I do understand that it's such a special thing that two people come together and create something.' And I'm thinking, 'What if we can't do that?' So I started crying and it was bad.

#### Homophobia

Weeks et al (2001) describe a "heterosexual assumption" as an "all-embracing institutional invalidation of homosexuality and presumption in favour of heterosexuality" (p.41). The medical institution can be one such case as there have been reports of some lesbians are denied access to New Reproductive Technologies (Edwards et al 1993; Schmidt & Moore 1998). Both of the lesbians in my study complain of treatment that is insensitive to their sexual orientation. Although they had some good encounters with "the two mom thing" they also had to fight heterosexism and homophobia. Jalila explains a time when she and her partner went into a small room to get a test done with a nursing student who was "not expecting lesbians" and made heterosexist assumptions:

She was doing the preamble stuff, 'when was the first day of your last period, have you had sex since your last period?' and I said 'yes I have.' Then the whole 'oh well then we can't do the test because you may be pregnant' and I say 'I don't have sex with men'. [Sonya] was just standing there and she goes 'hello' and it was very funny because the nurse was flustered. [Sonya] was displaced in lots of ways.

Further, Jalila's partner could not be told anything over the phone and she had to wait outside during many of Jalila's tests. Patty's OB treated her but when she needed to find a specialist she had:

a very difficult time finding anyone in the Kansas City area who is willing to help a same-sex couple. Most of the doctor's offices I called said, 'We need to see you and your husband.' I said, 'I don't have husband; I have partner.' 'I'm sorry. We can't help you.' I got that again, and again. I talked to [Renee's] aunt, and she said, "You need to call Doctor so-and-so. He's the one who helped me. He will help you out." I called his office, and he no longer helps same-sex couples because of the backlash from the Christian community.

Due to these experiences Jalila was suspicious of homophobia in many medical situations. For example, she talks about being screened by a psychologist before they could receive treatment. Other respondents also talk about screening but Jalila is sensitive to the focus on her relationship:

This woman was much more interested in us as specimens as an interracial lesbian couple than talking about anything useful. The other thing she was this gatekeeper of the patriarchy. Her main question was our coming out stories. Do our families know and all those kinds of things. Well, statistically with artificial insemination there a lot more boys than girls. So what is our plan to make sure that there are positive male role models in our child's life? What I heard was 'I have control of whether you move forward in this process and I'm going to make you say that men are important.' Do they make straight couples see that they are going to put you on crazy woman juice and what are some emotional safety plans? She could have said a lot of useful things it was really heinous.



## **Responses to Medical Experiences**

Many studies have looked at how patients respond to medical encounters, with special attention paid to medical compliance, patient satisfaction, and patient activism (see Broom 2005; Fox 1994; Madden & Sim 2006; Parsons 1952; Stacey 1997). The respondents in my study had a variety of responses to how they were treated by physicians, including deference to physician authority, monitoring their presentation/communication style, doing their own research, going to support groups, switching medical professionals, using complementary and alternative medicine, and engaging in some form of activism.

### **Physician Authority—to Defer or not to Defer?**

Much writing in medical sociology, including early works (see Parsons 1952), examines the idea of physician authority, to what extent it goes (un)challenged, and the effects of this power differential on patients. Integral parts of this dynamic are the diagnostic and treatment processes yet few studies examine “how the meaning of a diagnosis is created and how this influences its acceptability (Madden & Sim 2006:2963). Although one respondent says, “You’re making big decisions often fast,” none of my respondents felt rushed into making decisions that they regretted. There is, however, a range in how closely patient decisions complied with physician treatment suggestions. There is a continuum from deference to the doctor

with full acceptance of his/her medical opinion, to taking some amount of self agency in research and/or switching medical professionals, to being suspicious and/or disapproving of the medical establishment and using non-allopathic medicine. Further, whereas some people stayed within the confines of one of these categories with more regularity, others traveled between them, sometimes in a non-linear fashion but usually passed through them as stages as some became more critical and/or disillusioned by standard medical practice.

Most medical sociology studies point to social class as a significant factor in patient deference to physician authority (Lorber 1997). This is harder to see as a clear cut category in my study because all the participants could be considered middle-class, yet there is quite a range in the middle class, both in general and among my participants. In my study a more significant indicator of SES may be education. The women in the study who had not earned a college degree were more likely to defer. For example, one woman who only had some college talks about her physician, "With her being fresh out of medical school I had no problems trusting her." Whereas this woman felt that her physician was "up to date," others would be leery of the lack of experience of a new doctor.

Jaime is currently working on her BA, yet class is a related issue in that Jaime is probably at the lowest socioeconomic status of my participants (I am judging this by her and her partner's occupations, the size and location of her

home and her own statements about their financial situation). Although Jaime said she was “obsessed with internet research,” the internet can be both a tool for empowerment and/or allow patients to adhere to standard medical knowledge and practice. Further, even if one finds alternative knowledge, this is only one source of information and physicians may still have more authority. When I asked Jaime about herbal supplements that are supposed to increase sperm motility she said that her partner is not taking them because the doctors “said since it is not proven or disproven, just eliminate the possibility that it may be helpful.”

Jaime’s physician, as others do, is utilizing an older medical establishment tactic of disparaging complementary medicine (Tovey and Broom 2007; Winnick 2005) and patient agency. This older view may not be the best tactic as a few studies have shown that effective communication about complementary and alternative medicine has been reported by both cancer patients and clinicians to enhance the patient/practitioner relationship (see Tovey and Broom 2007). Further, although some physicians think the internet can enhance the doctor/patient relationship, other physicians see the internet as a challenge to their authority (Broom 2005).

Another possible factor in patient deference is seen in a fifth of my respondents who work or have worked in the sciences. They are among those who have more deference to medical authority as they are ultimately part of the medical industry that tries to present itself as a near exact science

in opposition to non-allopathic medicine (Starr 1982). This point is also fortified with its juxtaposition; Ellen's concentration in sociology has touched upon medical sociology and the social construction of science and knowledge and thus she was more critical of physician authority and took more of her care into her own hands as well as delved into some complementary medicine. She supplemented her medical care with meditation, a strict diet, exercise, herbs, and massage.

### **Patient Agency**

In opposition to patient deference there was also a recurring theme of the medical process causing people to realize, or reemphasize that, "you're on your own. You can't rely on them unless you advocate for yourself," that one has to "take control of medical care." As postmodernists point out, rationality has produced fragmentation and resistance (Turner 1992) that means turning to self-management (Hall 1998). This deference to physician authority was more often seen by those who had higher education, several with Masters' and PhDs. Tactics of taking care somewhat in one's own hands were: self-education, switching medical professionals, becoming political, and/or supplementing care with complementary medicine.

### **Self-Education and Switching Physicians**

Many attempted to self-educate through the internet where some helpful information was found. Some report, however, that it can also be

overwhelming and one has to sift through information that is based on a person's particular circumstances and perspective.

Several people talk about switching physicians due to dissatisfaction and as such my findings join “only a few studies [that] identify patient-level factors associated with the termination of the patient-physician relationship other than change in insurance” (Tai-Seale 2004:494). This strategy may benefit the individual if she or he finds more satisfactory care (although there may be hurdles in the middle, like one couple having to be re-tested because the previous hospital analyzed tests using a different system) yet exit alone is not necessarily a strategy for structural change. As Tai-Seale (2004) states, physicians may not know why patients left or how to remedy the situation, plus patient attrition may not cause revenue loss if they acquire new patients.

### **Presentation of Self to the Physician**

Others carefully maneuvered around their existing physicians. Reece felt like she was treading a fine line between having agency and not wanting to get on the doctor's bad side:

I'm learning to be more of an advocate and I don't want them to think that I'm being a difficult patient. My experience in healthcare is you get patients that are difficult. People talk about them being difficult and people get labeled. That hampered me knowing that on the other side how people could be. It is quite a system to negotiate for sure.

As seen, Reece is not completely eschewing the medical establishment but rather learning how to navigate within it. And as postmodernist Kleinman

(1988) points out, because no one can exist in a vacuum apart from mainstream society, the patients' voices will reflect, to some extent, dominant ideologies about disease yet this amalgamation, of personal experience and biomedical rhetoric, is in itself postmodern.

Similar to Reece, Iris tried to not be too "pushy." She realized that her physician did not like to answer questions so she changed her tactics, "We had all these questions, so we had to let go." On the flip side, Jaime's gentle attempts to be a self-advocate were met with resistance. When she went in for her first insemination the nurse asked if she had gotten a certain test that she administers. Although Jaime had not gotten the test, the nurse told her and her partner about it and told them to call if they had any questions. Jaime called at a later date and left a message with the receptionist:

'Just have so-and-so call me when she is not busy. I am in no hurry. I just want to ask her a question.' They said, 'We can't promise you who is going to call back.' I said that I didn't care if she called me in 2 or 3 weeks. 'She can't call you back. Whoever we have will give you a call.' I was like, 'You gotta be kidding me.'

Trying to change the system was not received well by the doctor's office and they took several "actions" such as refusing to transfer her paperwork to another clinic without a fee, and calling her a "pain."

Mai was also tagged as a "bad" patient. After her fertility drugs caused a brain hemorrhage that landed her in the ER she went back to her specialist: "He said if I was not going to take the medication and not listen to him then I was not serious about getting healthy." He then proceeded to tell (threaten?)

this 28 year old that he would give her a hysterectomy if she did not want to take his medications. There were no physical indications that she needed this surgery.

These stories mirror the postmodern discussion of compliant or deviant bodies. “Good” and ideal patients are docile bodies that accept physician knowledge unquestioningly (Fox 1994; Stacey 1997). Medical sociology studies show that doctors consider good patients to be those who seldom consult and only when needed, trust the doctor, comply, and do not expect too much. On the other hand bad patients over-consult, demand, insist on rights, lack trust, blame physicians for illness, are critical and ask too many questions (see Calnan 1984) yet more recent studies show that some physicians welcome patient questions and engagement (Broom 2005).

### **Complementary and Alternative Medicine**

Others (40%) deviated more from standard care and engaged in some form of complementary and alternative medicine (CAM), which is close to the national average of half of Americans having tried some type of CAM (Winnick 2005). None of my respondents said that their insurance covered their CAM, which meant even more cost added to the costliness of fertility treatments. Although postmodernists try to delineate themselves from Marxist and post-Marxist theorists and do not specifically focus on the profit-motive, many do look at consumerism as an aspect of our health culture

(Turner 1992) as people are paradoxically pushed to both be dependent on professionals and self govern, both of which require spending money.

Studies show that patients base decisions on CAM from physicians, the internet, friends, and family. People are also currently more skeptical of modern science and no longer accepting expert advice at face value (see Tovey and Broom 2007). In my study patient openness to complementary medicine came from several areas.

Sasha was quite proactive with research, western, and eastern treatments for herself plus she had her partner take vitamins. She felt like she had a relatively minor problem (and she did have relatively good success and got pregnant within a few months), especially when comparing herself to a friend who had undergone in-vitro fertilization. Sasha was already open to the idea of complementary medicine, saying she was born at home (not in a hospital) and comes “from a family of hippies who never took their kids to the doctor.” She has also been in liberal environments her whole life where there is more knowledge and availability of complementary and alternative medicine.

For others, however, the use of complementary medicine was from following physician recommendations. There are very few studies that examine the dynamics of patient-physician interactions in relationship to CAM use. What has been found is that there are physicians who are negative or ambivalent toward their patients’ use of CAM as they fear the



deprofessionalization of medicine (Tovey and Broom 2007). Yet the medical profession has recently responded to increasing patient use of CAM by working around it, co-opting CAM practices, or referring patients to CAM practitioners (Tovey and Broom 2007; Winnick 2005). Some postmodernists suggest that medical professionals should break from the strict biomedical model (Frank 1995; Kleinman 1988) and be more attuned to difference and patient knowledge and autonomy (Fox 1994) because medical knowledge is not completely based in objective, scientific truth (Cohen 1992; Laqueur 1990) yet the recent studies show that the new flexibility in the medical field is done to retain professional dominance. One also sees that the older deprofessionalization thesis (see Haug 1988) must adapt to newer times.

Leslie's entrée into complementary medicine was her doctor's recommendation to an acupuncturist. This CAM practitioner gave her acupuncture, herbal supplements, and had Leslie burn herbs over parts of her body. Instead of giving up alternative medicine when she became dissatisfied with this acupuncturist due to strange and insensitive statements, Leslie moved to another. She also started eating healthier, took time off of work, and enrolled in stress management and ceramics courses.

Kirk religiously took herbal supplements, even when he went overseas, because his doctor told him about a dietary supplement that has had some clinical trials and is supposed to increase sperm motility and count. He said,

“I can’t prescribe this stuff, but I can tell you about something that is out there on the market.”

Others turned to complementary medicine after years of frustrations with western medical doctors, which is why the medical profession recently shifted to trying to accommodate or even administer CAM (Winnick 2005). A postmodern critique states that the rational versus lived realities create a sense of disconnect between patient and practitioner (Turner 1992) so biomedical power and control get contested (Stacey 1997; Williams & Calnan 1996). Mai took a year off and looked for answers herself, including seeing an herbalist, a nutritionist, and an acupuncturist. She felt better for a little while but then she felt bad again so finally went back to her gynecologist, tried some hormonal medications to no avail and then was on her own again. She joined a weight loss study, lost 40 pounds and felt better for a little while.

Cassandra’s friend had been recommending a naturopath and after quite some time she eventually went to try to feel better (and dealing with the infertility was a secondary goal) when conventional medicine could not find anything wrong with her after her miscarriage. She and a few of her friends who used fertility treatments had several awful experiences with physicians not being able to accurately diagnose and treat symptoms or refuse to see outside of a narrow scope of practice. Symbolic interactionists have also found that diagnosis depends on selecting certain signs and symptoms as relevant, leaving other psychosocial factors out (Anderson & Bury 1988;

Jobling 1988; Scambler & Hopkins 1988), which creates a gap between the medical profession and what people are experiencing in their everyday lives.

Cassandra's disappointments with western medicine are mostly experiential, not just theoretical. She explains:

I have always had a great deal of trust in science and the scientific method. I could respect doctors who pursued medicine from that point of view. I just felt that many didn't do it that way. There was a lot of guessing... unscientific and really a foolish way to pursue diagnosing and treating a person. I had to find the right fit with doctors. That wasn't always easy to do. All these experiences together have perpetuated my mistrust of conventional medicine, particularly the inability of Western doctors to see the relationship between psychology of the mind and the body – or even to see the relationship between two different systems of the body.

As postmodernist Turner (1992) explains, "Neither health nor disease are straightforward matters" (p.125) and Cassandra herself points to an incomplete knowledge base. Although the infertility literature points to a link between severe endometriosis and infertility (see Brosens et al 2004; Gleicher and Barad 2006; Siristatidis and Bhattacharya 2007), which is what her specialists also told her, she has become critical and does not accept this at face value:

The statistic that was quoted to me was 40%-50% of women who have endometriosis are also infertile. But that means that 40%-50% of women are not. They're not really sure about the nature of the link.

For Cassandra, naturopathy not only treated the "whole person," but also seemed contrary to the guise of the exact science that medicine often projects. None of my respondents talked about physicians mentioning ambiguity or an incomplete knowledge base even though the medical

literature does admit that because there is a dearth of clinical trials with infertility treatments, that “factors other than scientifically derived data may be used to guide” a clinician’s decision-making process (Glatstein et al 1997:444). This ironically led Cassandra to be comfortable with her slight cynicism of complementary medicine: “despite the fact that he couldn’t prove everything that he was telling me I didn’t think that was a problem anymore, because I had just been through a lot of that kind of stuff.”

Cassandra’s naturopath found some underlying issues and she now feels better, has changed her diet and removed chemicals from her environment. She also thinks that the experience with the naturopath has made her lose her hatred of her body: “I think one of the most valuable things I got out of it was an ability to accept my body and acknowledge that it hadn’t done anything wrong.” For Aujoulat et al (2008), Cassandra is empowered. Contrary to past studies that define patient empowerment as the ability to control illness, Aujoulat et al (2008) say that this past definition reflects medical ideology and state that there is also another process at play; that self-empowerment also entails an acceptance that not everything is controllable and the ability to integrate illness and its boundaries into one’s sense of self.

An incomplete knowledge base and lack of holistic approach are not the only obstacles the medical profession faces when trying to gain patient trust. Leslie is skeptical of medical practice and goes so far as to say that she

has “conspiracy theories” that her partner does not believe in. She says that maybe it is a side effect of the fertility drugs that she is on but thinks that the physicians really just want money and will say anything to make her buy into the treatments:

Right before we started this process, I talked to my friend who had gone through a ton of fertility stuff. She told us to look out, because they are kinda like used car salesmen. I was like, ‘What?’ I think she is a really intelligent woman. It wasn’t like an internet comment that I didn’t put any real weight in. Then I started viewing things through that perspective. ‘Are they used car salesmen trying to sell us something? Is something weird going on here?’ I had never really thought that way of doctors before. Although, I have always been not fully trusting of doctors, because who really knows what’s going on in there? But I think I became more skeptical of motives in this process.

After her comparison of doctors to used car salesmen I asked Leslie if she would try another IVF attempt and she said, “You gotta buy a car, ya know? You gotta buy it somewhere. I’m still hesitant.” Leslie’s partner, Cory, also talks about having to put some trust in a doctor even with skepticism: “We trusted him enough that it is not just a complete scam. Hope takes care of the rest.” As postmodernists Williams and Calnan (1996) state, the public is increasingly “built around a reflexively organized dialectic of trust and doubt” (p.1612).

### **Getting Support**

Another type of patient agency was tapping into different support networks such as support groups, which several theorists see as a result of the postmodern condition (Fox 1994; Frank 1995; Kleinman 1988; Williams

and Calnan 1996). Several people in my study went to infertility or pregnancy loss support groups. Support groups operate on the idea “that only those who are experiencing the problem can truly understand it” and “have become increasingly popular over the past forty years, with most chronic illnesses having at least one such group” (Madden & Sim 2006:2969). Those who went had positive experiences. With the increasing use of the internet by patients/consumers (Conrad 2005), some went to on-line support groups as “voyeurs only.” Only Erin Garcia was part of both an on-line and a “real time” support group because she liked to be able to keep personal distance yet she also liked her face-to-face support group: “meeting our friends and talking is more personal. You can call somebody up and bawl.”

The face-to-face support groups worked well for several people, including both of the men who went to support groups who felt like they were not alone and could connect with others . The support group setting was an open environment where “you don’t have to worry about if it is a good time to bring this up.” Others mention that hearing other people’s stories made them feel a little sad (which other respondents said was their reason for not going to support groups) but also grateful that they did not go through what some others experienced.

“What works for one doesn’t work for another.” For those who chose not to get help they said that the support groups were too far away, they did

not have the time for them, or they did not feel the need to reach out in that way. Some reached out to personal therapists or to friends and family:

One person here at work had gone through fertility issues more than we had. She had recommended the on-line sites, forums, things like that. I decided to not do that because we had really talked about it a lot. I had a lot of support from [Kirk]. Also, we had some friends who were really supportive, even if they didn't always understand. I felt like I had people I could talk to about it. I know a lot of people get help from those, but then the whole idea of going to talk to a stranger about it, especially at first, wasn't really something I was comfortable with.

### **Patient Activism**

As Aujoulat et al (2008) state, "Only a few studies suggest that [patient] empowerment may be related to a process of personal transformation" (p.1229). My study will join these few others as I outline how the incomplete knowledge base, the gendered norms, and the exclusion of patient agency in the diagnostic process has created some form of activism in several women. None of the men in my study took much initiative to change institutions, perhaps because women were more actively involved in the fertility treatment process due to their bodies being the focus of treatments, plus there are the overall higher rates of women's more active involvement in the health care system (Lorber 1997). In addition, women are often at the forefront of social change movements (Weisman 1998). Edward, the social worker married to the sociologist, is the one man who feels an obligation to inform others about infertility issues. Some of the other men are not secretive about the issue but do not feel a social obligation to educate others about it.

Marita, on the other hand, feels strongly that it is now her duty to inform people that getting pregnant and pregnancy itself are not always such natural, easy processes for women: “I can get political about it. I feel like it’s my responsibility to dispel myths about reproduction, infertility, woman’s right to chose.” For one, she notes that what is natural is information that is kept from women and she now feels a personal mission to educate people around her:

When people see a pregnant woman you don’t go through the ‘oh I wonder if it’s easy for her to get pregnant.’ Why would you even think about that so it’s almost like I am perpetuating that myth by walking around pregnant. This is what is expected of women, they’re expected to do it well. You could have a partner, have the kids, have the career, and I feel like I need to be a walking billboard of ‘please ask me how hard it was to get here’. I gave up my PhD, and we’ve given up a lot of our marriage and we’ve given up a lot of our sanity for this. It’s a sacrifice we have chosen so please don’t think it was easy. Can I get that on a t-shirt? I think that’s the hardest thing, any conversation about being pregnant I always feel that I need to say ‘you need to know something’. We were really successful we probably don’t even travel down that infertility continuum very far. I can’t imagine the couples on the other end. It must be a million times more exasperating.

Yet Marita also understands that being outspoken is difficult and feels somewhat rejected when she talks about difficulties:

‘And if it’s not ideal, deal with it, you’re still pregnant or you chose that’. I can’t imagine being in a circle of older woman who work at [this university] and really get into how much this sucks, I think they would throw me out of the tribe. Cause you have this beautiful child, well yeah it’s not about my beautiful child. My poor friends are like ‘forget it, we get that you’re a feminist, the world is unfair’.

And when I asked Marita why she thinks that more women do not talk about infertility issues she answers:



I think it's the same reason that when you ask women in power 'did you ever feel discriminated' that they have this high need to say no and it was all sunshine and gummy bears. You're looking at them and it could not have possibly been.

This is an interesting gender commentary and perhaps because Edward had some amount of male privilege at his social work office, which is predominantly staffed by women, he felt more comfortable being more outspoken about educating people about infertility and the struggles he and his partner were going through.

Whereas we saw that the personal is political for some, Jalila and Patty's actions bridge the gap between the more personal and larger political arenas. Whereas they are just trying to create their own families, they are aware of the discrimination that they may have to face from society. For example, there is a raging debate between the umbrella group the Father's Rights Movement and various feminists about the availability of donor sperm for lesbian families (see Moore 2007) although as seen in chapter four, Jalila and Patty are simultaneously maintaining and bending ideas of the heteronormative family. .

Jalila and Patty do not discuss their families in the context of this larger debate but others talked about a larger political level. Two women have gendered analyses of insurance. One woman is upset that because fertility issues focus on women's bodies her insurance went up and Cassandra is upset that her fertility treatments were not covered yet "a 75-year old man can get his Viagra prescription – that's considered medically necessary." And

although she is no longer pursuing fertility treatments she said she would “definitely lobby for years, for decades, to change that law.” Others also became politicized surrounding insurance, as Jaime contacted state senators about trying to get IVF covered under insurance plans and Erin worked with her workplace’s large insurance company trying to explain the benefits of covering the higher tech and not just the low tech treatments.

All of this political activism, however, is relatively focused on individual rights. To the postmodernist, because power is decentralized, resistance must also be. In my study no one talked about advocacy for finding and fighting environmental factors that are suspected to have links to certain types of infertility. No one talked about better sex education because infertility can be caused by sexually transmitted diseases. No one talked about economic justice where fertility treatments would be available to all. This reflects both a general societal view that negates collective action and a privileged viewpoint where those who have the cultural capital/ class privilege to get treatments can focus on the issue at a more individual, rather than group level. As Rapp (1999) states, genetic knowledge and technology have uneven benefits and burdens for a diverse range of women. As such, the type of activism seen in my respondents is closer to consumer advocacy, which in essence maintains the status quo. A successful activism around infertility might look something like the breast cancer activism movement that has successfully

linked ideas of women as mothers and patient rights to breast cancer screening and treatment (Gibbon 2006).

## **Conclusion**

Although some of my respondents are still struggling with their infertility, this chapter ends my reports of their journeys in infertility. I now turn to my concluding chapter where I summarize my major findings and discuss its larger societal implications.

## **Chapter Eight: Conclusions**

This study bridges the sociology of families, gender, and medical sociology literatures. It draws on 28 in-depth interviews with women and men who themselves and/or their partners were currently in treatment for infertility issues, or had been in the last five years. They experienced a variety of fertility treatments, with a variety of outcomes.

### **My Findings**

I began by exploring the question of why people want to have their own children. Sociological and feminist theories have emphasized the social factors and ideologies that promote parenthood, and I have similar findings in that both men and women want to create a “normal” family that is built around biological kinship. What is interesting, however, is that some of my respondents attempt to create this family even with donor genetic material. For those who used donor genetic material, however, they had to first find a way to separate the idea of “normal” biological family with their desire to parent, thus becoming more flexible in ideas of biological connectedness among family members. Those who were unsuccessful at conceiving also expanded their ideas of what type of families they want, such as adopting kids. Another social reason for wanting biological children focused on the legal system that favors biological kinship in the “ownership” of children.

Aside from social reasons, however, I also find that a large majority of men in my study attribute their desires for children to the need to pass on a genetic code. The majority of women in my study, however, do not attribute their wishes for children to biological instinct. To return to the feminist debate on parenthood, then, this leads to the conclusion that there are strong social influences in women's decision to have biological children, including what their husband's see as their own biological desires. Further, there is currently little literature on the meanings that men themselves attach to fathering (see Throsby and Gill 2004) and this finding provides a glimpse into this issue.

Whereas some other studies have also found that men place more primacy on genetic connections to children than women (see Crowe 1985; Miall and March 2003; Webb and Daniluk 1999), no studies currently address what these men's (and women's for that matter) expectations are of what exactly gets passed on genetically, or in other words, how these people view genetics. I found that both women and men had a very rudimentary knowledge of genetics that ignores the complexities of how an individual's genetic make-up displays itself, and felt that having a biological child can give them some control over physical, personality, and health traits of their children due to their own observable/known traits or those of the egg and/or sperm donors.

Next, I found that all respondents followed the traditional, cultural script for finding the "right" time to get pregnant; that is, finding a partner, getting

married, and settling into careers seemed to signal it was time to have a child, and this was supported by their broader network of family and friends.

Women were the ones who decided that there might be an infertility issue and they were the ones to seek out medical intervention. Most women waited the standard year length of time defined by the medical industry, others were cued in due to medical difficulties and others were just “impatient.” Once women made contact with their physicians, they got a variety of physician responses based on the type of physician seen and medical and gendered cultural ideologies. Reactions ranged from being dismissive and too slow to act to being aggressive and acting quickly based on standardized medical knowledge of aging eggs and disease.

Current sociological studies do not delve into the infertility diagnostic process, and I found that testing was not standardized yet women’s bodies were always the focus of the infertility issues, and possibly over-diagnosed with polycystic ovarian syndrome, which I suggest could be a new case of the medicalization of women’s bodies. Also with diagnosis, although some amount of uncertainty is acceptable, all respondents eventually wanted a diagnosis, which had some positive effects such as making sense of symptoms and being able to forge a plan of action. On the other hand, getting a diagnosis led to women feeling a range of emotions from relief, to fear, to anger at one’s own body, to guilt for the inability to fulfill goals and role expectations. Women took on the brunt of the responsibility even if there was

male factor infertility, which was also tacitly reinforced by the medical establishment and their own male partners.

Once the infertility was confirmed, the decision to further medical treatment was based on physician optimism, financial ability, and views on the adoption alternative. All treatments, from low to high impact, took their toll on the recipients. The intricacies of the treatment process is not currently outlined in the sociology literature, yet this area is quite significant in the lives of treatment recipients. I found that women experienced life interruptions similar to many people with chronic illness, though theirs was the result of medical treatment. For women, treatments required major rescheduling and disruptions of daily life and long-term plans and caused a plethora of physical and mental side effects, some quite severe. Couples were faced hard ethical questions and difficulties in their relationships as a couple and with other friends, co-workers, and family. Many responded to others in their environment or reminders of children by self-imposed social isolation.

Finally, this study examined interviewees' perceptions of the doctor-patient relationship and satisfaction with care. Some were satisfied with medical treatments yet many more complained of impersonal treatment, the physician not listening or giving adequate information to the patient or other health care providers, insensitivity, and homophobia. Patients responded to their treatment in a variety of ways, including deference to physician authority (especially those with lower SES in my sample or those who work in the

biological sciences), adjusting their interactional styles with their physicians in order to not be pegged as a “bad” patient, switching physicians, going to support groups, and doing their own research. Others supplemented their care with complementary and alternative medicine, either upon physician recommendation, pre-existing openness to complementary and alternative medicine, or as a reaction to an overly rationalized and dysfunctional western medical model. Last, some women in the study took more of an activist stance in feeling obligated to educate others or change the insurance system.

### **Implications from my Study**

Due to my findings I have several suggestions for the field of reproductive medicine such as the development of a more sensitive system where professionals have gone through some grief counseling training in order to deal with failed treatments and pregnancy loss as well as a more sensitive gender sensitive reproductive medicine, one that initially tests men and women. Perhaps physicians should also not have what some in my study thought was false optimism and give patients a more realistic prognosis so people can make more informed decisions and not increase their disappointments and bitterness toward the medical field. Finally, more openness to the idea of complementary and alternative medicine may reduce a loss of patient trust.



## **Larger Societal Implications**

One of the larger societal implications of the use of fertility treatments include rising health care costs not only for those who use treatments but on all of society as the whole health care system gets strained. In the United States, the conception industry is estimated at \$3 billion dollars annually (Sabouin 2008). Costs are also displaced into other medical departments; children born through the use of fertility treatments have a higher chance of health problems and are two to four times more likely to have certain types of birth defects such as heart defects, cleft lip with or without cleft palate and certain gastrointestinal defects compared with babies conceived without fertility treatments (CDC 2008). This means that there is an increased cost for neonatal intensive care and pediatric units. The fertility industry simultaneously fails to put adequate funding into assessing many of the health risks associated with treatments (see Mundy 2007).

Further, this for-profit industry sells the idea of designer babies in very detailed descriptions of egg and sperm donors whereby parents may have unrealistic expectations about using ARTs to create children with specific physical, personality, and health characteristics and simultaneously leaves behind many children who need to be adopted into good homes. The Marxist critique would be that children are treated like commodities that one picks and chooses like any other item that is subjected to quality control. The picking and choosing of traits makes Ratcliff (2002) wonder about the parent-child

relationship. She says that in the past parents mostly took responsibility for their children and largely coped with problems yet today many are not even satisfied with “average” for their potential children (p. 233).

Others question the profit motive in treating couples after only 6 months or a year of trying to get pregnant and wonder if a waiting period of two years of unprotected sex was required before turning to assisted reproductive technologies, if many people would be spared the strong emotional involvement in and financial stress of a physically demanding process that often poses health risks and that has a very debatable success rate (Sabourin 2006).

There is also class and race privilege. First, the fertility treatment industry reinforces the idea of genetic determinism, which affects areas of health and medicine, and the criminal justice system, all of which have racist and classist implications (see Duster 2003). Second, the highest rates of infertility are among the poor (Mundy 2007), especially blacks and Latinos on Medicaid (Hill 2005), who cannot afford infertility treatments (Hill 2005; Mundy 2007). This then also leads to a privileging of those who profit from this industry—the biotechnology and pharmaceutical companies. Ultimately this could be seen as a form of positive eugenics where the white, middle-to-upper class is encouraged to reproduce.

Gender issues also emerge with the infertility field’s focus on women’s bodies. Although the common perception is of older women using fertility

treatments, women under 35 years old are by far the largest group of women using high impact fertility treatments-- they represented 40 percent of all ART cycles carried out in 2005 (CDC 2008). European data also show that women are seeking medical help for infertility at younger ages (Olsen et al 1996), which might result in unnecessary over-treatment due to false-positive diagnoses of infertility (Balasch 2000).

Further, the fertility industry is simultaneously driven and reinforces parenting norms, such as those of essentialist motherhood that feminists have long been battling. On the side of fatherhood, the idea that real fathers are biological fathers overlooks real societal issues such as deadbeat dads Moore (2007) and equal parenting responsibilities.

There is also at least one larger political debate surrounding the creation of families. Some men's rights groups under a more general fatherhood rights movement blame a monolithic "feminism" that uses sperm banks and thus views men only as sperm donors. Some of these advocates think that sperm banking is acceptable only for infertile, heterosexual couples. Thus, the initiatives these groups have, which are backed by several George W. Bush administration policy plans focuses on fathers and marriages; there are no such initiatives to support single mothers or gay or lesbian families. Feminists critique these movements for blaming women and trying to refashion law and mores as a reaction to their perceived loss of male power and privilege. Single moms who are under attack for using sperm banks and

bringing kids up in one- parent households say that traditional problems of mother-headed households are due to economic struggles, which do not apply to them (see Moore 2007).

Further, there are ethical dilemmas of the medical industry's role in creating and destroying "life," the further destruction of the environment through the creation and disposal of products from the medical industry, and a shift in the gene pool as people can bypass genetic conditions that create infertility and pass on their genetic conditions (see Mundy 2007) or have people reproducing with unknown half-siblings due to the secrecy and lack of regulation of the donor egg and sperm industry.

### **Future Directions for Study**

This qualitative study sets the stage for future studies, even similar studies to compare findings, especially if more men and lesbians can be included in the sample as there is a paucity of research on fatherhood, men and ARTs, and lesbians and ARTs. Other comparison studies may be evaluating my respondents' experiences to others who have used fertility treatments in the further past, or to those who are infertile but chose not to use fertility treatments and remain childless or adopt. There are also those on the other side of the ART industry—there is a paucity of research on fertility doctors' views as well as those of surrogate mothers here in the US or those in developing countries who "rent" their wombs for US couples.

Further, as I attempted to compare generalist versus specialist responses I noticed a dearth of literature on this subject in the medical sociology literature.

Further, there are no studies out there to my knowledge on views of sperm and egg donors, and it would be interesting to see how they view their donation, their role in the process, and those who use their genetic material. It would be interesting to also probe people who use donor egg/sperm about how they view donors and compare their views to data collected from the donors' perspectives.

Last, I just began to skim the surface on comparing the medical infertility literature to the sociology infertility literature, and given that the few studies that I reviewed revealed some interesting information, I think much more should be done in this vein.

There are also limitations of my study that can be fodder for future study. Perhaps my sample does not represent the general population with views toward biological children because they are an "extreme" in that they really desire children and made very concerted efforts to have children. More interviews about (biological) desires for children among parents and/or the larger population are needed. This, I believe, is very important as genetic technology becomes more and more available to the public. This technology has wide ranging societal implications and is important to study. Further, there is currently a debate within sociology about how much credence sociologists should put into genetic explanations; there are even a few

sociologists doing socio-genetic studies. Whereas I am not proposing to incorporate a genetic component to my study, I believe that my study of attitudes on genetics adds to the sociological conversation about how both the more general public, and the field of sociology, interfaces with genetics and what are some of the implications.

Further, I draw some preliminary conclusions about the lesbians (n=2) and men (n=8) in the study, which need to be followed up with larger sample sizes. My work can also complement studies from other fields such as medical/health psychology and medical anthropology as well as women's studies. There are also links to more global, cross-cultural studies—is there as much classism in other countries with universal health care? Is there as much medicalization? Today's failing global economy only perpetuates the selling of body parts and bodies. What will the future bring?

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## Appendix A-- Questionnaire

### Personal Information

- 1) When is your birthday? \_\_\_\_\_
- 2) What is your race? \_\_\_\_\_
- 3) What is your level of education?
  - a) less than high school
  - b) high school diploma
  - c) some college
  - d) Bachelor's degree
  - e) graduate/professional degree: \_\_\_\_\_
- 4) What is your partner's level of education?
  - a) less than high school
  - b) high school diploma
  - c) some college
  - d) Bachelor's degree
  - e) graduate/professional degree: \_\_\_\_\_
- 5) What is your occupation? \_\_\_\_\_
- 6) What is your partner's occupation? \_\_\_\_\_
- 7) How many times have you/your partner been pregnant?
- 8) How many children do you have?
- 9) When was your youngest child's birthday? \_\_\_\_\_
- 10) What type of insurance do you have?
  - a) none
  - b) Medicaid
  - c) private
- 11) What types of physicians were seen?
  - a) general practitioner
  - b) gynecologist
  - c) obstetrician
  - d) other: \_\_\_\_\_

## Appendix B--Open-ended questions

- When did you decide you wanted to become a parent/ when did you become a parent?
- Why do you want to be a parent?
- What led to that decision?
- When did you start to think there was a fertility problem?
- Were you or your partner the first to suspect fertility issues?
- Who initiated a discussion of infertility as a potential problem?
- Who suggested contacting a fertility clinic, physician, and/or support group?
- Was there agreement between you and your partner to get some kind of diagnosis or treatment?
- Were both you and your partner tested?
- Was your partner willing to be tested?
- Did you consider non-medical options, why or why not? What were the pros and cons of these options versus fertility treatments?
- Who was involved in the decision making process? Was anyone other than your partner involved?
- How long did you try to get pregnant without fertility treatments?
- What recommendations did you get from doctors?
- How was the information presented to you? What information? By whom??
- Who presented it to you?
- How much time did you have to think about the decision?
- What fertility methods are you using?(did you use)
- How long have you been in this process?
- How has this process affected you emotionally and physically?
- How has this process affected your relationship with your partner, friends and family?
- How has this process affected other aspects of your life?
- Has this process changed your views on parenthood? On the medical establishment?
- Would you repeat this process in the future?
- Would you recommend this to others?
- Does /did this process meet your expectations?
- (Why did you decide to stop trying?) Might you try again?

## Appendix C

### Study: The Decision to Use Fertility Treatments

My name is Ophra Leyser and I am a PhD student at the University of Kansas. I am writing my dissertation on people's experiences with infertility and would like to interview couples about this process. If you and/or your partner would be willing to fill out a short demographic survey and be interviewed for an hour at a time and place of your convenience I would greatly appreciate it. **Interviews will be audio-recorded and used for this project until the completion of my dissertation, which will be 2-3 years.** Your name will not be associated in any way with the information collected about you or with the research findings from this study.

**The benefits of this study include a venue for you to discuss your experiences and add them to the sociological research.** You may, however, be talking about stressful life events. If you feel overwhelmed and want to talk to a professional you may contact: Kris Probabsco at Clinical Counseling Associates Inc, 10925 Antioch #103, Overland Park, KS, 816-781-8550. Payment is expected through insurance or at your own expense.

You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

Please feel free to contact me regarding any questions that you may have about the study. You may also contact the chair of my dissertation, Dr. Shirley Hill, at hill@ku.edu. Additional questions about your rights as a research participant can be directed to (785) 864-7429 or (785) 864-7385 or [dhann@ku.edu](mailto:dhann@ku.edu) or [mdenning@ku.edu](mailto:mdenning@ku.edu).

Thanks so much for your consideration,

Ophra Leyser  
Email: [oleyser@ku.edu](mailto:oleyser@ku.edu)  
Cell: (785) 550-0313

I agree to take part in this study as a research participant. By my signature I affirm that I have received a copy of this Consent and Authorization form.

\_\_\_\_\_  
Type/Print Participant's Name  
\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date  
Best way to contact me: \_\_\_\_\_