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The hidden society : a sub-culture of women dealing with infertility

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**THE HIDDEN SOCIETY: A SUB-CULTURE OF WOMEN
DEALING WITH INFERTILITY**

A Thesis

Presented to

The Faculty of the Department of Sociology

San Jose State University

In Partial Fulfillment

of the Requirement for the Degree

Master of Arts

by

Sarah Elizabeth Mealey

December 2006

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ABSTRACT
THE HIDDEN SOCIETY: A SUB-CULTURE OF WOMEN DEALING WITH
INFERTILITY

by Sarah E. Mealey

This thesis examines the secret culture of infertility, its knowledge creators, and how the process affects gender identity. Many women looking to start a family discover that they have fertility issues, which leads them to discover all they can about available treatments. From the day of diagnosis, these women become part of a sub-set of the rest of the population. This paper makes visible a “sub-culture of infertility” that both shapes and reflects the infertility experience.

Using qualitative research methods, this thesis uncovers the unique sub-culture created by the infertility experience and the ways in which this culture is socially constructed. Infertility challenges gender itself—the ability to procreate, and to carry a child to term. Women facing this gender crisis can be aided by the availability of experiential accounts—narratives from women who have already undergone treatment—to help them further understand the infertility experience.

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This project is dedicated to my husband, Dave, and to my two children, Mara Rose and Christopher John. Working on this project and talking with women who were less fortunate than we were with their quest for children have made me appreciate the miracles that my babies truly are even more.

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INTRODUCTION

My personal journey into the world of infertility has taken me down both an intellectual and emotional road. Before my partner and I struggled to conceive I thought like everyone else, that as soon as we started “trying” that it would take no time at all. I was among the many who thought that I had control over my body or at the very least my ability to reproduce. “White middle-class women in the United States supposedly have the ability to determine the number of children they want, to the limit of children they will have, and to plan the spacing of these children... (they have) had a degree of access to and confidence in birth control technology... (and) grew up believing that the human reproductive process is readily subject to human control” (Greil 1991:109). Although my study is not intended to be limited to “white middle class women,” the previous quote demonstrates the feeling of entitlement in the ability to control one’s own reproduction. However, I quickly learned that I did not have control of my body, and that the idea that all women have the ability to conceive and give birth to their own biological child naturally is a concept that should not necessarily be taken for granted. Socially, a reproductive collective consciousness is created for us (the use of “us” refers to the group of women having to utilize non-normative methods to achieve pregnancy, myself included), where shared norms, such as birth control and the idea that reproduction is easy and controllable, etc., provide an “ideological common ground” for women to believe in or act in agreed-upon ways. When I realized that natural conception is not a “given,” the concept of infertility then became defined and understood.

Infertility was defined (or “discursively created”) and understood with the *in vitro* conception and birth in 1978 of Louise Brown (the first test tube baby) or when conception outside of the womb became possible (Sandelowski & Lacy 2002:34-35). The term infertility serves as a bridge between two worlds, the fertile and the barren. “Whereas barrenness used to connote a divine curse of biblical proportion and sterility an absolutely irreversible physical condition, infertility connotes a medically and socially liminal state in which affected persons hover between reproductive incapacity and capacity: that is “not yet pregnant” (Greil 1991) but ever hopeful of achieving pregnancy and having a baby to take home” (Sandelowski & Lacy 2002:34-35). Whereas those who used to be unable to conceive naturally would have to accept that they could not produce children at all, there was now a scientific method to help women conceive, thereby creating a “gray area” of between fertile and sterile.

Until women are faced with the possibility that they might not be able to conceive, and the choices of how to become pregnant become increasingly limited, the concept of infertility does not seem real nor is it fully understood. For these women, conception, pregnancy, and birth become even more of a desire and less of a right when the option to chose is taken away. In a televised documentary, “18 Ways to Make a Baby,” Anne shares in an interview the following:

“People that are faced with infertility don’t have the same decisions as people that aren’t. And these decisions, they’re not what we would want. These are the choices we are left with. If I could make a choice, I would like it if my husband and I could get pregnant on our own. And it’s easy to sit there and say what you would or wouldn’t do when you’re not in those shoes” (Holt and Williams 2001:4).

Women, coming to the realization that for them, conception is not simple, that the mere act of sexual intimacy with their partner will not produce pregnancy, often end up on a quest to discover everything they can about infertility to not only make sense of their own experience, but to understand what it means to others and to ultimately have a baby. This quest leads them to enter an “infertility culture” and transforms those experiencing infertility into members of an “Infertility Sub-Culture”. Those outside of this culture have no idea that this other world exists. Through my research and analysis I plan to make visible this “sub-culture of infertility” that both shapes and reflects the infertility experience.

My own personal experience with infertility has helped me realize the significance of this issue and has helped shape my quest to understand the social world of infertility of which I am now a part. From Resolve, a national support group for people going through infertility, we find data that shows that this world of infertility currently opens its doors to 1 in 6 couples who will have to explore infertility treatments (Resolve, Retrieved August 29, 2006). “Furthermore, there is increasing evidence that the prevalence of infertility has been rising in many parts of the world. This rise is largely attributable to an increased incidence in sexually transmitted infections...decline in sperm counts...biological causes, i.e., failure to ovulate, and some due to unexplained causes. Despite the prevalence and seriousness of infertility, the population and reproductive health field has largely ignored this problem” (Okonofua 2002:1). And as infertility continues to rise worldwide, the need to define and understand the infertility experience becomes more and more necessary. The topic of infertility is important

sociologically as reproduction can be used as “an entry point to the study of social life, we can see how cultures are produced (or contested) as people imagine and enable the creation of the next generation, most directly through the nurturance of children” (Ginsburg & Rapp 1995:1). During my observations and interviews a culture of infertility emerged, as I was able to see the complex social arrangements that make up this culture through social interactions, language, and meaningful symbols. “...Children are born into complex social arrangements through which legacies of property, positions, rights, and values are negotiated over time. In this sense, reproduction, in its biological and social senses, is inextricably bound up with the production of culture” (Ginsburg & Rapp 1995:2).

My research adds to Ginsburg and Rapp’s idea that the study of reproduction is linked with the production of culture. Undergoing infertility treatments creates a medicalized process that women are forced to follow and constantly negotiate through social interactions between men, the medical community, insurance companies, and social institutions, such as Resolve. This culture provides an experience that a woman can see as both empowering and disempowering at the same time: empowering because women can regain control in the infertility process by deciding what steps to take, but disempowering due to the fact that their decisions must be made within a framework or structure defined by medical professionals, insurance companies, and personal financial limitations. Additionally, there is language or terminology that is unique to the culture of infertility, such as “assisted reproduction” (reproduction through the use of technology), “IVF” (*in vitro* fertilization - a laboratory procedure in which sperm are placed with an

unfertilized egg in a Petri dish to achieve fertilization.), and “ICSI” (intracytoplasmic sperm injection - involves injection of single sperm in to single egg in order to get fertilization) that is not commonly recognized or fully understood by those outside of the infertility culture (MedicineNet.com, Retrieved June. 23, 2006). In fact, as the sub-culture continues to grow, and an industry grows around it, including medical specialists, pharmaceutical companies, and psychologists, it becomes more necessary to provide information to help not only new members of this sub-culture, but outsiders as well to understand the infertility experience from a medical, professional, and personal standpoint.

Harold Garfinkel (1967), founder of ethnomethodology, calls for meaning to be derived and found from the “accomplishment” of the individual actor in a specific setting: people actively working to ensure their social interactions make sense to others and to understand the actions of others. “Sociologists Joseph Schneider and Peter Conrad have recently argued that medical sociologists ought to develop “ethnography of illness” that focuses on the ways in which people who define themselves as ill and who are defined as ill experience illness” (Greil 1991:6). Greil contends that this argument can also be made for infertility, adding that he thinks it is beneficial to “distinguish between infertility as a medically diagnosed physiological characteristic of individuals, which he calls a *reproductive impairment*, and infertility as a socially constructed reality experienced by couples” (Greil 1991:6). Identifying and understanding the personal experiences of infertility helps us make sense of these accounts by both reflecting this culture and shaping it. Warren Handel terms this as *reflexivity*. In his article, “The

Philosophical Concerns of Ethnomethodology” he asserts that all accounts are reflexive, (Handel 1982:35). As seen in the following quote, reflexivity constitutes this idea of how our own personal story or account both helps shape and define the social world at the same time. “Accounts are always in this reflexive relationship with themselves because they are the medium of definition and accountability and because they make up the defined, accountable world at the same time,” (Handel 1982:39). To facilitate the sharing of infertility stories couples must be able to frame their personal experience within this “culture of infertility,” by understanding how this culture is constructed or accounted for. It is only when these infertility accounts are more public that this culture will be made more visible. Theoretical discussions of the creation of meaning through ethnomethodological processes are particularly important in the analysis of infertility to understand not only how it is constructed socially, but also individually what one must go through in a society where accounts of normative reproduction are privileged.

The theoretical work of Blumer (1969), Goffman (1959), Garfinkel (1967, 1970), Handel (1982), and Greil (1991), Ginsburg and Rapp (1995) discuss how reproduction is socially developed ethnomethodologically through the understanding of couples/women’s experiences and focusing on how that reality is both developed and structured by the culture they live in. However, both Ginsburg and Rapp (1995) expand our understanding of reproduction by looking at how it is developed beyond “social and cultural boundaries” utilizing a term called “stratified reproduction” which is used to describe “the power relations by which some categories of people are empowered to nurture and reproduce, while others are disempowered” (Ginsburg and Rapp 1995:3).

Ginsburg and Rapp also utilize “reception theory,” a theory based on ethnomethodology, which adds that images, technologies, and representations that are both produced and consumed provide cultural and social meanings (Ginsburg and Rapp 1995:6). Both Rapp and Ginsburg apply their theory on a global level to seek out specific cultures across the globe to gain a better understanding of the images, technologies, and representations (i.e., power relations) that make up the experiences of infertility. “In Western medical discourse, ‘infertility’ is usually defined as the inability to achieve pregnancy after a year (or two) of trying to conceive a child through regular sexual intercourse” (Van Balen & Inhorn 2002:12). Based on this medical definition and others from the medical community, an infertility criterion is established, and the infertility experience is then mediated by this medical structure. I am extending the theoretical argument of Ginsburg and Rapp in which they apply “reception theory” to seek understanding of the power relationships involved in determining who is encouraged and discouraged to reproduce within a society by seeking to provide a cultural framework around women’s personal experiences with infertility. I exclude men from this study only in the efforts to narrow my focus and methodological research. By looking at reproductive narratives surrounding infertility (non-normative accounts), issues such as gender, language, and industry can be better understood in relation to normative accounts offering a better explanation of reproduction as a whole. The sharing of infertility stories provides a context for how infertility is socially constructed and accounted for. By understanding the process by which couples come to understand their infertility, and how that experience is both constructed and re-constructed through the *ideology* and *social*

structure of society, provides a way to further understand infertility and a “culture of infertility” as a whole (Greil 1991:1-26). Pulling the experience of infertility out of everyday life and understanding how reproduction is separated into normative and non-normative categories help us to understand how infertility is structured, and how doctors, women, and others create fertility knowledge. The socially constructed nature of infertility and how it is created through individual experiences makes reception theory a useful model. Based on the idea that the infertility experience is socially constructed, and viewing this experience through a cultural lens, I was then able to formulate some questions for a thesis: 1) How do women initially experience infertility and their entry into a non-fertile world (paying particular attention to the medicalized experiences of these women, any stigma they may feel, and how gender is negotiated)? And 2) How do women work to manage the infertility experience (by understanding who generates, communicates and privileges knowledge over other accounts in this sub-culture) in their efforts to become part of the fertile norm? I seek to understand the process in which infertility occurs by breaking down the social construction of infertility by utilizing my knowledge of sociology. I am interested in the ways women actively construct their infertility accounts through normative and non-normative social structures, and the role experts (doctors, women, etc.) play in constructing this reality, by further defining the infertility process and examining the gender relations that create the dynamics of the “infertility culture” and thus contributing to the growing body of work on infertility.

LITERATURE REVIEW

The study of human reproduction has changed over the years moving from a more biological domain, focusing on “physical paternity” (along Darwinian, patriarchal, and biologically determinist lines), separating it from social life, to being classified as a feminine or maternal topic therefore not worthy of being examined theoretically (Franklin 1998:1-4). With the rise of the feminist movement and with more women entering academia, researchers have in recent years openly debated these attitudes and helped construct and re-construct human reproduction models making it worthy of theoretical focus (Rapp 1994; Greenhalgh 1995; Franklin 1998; Rapp and Ginsburg 1999; Van Balen and Inhorn 2002). Not only has growths in theoretical explanations of fertility allowed the “concept of reproduction” to be taken to the forefront of discussions surrounding human reproduction, but also new reproductive and genetic technologies have “widened” the concept, linking reproduction to technology and generating a new politics of reproduction (Franklin 1998:105-113).

These new reproductive technologies are changing women's experiences of pregnancy and childbirth, generating a political economy of fertility concerned with social, cultural, political, and economic forces underlying demographic change (Greenhalgh 1995). As reproductive technologies continue to improve and become more readily available, women who are forced to explore these options (new reproductive technologies or NRT's) need to be more closely examined as this non-normative segment of the population continues to grow in relation to the normative segment.

By examining non-normative reproductive scenarios, society gains a better understanding of the reproductive process as a whole. Women in the non-normative group will gain better resources to understand and relate to their experience and will also not be afraid of the joint partnership they must form with technology (in order to reproduce), which serves as a tool for both normative discursive control and erasure of the “normative” maternal body.

These non-normative experiences actively involve and call into question gender relations or how we come to understand our roles in relation to each other and within our own bodies. Gender is particularly relevant to discussions of infertility, because of its organization around women’s maternal bodies. “So profoundly do cultural ideologies about gender affect men and women that they consistently report feeling marginalized by them,” (Becker 2000:44). It is through these gender dynamics that we began to see the how and why this non-normative reproductive sub-culture exists. Traditional gender roles and power relationships are both reflected in the infertility culture and constructed anew by it. This can be seen in fertility issues surrounding normalcy, and the social constructions of masculinity and femininity, thus calling into question exactly who has the ability to construct these new cultural ideals.

By dissecting the social construction of infertility and looking at the ways in which women actively “do” and perform gender we can then begin to uncover the realities of these women. The culture of infertility both challenges and reinforces sociological notions of social identity through the struggle of gender norms. Candace West and Don Zimmerman (1987) discuss the performative nature of gender in their

pivotal article “Doing Gender.” They argue that gender is not assigned or achieved but instead constantly performed, interpreted, and accomplished. “Doing gender involves a complex of socially guided perceptual, interactional, and micropolitical activities that cast particular pursuits as expressions of masculine and feminine ‘natures’” (West and Zimmerman 1987:126). Infertility threatens how men and women fit into their gender roles, causing them to look for ways to make sense of how they are different within society:

“Women and men who struggle with infertility confront cultural ideologies surrounding gender norms. They are seeking a fit between their life situations and the cultural ideologies to which they subscribe. Stymied by the implausibility of this task, they have been forced to work intensively with cultural dialogues in order to reconcile their experiences with cultural expectations. In doing so, they have been performing gender,” (Becker 2000:237).

One of the major consequences of facing fertility problems is that it forces each partner to examine their gender role within society, and to attempt to find ways to understand themselves within a society that has not prepared them for this possibility.

In the next sections I will look at the ways in which social researchers have studied infertility, specially focusing on the lived experience of women struggling with infertility compared to those who are not (non-normative vs. normative reproduction), the process of infertility or how it is socially constructed, and fertility knowledge experts or those who have the ability to socially define this world. I will examine the benefits and limits of various perspectives, highlighting the gender dynamics that are at work, and finally situate my own research in relation to these theoretical projects. However, first I will look at reproduction as a whole examining the ways in which “high” fertility is socially privileged (normative reproduction), and how infertility (non-normative

reproduction) fits or does not fit into that picture by understanding how it is viewed socially (Inhorn & Van Balen 2002).

Normative vs. Non-Normative Reproduction

As new reproductive technologies emerge and the number of women requiring the use of them increases, the experiences of these women who turn to NRT's are forever changed as new research covering this topic continues to grow. "... (In) the past twenty years (we) have witnessed a veritable explosion of research on the social construction and cultural elaboration of women's reproductive experiences" (Greenhalgh 2002:3). Some prominent researchers who have sought to understand these reproductive experiences are Greil (1991), Franklin (1998), Rapp and Ginsburg (1995, 1999), Becker (1997, 2000), and Van Balen and Inhorn (2002). They have not only identified the existence of two separate reproductive experiences (normative and non-normative), but have sought to understand why woman experiencing infertility feel they are now reproductively a part of this non-normative or "deviant" (Greil, 1991) segment of the population once they discover they have problems conceiving.

In this section I will look at the ways in which social researchers have studied infertility, in particular how reproductive experiences have been socially divided, and how experiences with infertility separates women from mainstream reproductive accounts. I have selected these theorists for review, because their analysis on the social world of infertility provides a framework around reproduction and why social accounts of reproduction are separated into two classes. Understanding these class differences is

important in examining infertility as we can then begin to expand normative reproduction to include dialogs surrounding non-normative reproductive experiences. The following summary of Greil situates parenthood and provides an explanation of two reproductive accounts, and why we might culturally view the inability to have children as non-normative.

Greil (1991) in his book “Not yet pregnant: Infertile, couples in contemporary America,” offers that in American society, having children has become a social rite of passage into adulthood. With cohabitation becoming more and more common, marriage has become very closely linked with the decision to begin having children, and less of a move to adulthood. Biologically producing one’s own children, the “normality of parenthood,” is continuously reinforced by media images that present a consistent image of family as “people with children” as “normative.” Fertility issues therefore threaten not just one’s ability to bear children, but hasten one’s entry into adulthood. Those without children can be seen as “deviant” or non-normative from society’s perspective.

Franklin adds to Greil’s concept of two very distinct reproductive accounts. However, she looks at normative and non-normative reproductive accounts from a scientific perspective versus a cultural one. In her edited book, *Reproducing Reproduction* (1998), Franklin outlines the changing social dynamics of reproductive experiences and how new technologies are forcing new ways of looking at the standard conception story. Whereas traditional views of conception included fertilization, both conception and fertilization are now seen as two separate events, which Franklin believes lengthens the overall view of the reproductive process. With the increase of public

awareness about fertility issues, society has become much more aware of “what can go wrong” before conception occurs. With both unassisted (normative reproduction), and assisted conception (non-normative reproduction), there are a great many things that can prevent success. The conception narrative is further lengthened by the inclusion of this awareness into the overall story. Due to the increasing role science is playing in the conception process, the examination of the entire process of the formation of human life has widened. The traditional “sperm reaches egg and fertilizes” story has expanded, and there is more general societal awareness of the difficulties leading up to fertilization (Franklin 1998). Therefore women are much more aware when they experience infertility, and tend to feel they are now reproductively a part of this non-normative or “deviant” segment of the population. Due to the *felt differences* these women experience when confronted with infertility, Franklin adds that once pregnant, those who had struggled with infertility then become a part of the normative group, and the infertility experience is quietly dismissed.

There is a “felt” stigma attached to the inability to get through the “baby making process” without aid of technology. As a woman realizes that she must undergo infertility treatments in order to conceive, she may attach a stigma to herself for not belonging to the normative group of fertile women, in particular she may feel stigmatized as defined in the following quote:

“Scambler (1984) has made a distinction between *enacted stigma* – stigma that stems from intentional discrimination... and *felt stigma* – the shame felt by the stigmatized because of their internalization of societal evaluation of their condition and the resultant sense that they have failed to live up to the standards of “normality”...It would seem that for these infertile women, felt stigma was the

source of more anguish...a “secret stigma” hidden from outsiders, but nevertheless deeply felt” (Greil 1991:101).

In fact, it is not so much that society is discriminating against women undergoing fertility treatment, but a woman’s internal view of herself as not belonging to the normative reproductive group that creates this “felt stigma”, and causes so much pain. Rapp and Ginsburg add the idea of two separate cultural experiences of reproduction by separating normative and non-normative accounts into two separate social classes, and call for women of all backgrounds to document their experiences in order to de-stigmatize and empower all reproductive accounts as seen in the following summary.

Ginsburg and Rapp (1995) in their edited book, *Conceiving The New World Order: The Global Politics of Reproduction*, add in the introduction an examination of the role society plays, which empowers certain categories of women to reproduce and nurture. They employ the term “*stratified reproduction*,” developed by Shellee Cohen to discuss how within some cultures, women of certain classes, race, and position are more empowered and encouraged to produce and nurture offspring (i.e., young white women), while others are fully encouraged to assist in the nurturing (i.e., young Hispanic women), but discouraged from reproducing, as there is a stereotype of the economic burden these children may place on society. Rapp and Ginsburg’s examination discusses how institutions play a role in intervening in aspects of birth control, abortion, and child nurturing, but do so without acknowledging the impact of the pregnancy and burden child-rearing has on the women in that society. They further acknowledge the need for women to document and share their experience, as they are central to the reproduction and nurturing experiences, and it is through these documented experiences that the

female position is further empowered. They go on to add that women's reproductive experiences must be reviewed in its totality – not just through popular accounts, but through “disrupted accounts” as well. They highlight work under scoring the dilemmas of “disrupted reproduction” in which the “standard linear narrative of conception”, birth, and the progress of the next generation is interrupted by pregnancy loss, reproductive pathology, abortion, and childlessness” (Ginsburg and Rapp 1995:3-7). Due to the many alternative paths available to bring a child into the world (*in vitro* fertilization, adoption, foster care, etc.), the experience of women who think they can reproduce naturally--only to find out they need medical intervention--carries with it a narrative as important to the reproductive sub-culture as the more widely known stories of normative reproduction. Rapp and Ginsburg take reproduction and provide a new approach to looking at women's reproductive experiences by going beyond “standard” or normative accounts, and call for us to highlight “disrupted reproduction” or non-normative reproduction. Thus we begin to open the door to a new way of looking at conception, beyond the “birds and the bees.” Pulling the curtain on this isolating experience for many women (and couples), and demonstrating that this non-normative reproductive cycle has in itself many shared experiences, and is worthy of being examined. Becker adds to the idea that normative and non-normative reproductive accounts need to be documented, but also thoroughly examined. As she points out, it is through close examination of non-normative accounts that we can best understand what is normal, and how gender identity is so threatened for those experiencing fertility issues.

Becker in her books, *Disrupted Lives* (1997) and *The Elusive Embryo* (2000) discusses the ways in which normalcy is used in connection with how women see themselves in society, and how that view can challenge womanhood, manhood, parenthood, and the aging process. She contends that it is through examination of the disrupted experiences that we truly get a better view of society and cultural constructs that may be viewed as entitlements. In other words, those who are outside the “norm” can give us the best picture of what society has deemed normal—what being in the norm actually means. Despite the fact that the United States is a culture in which we are supposed to celebrate differences, core beliefs hold fast despite continued social change. Despite one’s desire to be different, we are nonetheless fueled by a desire to be normal—to belong (Becker 1997). As Becker points out, “People’s narratives of disruption are moral accounts of their lives. That is, the narratives reflect people’s interpretations of these moral ideologies and their efforts to live up to them” (Becker 1997:17). It is through the personal narrative that people struggle with their non-normative experiences in an attempt (successful or failed) to restore the normalcy to their experiences. Becker further adds, “When disruption occurs, the temporary or permanent destruction of people’s sense of “fit” within society calls into question their personhood, their sense of identity, and their sense of normalcy” (Becker 1997:30). Those who find themselves on the outside of “normal” society must rationalize their way back into normalcy in order to maintain their understanding of how they fit into society. This idea is very much present in the infertility experience.

Becker further points out the social need for couples with non-normative pregnancies to see their pregnancy as normal: “Yet when a pregnancy did occur because of technological intervention, the parents often made a concerted effort to treat the process *as if it were natural*” (Becker 2000:7). The toll on the couple that accompanies infertility treatment can also be overwhelming. “Many of the couples in our studies met, married, and began trying to conceive within a very short period. Infertility treatments thus become the testing ground for the relationship” (Becker 2000:37). Despite the initial medical intervention for fertilization, the couple will oftentimes look past that event itself, and attempt to fit the rest of their pregnancy into socially defined norms, almost as if things were now as they should have been in the first place.

This non-normative reproductive sub-culture tends to extend past the social environment and into the homes of the couples themselves, where gender plays a big role in how a non-normative path to pregnancy is dealt with. When unable to meet this cultural expectation, both women and men tend to hold onto traditional notions of womanhood and manhood (Becker 2000). “Medical treatment heightens women’s and men’s sense of abnormality and locates it in the body. Although infertility itself is not a disease, the health care system treats it like one” (Becker 2000:27). Infertility, in fact, can threaten gender identity at its core. “Pursuing infertility treatments invariably triggers a life transition, but it is not the treatments themselves that trigger this response: it is the process of having one’s gender identity assaulted” (Becker 2000:36). According to Becker, we see that infertility challenges one’s gender role in society, and it is through understanding this sub-culture, and those that are affected by it, that we can then work to

re-establish normalcy. However, with infertility on the rise, and an entire industry growing up around it, these couples are not as different and isolated as they may think and feel.

In their edited book, *Infertility Around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, Inhorn & Van Balen (2002) argue that:

“Despite the inspiring proliferation of recent studies on the relationship of reproduction to culture and politics, certain reproductive topics continue to be privileged at the expense of others. In particular, we now know much more about what might be called normative human reproduction – particularly “high” fertility that is “controlled” through “modern” contraceptive technologies, as well as successful childbirth at the hands of physicians and midwives, resulting in maternal and child well-being – than we do about non-normative reproductive scenarios and experiences,” (Inhorn & Van Balen 2002:4).

All media sources exalt pregnancy as wonderful and magical, but stories from those for whom pregnancy was not always so wonderful—if it occurred at all—are simply not widely known or available. It is as if society does not want to include reproductive narratives, which may include anguish, and involve science.

Both normative and non-normative reproductive accounts create two very different stories that are both worthy of examination. We need to understand the ways in which the various theorists noted above have defined and applied normative and non-normative reproductive accounts so that they can be socially shared and understood. Through a better understanding of reproductive technology we began to see how infertility is socially structured, and how knowledge of fertility is both socially and discursively created. Information on human reproduction; such as pregnancy, childbirth, and child rearing are extensive and ever increasing, however there is still a lack of acceptance (stigma) wither real or felt for those to whom pregnancy does not come

naturally. This experience is much more common than people may think, and raising the awareness and documenting infertility accounts can provide great comfort to those about to explore infertility treatments themselves. “Currently infertility affects approximately 10% of the population. Since infertility strikes diverse groups – affecting people from all socioeconomic levels and cutting across all racial, ethnic and religious lines- chances are great that a friend, relative, neighbor or perhaps you are attempting to cope with the medical and emotional aspects of infertility” (Resolve, Retrieved June. 24, 2006).

Resolve a national infertility support group raises such social awareness; however more discussion surrounding infertility by various players needs to take place, infertility will then become less of a non-normative experience for women.

We all know someone who has gone through the infertility process (whether they have shared it with us, or kept it secret), but few have an idea of what this process entails. By opening this invisible sub-culture and bringing it into the light through narratives, we help to reshape society’s definition of pregnancy to include more non-normative experiences. All of the authors noted above point to these two distinct social reproductive accounts: normative and non-normative. I agree with the authors above in that to understand the entire picture of fertility, non-normative accounts must be given a larger voice, so that these accounts can aid in the process of those affected by infertility. What I add to their research is the idea that normative and non-normative narratives need to serve as a cultural framework for studying fertility in general. To understand the modern fertility experience better, fertility and infertility must be viewed together, rather than separately. Rather than having to view oneself as part of the “other” cultural group

(non-normative), allowing women to have access to additional resources in which they can find narratives to closely resemble their own diminishes the feeling of isolation and inadequacy and furthers the sociological study of fertility by changing how fertility is understood in our culture. Additionally, finding parallels in other's narratives increases the sense of normalcy, which is so important given that infertility threatens our very identity as women. I will next examine the ways in which this social world of infertility is put together by breaking it a part and examining each step of the process.

The Infertility Process (Social Construction)

Infertility is shaped through a process that is both structured and organized. It is both socially constructed through medical definitions, narratives and meaningful symbols, and social interactions.

The process of constructing meaning about infertility begins once a couple suspects a problem, even before medical treatment is sought (Greil, Leitko, Porter 1989) and it is through their interpretations and choices that their infertility process (or experience) takes shape. "The most important decisions couples make as they define and resolve their crisis of infertility – whether to seek treatment, whether to undergo a particular diagnostic test, whether to stop treatment, whether to pursue adoption, whether to explore *in vitro* fertilization (IVF), and so on – are not medical decisions at all" (Greil 1991:6). Infertility is socially constructed experiences that occur through our daily social interactions with the outside world, how we have come to interpret medical definitions of

infertility (Western/US definition of infertility), meaningful symbols or narratives (“achieved pregnancy”), and technology (fertilization or IVF).

Medical definitions certainly structure and define the experience of infertility. “Infertility is a disease or condition of the reproductive system often diagnosed after a couple has one year of unprotected, well-timed intercourse or if the woman suffers from multiple miscarriages. Infertility can be male or female related” (Resolve, Retrieved June 23, 2006). Based on this medical definition and others from the medical community, an infertility criterion is established, and the infertility experience is then mediated by this medical structure. Through this narrow definition of what it means to be infertile some couples are forced to follow a process, depending on the doctor, which they might not particularly choose for themselves. “...Western medical definitions of infertility may diverge considerably from individuals’ subjective definitions, which are often based on socially relevant indigenous categories and systems of identity formation” (Ihorn & Van Balen 2002:12). These medical definitions seek to identify and categorize women into a medical process that might or might not fit their individual medical situation and tends to wipe away these women’s ability to create meaning about their own infertility experience and intentionally leaves them out in the cold when it comes to socially constructing their own reality.

Socially constructed narratives and symbols play a role in defining women’s infertility experiences as it creates social meaning. As quoted in Ritzer, Mead (1934, 1962:46), one of the most important thinkers in the history of symbolic interactionism, adds that “language is a symbol which answers to a meaning in the experience of the first

individual and which calls out meaning in the second individual. Where the gesture reaches that situation (the communication between the first and second individual) it has become what we call *language*” (Ritzer 2000:347). Language is the vehicle that we use to convey meaning as we find it, and what we use to convey our own narratives. It is through these experiences (in the case of my research, experiences dealing with infertility) we examine the interactions involved, the use of symbols/communication in these social interactions, and the social actions resulting from the interpretations we have for them, and also being flexible enough in adjusting to different situations and contexts that arise from them (Adams and Sydie 2001:502-505). Narratives are important to understanding the infertility experience, because it is through our personal experiences that narratives get created and re-created. The physicians involved help give meaning to and further define our social experiences. As quoted by Riessman, Langellier (2001) states “Narratives developed during research interviews provide a window into the process. When we tell stories about the events in our lives, we perform our preferred identities” (Riessman 2002:152-170). And in fact, reproduction has come very much to the forefront of social research in the past several years. “... (In) the past twenty years (we) have witnessed a veritable explosion of research on the social construction and cultural elaboration of women’s reproductive experiences” (Greenhalgh 2002:3). Many researchers studying infertility have used narrative analysis to study human life and/or health and illness, such as Riessman, 1993, 2002; Franklin 1995, 1998; and Becker 2000. By piecing together women’s narratives, the world of infertility is socially constructed, and a broader view of the reproductive experience as a whole is created. The following

summary of Riessman (1993, 2002) offers how not only narratives serve as a mechanism for developing “discursive contexts” on infertility, but also serves as a way in which to help those experiencing infertility.

Riessman (1993, 2002) adds in her article “Positioning Gender Identity in Narratives of Infertility” that “stories women developed were my focus, because narratives are a particular significant genre for representing identity and its multiple guises in different discursive contexts (Mishler 1999)” (Riessman 2002:152). Social positioning in the stories--how narrators chose to position audience, characters, and themselves--was my point of entry, because “fluid positioning, not fixed roles, are used by people to cope with the situation they find themselves in (Harre & van Langenhove 1999:17)” (Riessman 2002:166). By using narratives, people shape the events and characters involved in such a way that it allows them to understand and integrate events that resolves inner conflict. In other words, narratives serve as a coping mechanism, allowing women to come to terms with their own situation by telling their story from their perspective.

Franklin (1998), in her edited book *Reproducing Reproduction*, adds to the idea that woman actively sharing their fertility experiences helps to create social meaning for them, by pointing out that it is not just the story itself, but the language--specifically technical language--utilized to explain these experiences that help to define social meaning. Franklin (1995, 1998) adds that specific language is used to explain narratives involving reproductive technology, specifically “achieved conception,” as seen in the following quote:

“The representation of assisted reproduction as natural science in the service of the natural family draws upon recognizable and traditional conventions, and invokes well-established systems of belief such as those concerning the value of the nuclear family and of scientific progress. Less recognizable is the account of conception such representations foreground. Emergent across many different representational and discursive sites are narratives in which conception is not only assisted, it is achieved. Its achievement, in the laboratory by teams of professionals, constitutes an unfamiliar primal scene. This altered version of “the facts of life” is, I argue, an emergent metanarrative of achieved conception derived from the world of assisted reproduction ” (Franklin 1995:328).

Franklin then goes on to explain how “redefinitions of reproduction evident in accounts such as these indicate the extent to which meanings derived from the world of achieved conception are beginning to influence mainstream representations and understandings” (Franklin 1995:333). Through the use of language Franklin points out that “new conception stories” are being developed and becoming more common and accepted.

Through a new common language, a language I call “fertility talk,” technology comes to be seen “as a product of nature” itself thus legitimatizing “through naturalization” the assistance of reproductive technologies.

Although technological growth plays a role in how infertility is socially constructed, we must keep in mind that “technology is not an agent of social change, people are” (Franklin 1998:5). So, what becomes important here are our interpretations and how we manage of our infertility experience when utilizing NRT’s. It is easy to be guided by the technology utilized in the infertility process. Young (1984) points out that the pregnant woman’s “condition tends to be defined as a disorder, because medical instruments objectify internal processes in such a way that they devalue a woman’s experience of those processes and because the social relations and instrumentation of the medical setting reduce her control over her experience from her” (Young 1984:55).

Young calls for women to actively restore value to their experience since the medical community can inadvertently take control away. It is important that these women actively pursue and create social meaning in their own lives while navigating through the infertility process and utilizing reproductive technologies.

Becker adds to Franklin's idea that women's narratives and the use of language to explain their stories is critical. She adds that not only the narrative and language used is of value, but also the interpretation of these stories by these women must be examined as explained in the following summary.

In her book, *The Elusive Embryo* (2000), Becker examines how difficult it is for women to seek social change. By attempting to find and understand meaning in their infertility experience, women become more aware of the isolation and separation that arises from this experience. And in doing so, become more socially aware of the need to bring the infertility experience out from the shadows, to help other women just beginning their journey through infertility.

“One of the abiding frustrations of those seeking social change is the resilience of certain dialogs within society that maintain cultural ideologies and thereby impose a limited view of possibilities. People, who repeatedly attempt to live up to cultural ideologies, yet fail to do so, experience acute social discomfort and emotional pain. They may eventually come to see those ideologies as interfering with and delaying their attempts to find alternative ways of regaining a sense of normalcy and thus finding meaning in life. I believe that this is why so many people volunteered to participate in this research: out of conviction that ideas about fertility and parenthood in United States society need to change and that, collectively, their voices might make a difference” (Becker 2000:25).

It is important here to look at people's experiences and how they interpret them, because it is through these interpretations that social life is constructed and re-constructed.

Franklin (1998) adds in addition to “acknowledging the importance of culturally

grounded accounts,”--which highlights the works mentioned above--it is also important to look at the global cultural influences that surround the infertility experience, rather than just the local, regional, or national influences (1998:5-6).

Through my own personal experience I began to wonder if I was alone while going through this infertility process. I wondered what other women were going through, and what exactly the infertility process looked like. I wanted to wrap my arms around the process, make sense of it, and know what each step looked like. This led me to not only understand what I was going through personally, but to understand what others were experiencing by interacting with others to see how they have come to define and/or construct their own social reality.

All of the authors noted above point to the non-normative infertile culture as being separate and distinct from the normative fertile culture. They also point to the idea that to better understand the social construction of infertility, a woman's fertility narrative, and the language and symbols utilized, must also be examined. I agree with the authors noted above that the use of narratives provide a window into the use and understanding of the infertility process. What I add to their research is the application of personal narratives, and how through the examination and connection of these narratives the process of infertility emerges. By application I mean that a women's infertility narrative must be a point of reference and examination always when studying infertility. Without this critical piece of reference would be to leave out important information, critical to understand this culture, in sense leaving out important information regarding its citizens.

I utilize their narratives regarding the “process of infertility” to not only open dialogs, but through their explanations of their process gather rich data. By taking a closer look at the process chosen by the women I interviewed and what that process has meant to them, I uncover commonalities in the interpretations and experiences of these women and their reflections on a process that took reproductive control away from them, and the social and cultural influences in place that affect the standard of normalcy that infertility threatens. As women fight to create their own meaning of infertility I feel it is equally important to dive deeper into the actors involved in the process to create meaning or socially construct infertility narratives. Who are the knowledge experts’ involved, and whose knowledge is privileged?

Fertility Knowledge Experts

The social construction of infertility goes beyond the study of personal narratives and language utilized to construct them, to include the actors who have the ability to generate, communicate, and privilege knowledge over other accounts in this culture of infertility. When I was first confronted with infertility I wondered who these actors were. Who has the ability to create and structure this world of infertility and how? It is important to break apart and understand whom these knowledge creators are and to take a look at both technical knowledge (both medical and professional) and women's experience as important bodily knowledge creators. What I am calling for is that all three of the different infertility knowledge experts have a hand in defining the infertility experience, and help to make the experience more positive and relatable, and that all

three knowledge creators (medical, professional, and experiential) should be acknowledged and studied when breaking apart the culture of infertility. And while all three knowledge creators are equally important, most often medical expertise appears to be privileged over any other within this culture, as can be explained in the following history of the rise of medical expertise in America.

The rise and fall of midwifery demonstrates how the medical profession has come to dominate a woman's reproductive experience. "Thus the triumph of the male medical profession is of crucial significance for our story: it involved the destruction of women's networks of mutual help—leaving women in a position of isolation and dependency—and it established a model of expertism as the prerogative of a social elite" (Ehrenreich and English 2005:38). The shift in experiential expertise in favor of medical knowledge can be traced back to the destruction of midwifery. "By the 1950's, African American midwives in the South played an increasingly marginal role in the reproductive health care system – the end point of a deskilling and modernization project that had begun in the early 1920's as southern medicine and federal health programs became occupied with asserting the primacy of allopathic medicine and increasing numbers of women turned to scientific obstetrics and hospitals for their birthing and pre- and post-natal medical care" (Fraser, 1995:44). The same article goes on to discuss how its association with the oppressed black community stigmatized midwifery. While the goal was to promote the sanitary conditions offered by the medical community, in the South, doctors and nurses played upon the negative sentiments toward the black community to achieve this goal. Despite decades of knowledge passed from midwife to midwife in the black community,

and called upon by the white community as well, the “strategy was to draw on the negative historical associations of midwifery and African American culture while elevating birthing (severing its connections to black women) to a scientific realm” (Fraser 1995:45-46). The medical community completely devalued a rich source of information regarding birthing, exalting its own point of view as the only point of view. And while done for the right reasons—to improve sanitary conditions and decrease infant mortality rates—it was done exploiting a racial bias already existing in the communities of the South and leaving behind the life experiences these women brought to the birthing process.

In the late 1960’s a group of women within the United States met and discovered with frustration that their shared life experiences were dominated with “misinformation” from the medical community and by sitting down and “weaving together” their own experiences “along with the health and medical information we carefully researched and a political critique of the profit-oriented medical system, into a useful, women-centered body of knowledge” (Our Bodies, Ourselves (OBOS) 2005: XII). The creators of the women’s health care collective, OBOS--a book created for women by women about women’s health--agree that women and their experiences serve as important contributors to the creation of health and medical information. “By disseminating women’s experience and knowledge as valid information, OBOS challenged the paternalistic medical system” (OBOS 2005: XII). Their work empowered the concept of narratives as a crucial aspect in examining the culture of reproduction. Many researchers studying infertility share similar sentiments of how technology and a woman’s experiential

knowledge are at odds with each other, such as Rothman, (1982, 1988), Lazarus (1994), Rapp (1995), and Franklin (1998). These researchers have weaved together multiple narratives regarding fertility topics to not only better understand how this world is socially constructed and who theoretically contributes to it, but have sought to understand through these narratives why this occurs in the first place. The following summary of Rothman's work depicts how human experience takes a second seat to that of technology or medical knowledge.

Barbara Katz Rothman (1982, 1988) describes how human experience now plays a supporting role to the devices used to monitor all aspects childbirth. The increasing use of medical devices during the birthing process, makes the birth process very technical, and devalues the experience for many women. The following quote demonstrates how technology is playing a major role in the experience itself, while undermining the experience for many women:

“Monitoring, both archetypal and symbolic of medical management, is dangerous and expensive. But even for women and babies who are not physically compromised, who do not have unnecessary surgery, infections or hemorrhage, the technique is not benign. Monitoring has profound effects on the quality of the birth experience. One of the nurse-midwives I interviewed responded as follows to the changes in the hospital service where she works that came with the introduction of electronic monitoring: "We're going to have centralized everything, man. A woman comes in for labor, you put an electrode in her rectum to record temperature, you put an internal monitor on the [fetal] head, you put the other one in the uterus, you put the blood-pressure cuff on--that's it, baby--you don't have to go in there till the head's out" (Rothman, 1982:47).

As this quote makes clear, women's own knowledge and experience of the date they conceived or when labor contractions started or how far apart they are, are becoming less and less important with the development of technological devices. Rothman adds that technology offers medical personnel an alternative source of this critical information.

Technology now seems to play the dominant role in the delivery process, exaggerating the role of the medical knowledge creators, and diminishing input from the experiential.

Lazarus points out that the dominance of medical technology during pregnancy can be seen in the rise of Cesarean births in the past several years, and the use of ultrasounds to determine problems with the fetus. While many women refuse an amniocentesis because “they know the baby will be o.k.” (1988:97), the decision to do an amniocentesis or a Cesarean Section is often out of the control of the pregnant woman. Too often, these decisions have to be made at a time when the fetus is shown to be in great danger of survival, and the “choice” comes down to choosing whether to let your child live or die. And with Cesarean Section surgeries in particular, it is now presented as a routine way to deliver (Browner and Press 1992; Rothman 1988). Lazarus adds to the idea that technology can alter a women’s medical experience, by inserting the element of her relationship with her doctor and whether she has the financial means to get good medical care. This she adds truly dictates a woman’s experience during pregnancy and labor.

Ellen Lazarus (1994) adds that childbirth is as much about the healthcare that is available to women as it is about biology. A woman’s reproductive choices or lack thereof, technological or otherwise, dictate her experience. Women can become passive participants in their own pregnancies, allowing the medical experts to dictate the experience for them. She studied the relationship that women from different classes (middle-class, working-class poor, and female health professionals) have with the medical system. She found that all women, regardless of class, wanted information,

although poor women who used health clinics had less access to information, and were not able to have choice in the selection of their doctor. With less information available to them, they were unable to make informed choices about the medical aspects of their pregnancies, reinforcing a stereotyped belief within the medical community that poor women were too ignorant to make choices, and needed the medical community to guide them. Still Lazarus concludes that although the two groups of middle class women could exercise more control over what they wanted in terms of doctor care, and type of birth experience, in the final analysis, "...it was never enough. No matter what they knew, it could not empower them within the medical system. Knowledge itself could not give them authority, nor could they know all the contingencies of the birth process or of institutional care" (1994:37-8). The medical system, it seems, has too much control over the birth experience, overpowering experiential knowledge, and leaving women in a position where they do not have as much control, as perhaps they should.

In the following summary Rapp adds to this idea, that medical experts do in fact play a significant role in the birth experience of women, but the language used by women to explain their own bodies derive in fact from medical technology used by medical experts rather than their own terminology to explain their own bodies. In her essay on amniocentesis, Rayna Rapp (1988) argues that when medical science is taken as the authority in matters of reproduction, women's bodies are no longer the sites of experiential knowledge. "[W]hen pregnancies are medically managed; most women learn to re-describe their bodily changes through the language of technology, rather than dating their pregnancies experientially. There is thus a continuous negotiation circling the

description of any pregnancy in which a woman reveals and embeds herself and her perceptions of her fetus in a language shot through with medical, personal and communal resources" (Rapp 1988:31). Medical terminology becomes the predominant method of understanding pregnancy, disregarding a women's personal experience.

Sarah Franklin, in her edited book *Reproducing Reproduction* (1998) and from her article Postmodern Procreation: A Cultural Account of Assisted Reproduction (1995), adds that power and knowledge/language --specifically technical language-- are utilized not only to explain, but to control, women's reproductive experiences.

"Here, a male dominated and quintessentially patriarchal system of power and knowledge was deployed to name, define, and control a territory located inside the women's bodies. Thus the cultural elaboration of this territory with medical-scientific discourse is cause for much concern. Reproduction is increasingly subject to (and the object of) the hegemonic gaze of the clinician, and his (or, increasingly in the field of assisted reproduction, her) technological apparatus of monitoring, management, and surveillance is perceived as threatening" (Franklin 1995:335).

Franklin (1995, 1998) adds how the power of medical knowledge and language controls the reproductive experience, leaving women to question their bodies, rather than relying on their own bodily experience or knowledge. The main goal of her work is to "reproduce reproduction," that is to change current definitions of reproduction and the "facts of life" to include the "number of emergent reproductive service industries, such as surrogacy... (Franklin 1998:8). Without understanding what these new technologies are, it serves to only widen this gap. A lack of understanding puts women in the position to serve as patients vs. actual knowledge contributors in their own reproductive process. She argues that a change in the way we view reproduction will have significant "cultural consequences in the wider systems of knowledge and belief to which they make

reference” (Franklin 1995:333). Hence, we are all affected by the emergence of new reproductive technologies, especially for those that not only operate them, but for those who are forced to utilize these new reproductive techniques.

All four authors point to the power that medical experts have in the reproductive process, and how that power has grown considerably over the past century. Pregnancy and childbirth are understood by society through the use of medical terminology, as experiential and professional knowledge play smaller roles than they have historically. Advances in technology only serve to widen this gap, as women lose more and more control, becoming more of a patient and less of an active participant in their own reproductive process. I add that we are all experts in the construction of infertility, as women are co-equal with doctors because of our experience. Narratives become powerful sources of knowledge that anyone can use to not only further understand the culture of infertility, but also to further understand the social construction of our society.

Literature Review Conclusion

Women’s narratives offer a unique way to view experiences with infertility; they demonstrate a “particularly significant genre for representing identity and its multiple guises in different discursive contexts (Mishler 1999)” (Riessman 2002:152). I argue that it is through a collection of narratives that discursive representations of this culture emerges and one can then begin to understand this way of life. “People’s narratives of disruption are moral accounts of their lives. That is, the narratives reflect people’s interpretations of these moral ideologies and their efforts to live up to them” (Becker

1997:17). They help women create social meaning, and in doing so, are helping to expand the traditional view of reproduction and “influence mainstream representations and understandings” (Franklin 1995:333). Ginsburg and Rapp (1995) use “reception theory” to explain how images and technologies, that are both produced and consumed, provide cultural and social meanings. I extend this work by arguing that, in addition to images and technologies, women’s narratives offer a unique window into the world of infertility by providing a cultural understanding of infertility. Understanding the process by which couples come to understand their infertility, and how that experience is both constructed and re-constructed through the *ideology* and *social structure* of society provides a way to further understand infertility (Greil 1991: 1-26). The study of the culture of infertility is key to understanding reproduction, as it exists in our society today. In this sense, reproduction, in its biological and social senses, is inextricably bound up with the production of culture” (Ginsburg & Rapp 1995:2). During my observations and interviews a culture of infertility emerged, as I was able to see the complex social arrangements that make up this culture through social interactions, language, and meaningful symbols. It is important to study infertility in that all reproductive accounts must be viewed when looking at reproduction as a whole. The ability to reproduce “naturally” is something that many of us have taken for granted as our natural right. In fact, with couples marrying at much later ages these days, pregnancy is often viewed as the rite of passage into adulthood (Greil 1991).

I argue that upon their entry into a non-fertile world, women initially experience infertility through medicalized experiences where a woman’s sense of normalcy, and the

stigma associated with infertility, affects how gender is negotiated. When reproduction does not come easily, our sense of selves – in fact our sense of gender itself – is called into question. Since the infertility experience calls gender into question, causing “acute social discomfort and emotional pain” (Becker 2000:25), it has a profound effect on gender. Gender is, in fact, fluid and continually evolving (West and Zimmerman 1987:126), and the impact that the infertility experience has on the individual shapes society’s understanding of gender. By observing gender roles it offers 1) an insight into the ways that both men and women shape their infertility experience through their relations with each other, and 2), it offers an understanding of the dynamics of this “infertility sub-culture”. Losing control of the reproductive process can damage a woman’s sense of control over her own body. “So profoundly do cultural ideologies about gender affect men and women that they consistently report feeling marginalized by them” (Becker 2004:44). The stigma associated with infertility can be found both externally (real stigma) and internally (felt stigma). I argue that it is the felt stigma that women impose upon themselves that significantly shapes their infertility experience in that socially only popular accounts of reproduction are privileged, leaving them to feel inadequate. Understanding both non-normative and normative reproductive accounts, along with knowledge gained from all knowledge experts can help empower a woman to take back control, and to overcome any felt stigma.

Through my review of the literature, and my own research of women undergoing infertility, I add that the infertility experience must be managed through an understanding of who generates, communicates, and privileges knowledge over other accounts in this

sub-culture. The contested yet important role of knowledge is both constructed and shaped by knowledge experts and is critical to understanding this experience. For example, medical definitions and symbols certainly structure and define the experience of infertility. The impact of the knowledge creators within the culture of infertility plays a major role in defining the experience for women. During the reproductive process (both normative and non-normative), knowledge comes from three sources: medical, professional, and experiential. In the twentieth century, medical knowledge has taken a dominant role in the reproductive experience (Fraser 1995:44), causing women to take a more passive patient role in their own pregnancies. The diminished role of experiential knowledge needs be given more attention. This is especially important for women experiencing infertility due to the emotional trauma the process can cause. When infertility issues arise, knowledge—and who is controlling the dissemination of information—becomes crucial, as this knowledge is used to chart the path to pregnancy. Current literature is helpful, but is often too narrowly focused on one woman's particular experience or on medical information, and does not offer enough knowledge to someone who has crucial decisions to make in a very short period of time about which course to take. This project tries to combine many voices of women who have or who are currently undergoing infertility to give them a much needed voice. Therefore is important for women to utilize and be aware of information from all three sources: medical knowledge, professional knowledge, and experiential knowledge. Professional knowledge (that of midwives and others not directly related to medicine) has been minimized by the medical community (Fraser 1995:44), as the result of an honorable attempt to improve sanitary

birthing conditions at the expense of generations of experience or experiential knowledge. In fact, women going through the infertility process often disassociate with their own bodies, and willingly become passive patients, letting their doctors dictate their course of treatment without truly examining their own preferences and viewing their pregnancy experientially (Rapp 1988:31). A balance needs to be struck between the three knowledge centers (medical, professional, and experiential) so that women can take ownership of the process, empowering themselves in the process, rather than being mere subjects of constant testing and monitoring.

METHODS

Grounded Theory and Qualitative Methods

As the number of women who face infertility continues to increase, so does the need for our understanding of this issue.

“Infertility is a major reproductive health problem throughout much of the world. Its prevalence in industrialized countries ranges between 6 and 10 percent of women of reproductive age; in developing countries, it may be considerably higher. Furthermore, there is increasing evidence that the prevalence of infertility has been rising in many parts of the world. This rise is largely attributable to an increased incidence in sexually transmitted infections...decline in sperm counts...biological causes, i.e., failure to ovulate, and some due to unexplained causes. Despite the prevalence and seriousness of infertility, the population and reproductive health field has largely ignored this problem” (Okonofua 2002:1).

Infertility is a particularly important topic to research as it addresses the exclusion and silencing of the infertility experience in normative discussions of reproduction, and gives a voice to the women navigating this experience. In addition to its social implications, women who have dealt with, or are currently dealing with infertility became my choice of study, because I wanted to understand at an individual level the process women undergo when first confronted with fertility difficulties, and how they then cope with the medical, professional, and societal stigma attached with “infertility” at a more social level. While both women and men are affected by the social implications of infertility, I chose to focus only on women to narrow my focus and methodological research. In addition, my own personal experience with infertility has aroused my curiosity about how other women deal with the inability to reproduce “naturally.”

I found numerous sources that draw on a sociological view of women and reproduction, anywhere from pregnancy and birth to women and medicine (i.e., Rapp,

Reinharz, Grail, Franklin, Becker, etc.), which influenced my own research methodology. Utilizing the methodologies set forth in these papers I constructed my own methods, paying specific attention to the method set forth in Rapp's piece, "The Power of 'Positive' Diagnosis, Medical and Maternal Discourses on Amniocentesis" (Rapp 1988:103-116). In this piece she developed her sample by utilizing personal networks and allowed women to share their personal experience with her, adding in questions during the interview process specifically related to her research. As she explains, "My sample was developed using medical and personal networks and responses to an article I published on amniocentesis in a nationally circulated women's magazine" (Rapp 1988:290). From her research she developed themes, and in her write-up she added in quotations to support her main ideas or categories, which emerged from her data. I followed a similar process in that I wanted to follow a methodology that not only allows women to have a voice and share their personal experience with infertility, but also allows me to probe and understand the ways in which these women have coped with the medical, professional, and personal stigma attached to it.

To uncover the social organization of infertility, and the role experts (medical, professional, and personal/experiential) play in constructing this reality, I utilized inductive research methods and the philosophy of grounded theory. I chose to use inductive research to provide a more qualitative look into the actual experiences women have after finding out they need to involve science through the use of IVF, embryo donation, etc. to have a child of their own. The very nature of qualitative research, and the multi-methods utilized (i.e., in-depth interviews and participant observations), allows

the researcher to look at a smaller amount of data more closely, and dig deeper into the actual experiences of the subjects, taking a moment to step in their world or culture.

“Feminist researchers combine many methods so as to cast their net as widely as possible in the search for understanding critical issues in women’s lives. The multi-method approach increases the likelihood that these researchers will understand what they are studying, and that they will be able to persuade others of the veracity of their findings” (Reinharz 1992:201). In using the inductive method, data is collected and then analyzed and categorized into common themes that result in the creation of social theory (Glaser and Strauss 1967). In their 1967 work *The Discovery of Grounded Theory*, Glaser and Strauss discuss a grounded approach to sociological research. “Theory based on data can usually not be completely refuted by more data or replaced by another theory. “Since it is too intimately linked to data, it is destined to last despite its inevitable modification and reformulation” (Glaser and Strauss 1967:4). A grounded research approach was more appropriate to utilize for this research as it is more concerned with the data and what social theory is generated from it, rather than the inverse or deductive research, which arose out of the natural sciences and the legacy of positivism where one starts out with a hypothesis and then collects data to test the validity of that hypothesis (Esterberg 2002).

It is important to my research that I take the time to understand the social world of infertility as lived through the experience of women who have or who are currently experiencing it. “According to Patti Lather, research can emancipate participants when certain research approaches are taken. The most effective emancipatory approaches are interactive interviews in which researchers self-disclose; multiple, sequential interviews;

group interviews; negotiation of the interpretations; and dealing with false-consciousness in ways that go beyond dismissing resistance” (Reinharz 1992:185). While doing my field research I utilized the methods set forth in ethnographic field studies to better understand the experiences of the women I interviewed. Emerson et al. wrote, “The ethnographer seeks a deeper *immersion* in others’ worlds (or cultures) in order to grasp what they experience as meaningful and important” (Emerson 1995:2). As opposed to quantitative research, where research data is derived from questionnaires and surveys only, I chose to use qualitative research tools to gain a better understanding of the experiences that women have with the infertility process, as it allowed me to better develop a relationships with my research participants by interactively sharing our encounters with infertility. To use questionnaires to compile data about these experiences would completely miss the benefits qualitative research provides--an opportunity for these women to tell their stories--which is so crucial in trying to understand the social organization or the culture of infertility and the actors/experts involved.

Qualitative research methods allow me to tap into this culture of infertility, by allowing me to explore my question and better gain insight into the social construction of infertility and the role experts play in constructing this reality. I utilized in-depth interviews and observations for this study. Qualitative methods are the best way to explore this issue and to focus on the unique culture created by the infertility experience and the ways in which this infertility culture is constructed through normative and non-normative reproductive discourse.

Feminist Research and the Study of Women

I chose each research method with the intent to privilege the voices of women, who have generally been excluded from social science research. My goal was to give women who have gone through or who are going through infertility a voice, and through the use of “semi-structured interviews” a means through “active involvement in their responses to construct meaning and data about their own lives” (Reinharz 1992:18). In contrast to methods identified within a positivist perspective, such as testing or large-scale surveys, which generally seeks to attain value neutrality, feminist researchers generally consider contemporary ethnography (observation, participation, archival analysis, and interviewing), content analysis, and the use of personal experience to be a valuable asset for feminist research (Reinharz 1992:180-194). Utilizing these methodologies not only “emancipates,” but allows the researcher and the researched to develop a special relationship where an emphasis can be placed on a women’s experience thus create a better understanding of what is being researched (Reinharz, 1992).

Feminist researchers do not typically see the use of personal experience as threatening the objectivity of methodological research. Rather, many feminists view its use as serving to validate their research. “Feminist women must deliberately...integrate their repressed, unconscious female subjectivity, i.e., their own experience of oppression and discrimination into the research process” (Maria Mies in Reinharz 1992:263). My own personal experience with infertility is an important part of my thesis project as is the personal experiences of all of the women I interviewed. I found that during the interview process I served as not only a researcher, but depending at what point in my process of

infertility I was in when I interviewed these women, they either served as my personal mentor or I became their friend guiding them through their own process of infertility and/or IVF. This interview process became unavoidable, and was also identified by Ann Oakley in her article: "Interviewing Women: A Contradiction in Terms." Oakley says that,

“It would be the understatement of all time to say that I found it difficult to avoid answering these questions (questions asked of her by the interviewee) as honestly and fully as I could. I was faced, typically, with a woman quite anxious about the fate of herself and her baby, who found it either impossible or extremely difficult to ask questions and receive satisfactory answers from the medical staff with whom she came into contact, and who saw me as someone who could not only reassure them but inform them” (Oakley 1981:43).

The value of my thesis project comes from the narratives that these women and I share--the insight, the joys and sorrow, the successes and failures--which we go through while undergoing the infertility process, as well as the interpretation and explanation I offer after careful examination and study of the topic. "Narratives developed during research interviews provide a window into the process. When we tell stories about events in our lives, we perform our preferred identities" (Riessman 2002:152). By compiling these narratives through in-depth interviews and observations I am hoping to privilege the voices of these women who are experiencing infertility and therefore better define the social organization of infertility. "A feminist interviewing women is by definition both inside the culture and participating in that which she is observing" (Oakley 1981:57). With the delicate nature of the topic of infertility, I could not help but step out of the role of pure sociological observer and interviewer, as I had information and assistance to provide first-hand to the very women I was hoping to reach through this paper.

Data Sampling and Collection

The data collection spanned over the course of the year 2004, following project approval from the Institutional Review Board at San Jose State University. I draw on two sources to develop this analysis: in-depth interviews and observations. I conducted in-person interviews and made onsite observations at an infertility conference,

I conducted ten interviews from June 2004 to October 2004, each lasting one to one and a half hours long. In addition to the interviews, I did one field observation for approximately eight hours at Resolve's Family Building Symposium, sponsored by the Northern California Resolve Chapter in September 20, 2004, where I was able to observe women and their partners who are currently struggling with infertility. Both of these sources related to the normative and non-normative discussions surrounding infertility that helped me situate the data within the lived experiences of women struggling with infertility.

Interviews

My first source of data was from in-depth interviews, which I conducted in person with each participant. The interview sample was developed using personal networks and snowball sampling. I asked personal and professional contacts to inform anyone they might know who is involved or was involved in the infertility process about my project, to give them an opportunity to share their personal infertility stories with someone who has also gone through the process. The qualifications for employing subjects for this study were only that they had experience fertility problems and sought help. Participants

were recruited throughout the United States based entirely on their willingness to participate.

Through personal networking, snowball sampling, I decided upon 10 women to use for my study. Two women considered being interviewed, but one was near her due date (she conceived utilizing IVF) and decided it would be too much and cancelled, and the other woman never e-mailed me back to set-up an interview date after the initial introduction. Of the women I did interview, 8 were white, and 2 were Latina, and ranged in age from 30 to 54. The age range I originally required of my research participants was between the ages of 27 to 45, however one interviewee fell outside this age bracket. I felt it was important to capture the story of this 54 year old women, who at 45 went through the infertility process, but when it came time for her and her husband to be tested (on why they were not able to conceive naturally) she opted out, and today at 54 still regrets that decision. This method of finding participants resulted in 10 interviews, all of which were conducted from June 2004 to October 2004. All interviews were conducted in-person, and all consented to having their interviews tape-recorded.

These sessions were usually conducted in a neutral location such as a shopping mall or coffee shop. The participants were informed of the purpose of the project, and many were willing to share their experiences for the simple hope that it might one day help someone else going through the process. Interview participants were asked to give one hour of their time for the interview. However, in many cases, the storytelling aspect of the interviews took the interview past an hour, as this seemed a very cathartic experience for most, and I did not want to undervalue their stories with a hard stop at the

end of the hour. Such a continuation was at the sole discretion of the participant's ability and desire to continue.

Participants were asked a series of open-ended questions about their experience with infertility, how it was discovered, how they began to explore solutions to their specific issue, and how those solutions succeeded, or failed. Because this study was interested in capturing what participants have defined as important, rather than what the researcher defines as important, most questions arose from previous comments or responses provided by the participant.

I began with a list of questions to help guide the interviews, but in many cases, my questions would stray from my own list, following a direction the participant needed to follow in order to tell her story or feel she was actively participating in and sharing her own narrative. "The analysis of narrative is a primary means for uncovering how disruption is experienced and how continuity is created, and for examining disparities between cultural ideals and people's experiences. Narratives enable the narrator to reestablish a sense of continuity in life" (Becker 1997:18). There were some difficulties in many interviews because the participants would always ask what got me interested in the research. But quickly, I realized that I had to be willing to share my own experience to help establish rapport with my subjects. It would not be appropriate to record and transcribe these interviews which touched on one of the most painful life experiences these women have had, without being willing to share my own experience. Additionally, as a feminist researcher, reciprocity was important in order to avoid the potential for exploitation, which is possible within the relationship between the researcher and the

participant. The idea of this research paper was born out my own personal experience with infertility: I sought out others to understand how they constructed their own realities through their own personal experiences with infertility, so I could better understand my own. So, not to share my own experience when asked by the interviewees would have not remained honest to the true intentions of my research project. “I have a feminist distrust for research reports that include no statement about the researcher’s experience. Reading such reports, I feel that the researcher is hiding something from me or does not know how important personal experience is. Such reports seem woefully incomplete and even dishonest” (Reinharz 1992:263). To truly find a topic of interest to study, there has to be some type of personal draw. If the author is willing to share this personal aspect, it allows the reader to gain more insight into the issue, and to better frame the author’s writing within the context of the author’s personal experience.

Participant Observation

In addition to the ten interviews, my second source of data was a field site observation at the September 20, 2004, Resolve Conference in Oakland, California. The conference was held at Holy Names College, and broken down into five sessions, with ten to fifteen different topics of interest to choose from (adoption, IVF, etc.). Each participant could choose five to attend during the day. Attendance was granted for a \$200 per couple fee. It was very much like a high-school schedule where once the period was up, you had to move quickly to get to your next class. Given the physical layout of Holy Names College, sprawled across the Oakland Hills, it was difficult to find the

location of your next class and get there on time, much less interact with other participants in-between classes.

Although not unusual, in observing these participants, I did feel somewhat guilty that no one knew I was observing them. I resolved these conflicts by being a participant first and researcher second, where I observed only those situations that stood out to me, and talked to other participants as my peers. I overcame the torment of no one knowing I was observing them by reminding myself that this was a public place, that I was a member of Resolve, and that I paid to be there. My dual role within this space, as both participant and researcher shaped my experience as a researcher by influencing what data I reported on and what I excluded. Playing the role of both a participant and researcher within this site, I was able to observe only one session per period. The sessions attended were those that my husband and I had agreed fit best with our situation. This dual role proved to be difficult in that I wanted to be there to learn and gather information for my own personal experience, and focus less on the experience of others. The following is a quote taken directly from my field notes that demonstrates this struggle. “I sit back, relax, and eat. I think about the day so far, and question internally the difference between observing this day or just attending, and how difficult it has been to take in the information that I want to leave with as opposed to trying to observe everything in order to capture it for later field notes,” (field notes, 9/20/04). This participant observation struggle is explained by Reinharz, where a “respectful distance” by the researcher should be maintained to avoid identifying the people studied, however a developed “closeness” is said to increase our understanding of who is being studied. In the “respectful distance

model” a developed relationship represents the researchers’ inability to maintain objectivity or “maintain his/her own separate identity” (Reinharz 1992:67). I struggled with this during my own participant observation, because I was there to gain more information for myself as a member of this culture struggling with infertility, as well as to understand others. I was close to these members as we were all there to gain personal information to help us through this infertility process, and I did not want to intrude on their day and take away from that.

Also, this environment did not lend itself to sharing each other’s experiences both within the classroom and outside, as it was difficult to approach others within this space. Within the classroom, presentation were given as lectures, not as discussions, and we as participants were forced to listen and not interact--which presented struggles in getting to know these people. Outside the classroom, I found that we were all concentrating on trying to get to our next class on time as classes were held in one of four different locations widely spread throughout the campus. Also, due to the personal nature of the topic it felt invasive to go up to these people or intrude on these couple’s day. These notes were taken at lunchtime, where I noticed that there were very few couples sitting together. This is the first time that the private nature of the social organization of the infertility process was so obvious. It seemed as if the sensitive nature of the topics discussion in the various sessions left the couples in a space where they just wanted to share with each other, and absorb what they had heard during the morning. There was a lot of information to absorb, and with so many people well into their own private journeys through the infertility process, the only big break in the day ended up looking

more like a time to rest our individual brains, and try to relax and build energy for the afternoon sessions.

But, the simple fact that I attend this full day conference allowed me overall insight into the vast structure or social organization of the infertility experience by observing Resolve's effort to bring together so many different solutions on how to resolve infertility and achieve parenthood together at one time.

Data Analysis

Over the course of one year (June 2004 to October 2004) I collected data, mainly in the form of interviews and one participant observation, which I then transcribed and analyzed using a qualitative approach. An inductive approach starts with the data, and using coding and memo writing, harvests the data to create categories and themes that emerge from the data itself. These themes then create the hypothesis, rather than starting with a hypothesis and setting out to prove or disprove it, as you would using a deductive research method. After all of my interview notes were transcribed from an audio form and printed, I was left with about 400 typed pages of data to analyze. "Intellectually and operationally, analysis *emerges* from the interaction of gathered data (task 1) and focusing decisions (task 2). The purpose of this process is to achieve analysis that (1) are attuned to aspects of human group life, (2) depict aspects of that life, and (3) provide perspectives on that life that are simply not available to or prompted by other methods of research" (Lofland & Lofland 1995:5). I began my analysis by following a systematic open coding process as I read through each line of data and made detailed notations in the margins. My notations would often be short descriptions of concepts or themes that

emerged from my interview and field note data. On a separate sheet of paper, I began to jot down some concepts that were recurring. After I had completed the “initial coding process” with all of my interview notes (and one field note from my participant observation at the Resolve Conference), I turned to the list of themes generated from the data and organized a list of the most common themes, often grouping them based on their relation to one another. I then assigned a color code to each theme. I then recoded each them with a tentative color-code in mind, utilizing a process called “focused coding” (Lofland & Lofland 1995:192). I reread all of my data and grouped my notes into categories by marking them with the appropriate colors and by writing short memos about the themes I uncovered.

I coded and wrote memos following the “constant comparative” method established by Glaser and Strauss (1967). Memos can and should be used to make sense of or clarify the data so the researcher can offer a stronger and more accurate analysis (Glaser and Strauss 1967). The majority of the remaining analytical work was completed during the writing process, which involved actually writing drafts of my findings and writing memos.

“The constant comparative method is concerned with generating and plausibly suggesting (but not provisionally testing) many categories, properties, and hypotheses about general problems,” (Glaser and Strauss 1967:104). Following this “constant comparative” method of analysis set forth by Glaser and Strauss (1967), I made sense of the data I collected. “The constant comparative method is concerned with generating and plausibly suggesting (but not provisionally testing) many categories, properties, and

hypotheses about general problems,” (Glaser and Strauss 1967:104). In utilizing inductive methods--a particularly feminist approach--it allowed me to document these women’s reproductive accounts, and interpret the meaning of them. “Understanding the experience of women from their own point of view, covering their meanings and interpretations, corrects a major bias of non-feminist participant observation that trivializes females’ activities and thoughts, or interprets them from the standpoint of the men in the society or of the male researcher” (Reinharz 1995:52). Starting from my own “personal experience” surrounding infertility, and using inductive methods to understand others I was able to understand and develop a rich research project.

It is important to make clear the analysis and theorizing involved in every aspect of qualitative research; it is not a process reserved at the coding stage only. At every step of the process, the researcher makes decisions on what to record in field notes, what to transcribe from recorded interviews, and what categories to create during the coding phase (Emerson et al. 1995). Each phase of qualitative research is informed by the researcher’s choice to include or exclude. I will now address several important ethical considerations in doing this type of research.

Ethical Considerations

Although risks appeared to be minimal, some interview questions did cause minimal discomfort for some participants. As the nature of the subject matter is a very delicate one, it caused some subjects to recall past feelings and emotions of their experience through the infertility process and caused some to cry. I found that this discomfort and distress was temporary. Also, this emotional response is to be expected

as part of the experience, and also indicates how infertility is structured as an embarrassment, something to be ashamed of. However, all women reported back to me after the interview that they felt good that they had an opportunity to share their emotions in a safe environment, and it provided them catharsis, or allowed them an outlet to discuss emotions and situations for which they may have previously found no true sounding board.

None of my participants reported, nor did I perceive that any of them felt, any pressure to participate in the interviews (due to the manner in which I obtained my sample, many of the women I interviewed were often friends of friends). It seemed that their participation accomplished not only sharing their experience in an effort to help other women who are or will undergo a similar struggle, but served as a way to bring closure or resolution to their own experience.

Informed Consent and Confidentiality

Participants were informed before the interviews about what they would be asked to talk about. I openly communicated my research interest and intentions before interview meetings were arranged. Potential participants were informed that this research would be kept confidential and that if they wanted to terminate the interview at any time they could freely do so, or refuse to answer any particular question.

Pseudonyms are used to insure privacy and confidentiality of all participants. Identifying markers of any person mentioned have been altered or concealed in this report, and will on any publications that may emerge from this research. Materials containing subject interviews such as tapes and disks are locked in my office and will be

destroyed upon completion of the research. Under no circumstances will anyone have access to these materials.

FINDINGS

Introduction

When my husband and I started discussing that we were ready to start our family, with anticipation I started watching a TV show called “The Baby Story” on the The Learning Channel (TLC). This half-hour show highlights how the couple met, their pregnancy discovery, preparation for the birth, the birth, and then shows the couple and new child or children (if there was a multiple birth) a month or two later to illustrate how they have all settled into their new life together. I found myself drawn to these stories, looking for similarities between the couples shown and my husband and me. This show allowed me to day dream if you will, about what our “baby time” would be like, and made me look forward to this period in our life even more. This was at a time when we were trying to conceive, and it was several months into our attempts that we realized we needed to look for medical help. Subsequently, I found that I was not able to watch this show. It was depressing for me to know that the many stories on this program were ones I would never share. My own story was not included. As women confront infertility, they are suddenly thrust into a world of non-normative reproduction. They are unable to conceive in ways that are defined as “normal” and “natural.” Non-normative reproduction is constructed in two key ways for these women. First, the medical construction of infertility as the opposite of fertility (and consequently dysfunctional) shapes the ways that women are able to make sense of themselves and their bodies. The result is often disempowerment and a fragmented sense of self. In a second and related

experience, women facing infertility are confronted with an attack on the very core of their identity as women.

In the face of a medical-corporate infrastructure that serves to disempower them and an experience that necessarily assaults their sense of femininity (in a culture that defines womanhood largely through reproductive capabilities), these women search for ways to manage their experiences. When I was dealing with external definitions of myself as an infertile woman, I discovered “The Adoption Story,” on the Discovery Health Channel. “The Adoption Story” shares the same premise as the “The Baby Story,” but instead of showing the birthing process it shows an adoption, and the key difference is the exchange of the story of pregnancy discovery with the discovery of infertility. I found myself living for the first five minutes of the show where the couples would share their infertility experience (although not all couples shown were adopting due to infertility). I was searching for a shared experience, a new world that would take me away from the pregnancies that were occurring around me, and on TV to a community that would understand what I was going through, where I could learn how to manage this experience, a place I would feel at home.

What I found, after I first began thinking about this project in 2003, is that two distinct cultures – the fertile and non-fertile – do exist within our society. And when I discovered that I had fertility issues, I instantly felt that I was different from the majority of fertile women. My separation from the normative group was almost instant. I was about to undergo treatments that seemed very hush-hush, as I did not mind talking openly with friends and family about our situation, but it was clear that some people just did not

want to discuss infertility and the treatments to become pregnant. For example, at my in-laws Christmas party I began to openly discuss our fertility issues, when I heard my mother-in-law sigh a sigh of discomfort. I would soon come to discover that there was a vast sub-culture of infertility that I was now a part of and those that were not a part of this world either did not understand it or were embarrassed by it as in the case of my mother-in-law. I began to learn more about the people who made up this culture, this new spoken language (IVF, ICSI, Egg Donation), and those who are responsible for the constant development and re-development of this community – *the knowledge generators*. Women experiencing infertility manage the experience through understanding the production of knowledge within the infertility culture, and by seeking and producing knowledge of their own. In addition, how they manage non-normative reproduction through their attempts to become part of the fertile norm.

The study of the culture of infertility is key to understanding reproduction as it exists in our society today. In the sections that follow I break down this culture of infertility by showing 1) how women initially experience infertility and their entry into a non-fertile world, paying particular attention to the medicalized experiences of these women, any stigma they may feel, and how gender is negotiated, 2) how these women then work to manage the infertility experience by understanding who generates, communicates and privileges knowledge over other accounts in this sub-culture and their efforts to become part of the fertile norm.

Two key concepts examined in this project--culture and gender--need to be clearly defined. While both terms are very commonly used in both sociological circles

and in everyday conversation, they can each take on multiple meanings, and it is important to understand them in context. As used in context for this research, we refer to culture as a social construction, containing social, political, and cultural meanings, which serve to organize people according to socially, defined characteristic (Franklin 1995). More specifically, for this project, we refer to the organization of people to examine the culture of infertility.

Another social concept, gender, refers to the constructions of femininity and masculinity, although these do not necessarily coincide with physiological sex. Gender refers to the socially constructed differences between men and women, whereas sex points towards the anatomical and biological differences between male and female (Oakley 1972). As with culture, gender information about subjects was included when available through interview data.

Experiencing a Sub-Culture of Infertility

As a woman journeys through the infertility process (and experiences infertility), an infertility culture begins to emerge. Through personal research, medical appointments, and networking with other women, it becomes clear that there is a community available to help women through the infertility process with information and support; it is just much more difficult to locate than the community that is available to pregnant women. By examining this infertility sub-culture and the non-normative reproductive experiences that have created it we can then begin to break this world apart and work toward including infertility as part of the larger reproductive experience.

“Women and men strive for normalcy in their daily lives; infertility disrupts that sense of

normalcy. When conception does not occur as planned, I have found that women and men socially experience a feeling of difference from others. Feeling different provokes a reexamination of cultural assumptions about fertility, gender, and family” (Becker 2000:33). This “sense of difference” I argue creates a feeling of distinction and moves beyond “reexamining cultural assumptions” of the fertile world, but transforms those experiencing infertility into a non-fertile culture where one feels not only different from their fertile sisters, but now must constantly renegotiate between these two cultures.

Please consider the following examples from my interviews:

“I’ve noticed that infertility jokes really make people uncomfortable. I remember being at choir practice, and the director complaining that our performance sounded kind of barren. I chirped up, “that’s me!” and you could have heard crickets chirp” (Jan 7/10/04).¹

“I have had to tell my son’s teachers to be sensitive when talking about where babies come from. Only one way is discussed when talking about family planning in schools...the “birds and the bees” only” (Jan 7/10/04).

“And I would say that—and the support that I get, I still get the support every week on Tuesdays (from a Resolve Support Group she still attends), I go see these women that went through the same thing that I went through, from my support group, but they are the only ones that truly can understand what we all went through. You know, and some of them used an egg donor and some used egg donor from a family member, some used egg donors but they got pregnant with twins and there are mothers with twins all over the place. They are the ones that understand—and other people don’t really understand and I don’t ever try to push the point or—make it become a big point of discussion” (Lea 7/12/04).

Interview with Tessa:

S: Do you find that, you know, talking about the difference between letting go of, you know, what you’ve gone through...do you find that you relate to other women differently?

T: Oh, oh my God. You don’t want to be bitter, but you are. You can’t help it, its human nature. So this is interesting: “my sister”² got pregnant twice

¹ All names have been changed to preserve the anonymity of the informants.

² Changed names and added the phrase “my sister” to preserve the anonymity of the informants.

during our full process of trying to achieve pregnancy. And pretty much, in a second, I think with the first, I think she achieved it immediately. And we were actually (laughs), “This is so frustrating, were banging our heads up against the wall, going ‘Why aren’t we getting pregnant, why are we not getting pregnant?’” She achieved, actually, three pregnancies. (Tessa 10/09/04)

All three of these women point to the isolation that comes with the infertility experience. Through forces beyond their control, they are outsiders looking in at the fertile norm, who many times do not even know how to respond to or interact with infertile women when the subject is forced upon them. There is a social/felt stigma attached to infertility that can only be eliminated by a better understanding of the process itself (Greil 1991:101). This understanding must come from a closer examination of the stories of women who have gone through the process.

The Medical Construction of Infertility

Through both observations and interviews I found that infertility is shaped through a process that is both structured and organized. This structure is a part of the infertility culture. Infertility is socially constructed through our daily social interactions with the outside world, how we have come to interpret reproductive narratives involving technology, medical definitions of infertility, and language/meaningful symbols. “...The social construction of the family is seen as a political process that unfolds over time. It is political in that relations of power within society both shape reproductive practices and in turn are shaped by them” (Geenhalgh 1995:15). Examining how infertility affected the social construction of the family, and more specifically the effect that infertility has on women as they strive to create a family was my motivation to research this topic and

explore the narratives of women who have faced infertility—whether it ended in offspring or not.

To more closely examine that world of infertility, I chose to interview ten women who went through or were currently going through fertility treatments, and other options to bring children into their lives. I began each interview with each woman recounting her personal infertility experience. These interviews typically started with introductions and then quickly moved to the question, “When did you first start trying to get pregnant?” or “How long did you try to conceive?” What followed was typically an explanation of their entire fertility experience, and what developed was a narrative that was rich in detail and data. What I discovered was that it was important for these women to share what they have gone through—that it was important for them to be able to share where they started, what they endured, and the end result. In addition to discussing their experience they wanted to know what I had undergone. “I had found, in my previous interviewing experiences, that an attitude of refusing to answer questions or offer any kind of personal feedback was not helpful in terms of the traditional goal of promoting ‘rapport’ (Oakley 1981:49). Most of the one hour of interviews I conducted surrounded discussions on what we had gone through and the process we were forced (although by choice) to endure. Allowing the interviews to take place as if they were a conversation with an old friend allowed me to not only gain access to some very personal information, but also allowed for the narratives of the infertility process to unfold. Consider the following quote from my interview with Elle as an example:

S: When did you first start to try?

E: We started trying in September 2002.

- S: Ok.
 E: Um. And I did—well I did get pregnant in October.
 S: Ok.
 E: But then I miscarried. Right around Christmas.
 S: Oh. Ok.
 E: That was my first bout with at least a miscarriage.
 S: Wow.
 E: So, [laughter]
 S: Hmm. That makes it very hard. A couple months ____, too.
 E: Yeah. I think it was the end of October when we actually conceived. So, it was really a month and a half or so. But, I was about 7 weeks when I miscarried.
 S: That was in 2002?
 E: That was in 2002.
 S: Ok.
 E: Yeah. And then, do you want me to continue with the story? Or do you want to go through the outline?
 S: Yeah, no, go ahead.
 E: So then, yeah, let's see. So, that was a shock because I didn't know anybody who had gone through this or whatever. So, I never had expected it. I just thought, "Oh, we're gonna have a baby". You know. Exciting, great! But anyway, went through that, and then in 2003, we started trying again. And—I'm trying to think what month it was. In, I guess it must have somewhere in April I got pregnant again.
 S: Ok.
 E: And in May, on May 20th, I had a miscarriage at 9 weeks.
 S: Oh.
 E: I don't know, maybe I'm not thinking right, but I just know in May--it was 9 weeks and May was the time; anyway, I miscarried again. And that one was an even bigger shock because I had gone through the ultrasounds and things were going ok for a while. I started spotting and then I went in for another ultrasound and they didn't find a heartbeat, so we were like, Oh my gosh. Anyway.
 S: Oh.
 E: Yeah. It was—no fun, no fun. So they—anyhow, so, a second one, after the second one they said, Well why don't we do like an infertility workup on you. And they were gonna refer me to an infertility specialist. Yeah, that's a good idea (said that sarcastically), (Elle 8/5/04).

As you can see from this exchange, I worked very hard to build rapport with my subjects, and to allow them to take the conversation where they needed it to go, while at the same time ensuring that my overall objective and questions were addressed. We can also see from the example above that after the first miscarriage Elle felt confused and did

not know anyone else who had gone through a miscarriage. And she sarcastically said the doctor was willing to refer her for a fertility work up after she suffered through another miscarriage. Nessa, another woman I interviewed, had a similar experience, but she had to go through three miscarriages before she would be referred for genetic counseling. Please read the following exert from my interview with her:

N: In order to get genetic testing through the insurance, you need a doctor to approve it, and at that time, our doctors would not approve it. So, the motivation with my letter, stating the history—all the tests we'd had, his family history that I had done, um, my concerns, some of the research I had done—um, was primarily a motivation to get us through with genetic testing. Because what they said is, "You have to have at least three miscarriages before we'll approve genetic testing." I didn't buy it, I just thought, "We've had the two, and they were right in a row, you know, c'mon!" So, we got denied, to go through genetic testing. And it wasn't by my primary care, it was by his provider, and I called the PAM Clinic, and I told the nurse that she better clearly take a message that I was not somebody in a place that I wanted to be yanked around anymore. I said it was disgusting that this man would deny our referral, after all the work that I had done, my husband is going down there speaking with you personally, and speaking with him about something personal. So then, in thirty-six hours, we had a hand-written referral from my physician saying we could go and get genetic testing. So, (laughing) I'm not sure, you know, the woman at genetics even said, "It's really strict, we've never received a hand-written referral like this." And it was on, like note paper, that said, "You can have genetic testing." But I think they have these standards. I have no beef at all...

S: Who has these standards?

N: They have, you know, I think the clinic I went to and any other place, has these standards about, you know, they have to have so many miscarriages before they see all of the clients. But we'd also had an eight-page letter about my entire husband's genetics background, anyway, you know, in his family. So I felt like all the pieces were there, you know, and, and I don't think it was any fault on PAM Clinic, I think that it was those people were committed, you know, "It's two miscarriages—it's not enough And let me know, once you have had three," (Nessa 9/17/04).

Based on the above examples of when it is ok to refer someone after going through a miscarriage, the medical community creates "standards" to follow, thus an infertility criterion is established. The infertility experience is then mediated by this medical

structure or process. Medical definitions certainly structure and define the experience of infertility as well as others. Women are forced to work within a structured process to try and maintain control of their reproductive experience, often negotiating within the system to get what they need. “In Western medical discourse, ‘infertility’ is usually defined as the inability to achieve pregnancy after a year (or two) of trying to conceive a child through regular sexual intercourse” (Van Balen & Inhorn 2002:12). It seems as if at the very onset of difficulties becoming pregnant, the medical community is already dictating the time frame for determining whether help is needed and further testing should be done, disregarding the intuitive feelings of the patient, resulting in their disempowerment.

Consider the following examples to both the medical and insurance communities determining and imposing a process that the patient might not necessarily want to follow:

“...I went to an OB/GYN, a regular OB/GYN, she said she doesn’t want to see me until after trying for a year. Um, I feel like I wasted time...” (Nessa 9/17/04).

My interview with Deanne showed that she had a very similar experience:

S: How long did you try before you started to question something was wrong, so like, two years or a year.

D: Yeah, like maybe a year, like because our my gynecologist had already said so try for a year, because I said we were ready to start trying, to try for a year and if there are any issues, then we’d revisit.

S: Ok.

D: So once we had the ectopic (pregnancy) then we knew Ok, there was a problem, and he was, that doctor, once I went to him to go Clomid, he was already an infertility specialist, but he didn’t do IVF, but it turns out he actually wasn’t that great and I um-- Like this was not my regular, like I switched to him because I know. Oh. He’s an infertility guy and he’s good.

S: Ok.

D: And it turns out he wasn’t that good, because I was so ignorant about infertility and the drugs and what the processes were, it wasn’t until I went to my doctor in San Ramon that I said that guy was really bad, like he had us do Clomid and he saw that there were a lot of eggs there and he said let me just call my other friend doctor and maybe we can do IVF you know, and we can

just harvest them and just do it. Then I realized this was like the stupidest thing I've ever heard.

S: Hmmm.

D: Yeah, let's just switch, well, in the middle of the cycle too, a doctor who I had no relationship with, had no control of my cycle, who, you know, (Diane 8/12/04).

Not only do medical professionals impose their process, but insurance companies play a large role as well, by approving or denying certain procedures and tests, and mandating who can receive benefits:

D: I work for...and they for some reason really and I know several people in my company, who have gone through (IVF), like I was the first person I am aware of that did it, and then now I have like 3 other people who have gone through it, one gal has twins.

S: Wow and now they no longer cover it?

D: I don't, well, Cigna itself, only the rider says you get 3 tries and if you have a live birth, say like if you do it the first time and you get a live birth, then you are done, you don't get another try.

S: Oh, wow, Ok.

D: Yeah, so that was really--

S: Yeah, that's very cool.

D: Very, very cool. So that's why now, it's like Ok, I want to do it again, but

S: Yeah, where you go, yeah, I mean

D: Bite the bullet, (Diane 8/12/04).

The quotes taken from both my interviews with Nessa and Deanne demonstrate how both the medical and insurance communities have the ability to shape and structure the infertility experience, by determining when women may begin to seek treatment and testing, and by narrowing the treatment options. The medical community imposes a process by establishing a predetermined time period, after which they will approve further testing. Insurance companies impose a structure around the infertility experience by defining when, how much, and what tests they will cover for infertility. This structure frames each individual woman's experience, depending on what doctor she is going to,

medical insurance coverage, and personal finances – if medical insurance does not cover infertility. The inflexible infertility experience leads many women to feel out of control.

Technology and Control

A lack of control within the infertility process was often echoed throughout my interviews. This was often seen in the need to “take breaks” after failed procedures (due physical and emotion stresses), pointing again to the overwhelming nature of this imposed structure. Then again I found instances where this structure is appreciated, given that it forces control into a situation that seems in complete lack of it. Through each examination and lab test to uncover what could possibly be wrong with their bodies, a loss of control can be felt, a loss that seems to magnify itself with each new step in the process. This structure helps breaks down this experience into a process that is more manageable, and makes it easier as seen in the following interview with Tessa:

“He’d always pull out a piece of paper, and he’d always review everything. And so we sat down with him, and he said, “So, we said we were going to start here, and that we would do this, and this”...So we were at the point where it was, OK, we have either IUI, or we have *in vitro*. He said, “Typically, we start with IUI, and then we would go to *in vitro*. The only reason that we wouldn’t do IUI is if you had blocked tubes” (Tessa 10/09/2004).

Loss of control during the infertility process can leave women feeling as if they are bystanders in their reproductive experience. Therefore it is important for infertility patients to gain the control back through empowerment building activities. The women I interviewed discussed the ways in which they gained this control back, through letter writing to their doctors, networking with other women, and taking breaks from the process. Recognizing the structure created around infertility is important. This structure

has provided people who are experiencing infertility the support needed to face this difficult issue, but at the same time can make them feel overwhelmed when the structure imposed is not organized or not necessarily what they feel they must follow. “I was feeling very much like (pause), uh, you know, like a bottle floating in the ocean. I, I just didn’t know which direction we were going to be pulled, and, um, I had—we had so many doctors we were trying to work with...”, (Interview with Nessa on 09/17/04). This structure can be seen as both empowering and disempowering for people, and recognizing this to create a balance between the patient’s needs and the medical structure that surrounds it will give a better sense of control over a situation that does not have any.

All of the women interviewed for this paper, myself included, have had a feeling of initially being alone in this infertility process, when the simple fact is that there are other women who have gone through this and they can offer their experiences and in turn offer support to the new members of the sub-culture, who will help to further shape the sub-culture with their experience. While the infertility process differs for each woman based on her individual medical situation(s), there is a wealth of information that can be provided at the beginning of the process to ease concerns and clarify expectations that would help all women and couples. What is lacking is a wide distribution of this literature, and direction from the medical community to the resources that women need to understand the infertility experience, medically and emotionally.

The Power of Language and Meaningful Symbols

The infertility process can become overwhelming when the medical and insurance communities are heavily involved in forcing the process one way or another. Franklin

utilizes the term “achieved pregnancy” to explain the idea of a structured fertility experience that involves many people: “In the context of assisted reproduction, successful conception and procreation have become achievements, realized through teamwork and the helping hand of technology” (Franklin 1998:336). The intimate act of lovemaking is replaced by a team of scientists, all of whom get a piece of the credit should a pregnancy be achieved. The terminology that is unique to the culture of infertility also gives power to those who possess the words, and have the power to shape the experience for those who are in new and unfamiliar waters. The ability to use and speak this new language generates power by giving those who speak it the ability to frame their experiences. When reviewing my interview transcripts, I found were that these women were not only sharing a personal narrative, but a language unique to this sub-culture centered on technology, as evidenced in the following interview with Tessa:

S: Like ovum donation?

T: Well, there was one, they had we ended up doing called assisted hatching...

S: Oh, OK.

T: I don't know if you had heard of it, but it's kind of like, it's almost like they put like an acid, they spray an acid on the egg—actually they did it on the embryo, after it's been fertilized. They kind of strip down the outer edge so then it allows it to attach to the uterine wall better.

S: I've heard of it, like embryo glue, but I don't know if it's the same thing.

T: I don't know. But I think your body naturally does it, so it can attach to the uterine wall, but, um (pause), because the first time I didn't achieve the pregnancy there was, “You know, let's try assisted hatching, let's try, let's do something a little bit differently to see if it might work. And we don't know if that's what caused it, but that's when both embryos attached. So, but, he was doing this whole presentation showing this on his laptop.

S: Wow.

T: So it was really neat, because he was trying to (pause) cater to the couple we were. Like he knew we were both in high tech, and um, yeah I can tell, you know, he really wanted to get to know you, and make this a process that was easier for you to understand and just...

S: Wow. That's neat, (Tessa 10/09/04).

Deanne also made use of the medical jargon familiar to those who have undergone fertility treatments:

- D: That's kind of like my gut, like when I go see Dr. E at Kaiser, I want to hear what she has to say but I pretty much already decided that unless she's got something really compelling, I am not going to go under and have her do some procedure to look at this further, I don't know what she is going to suggest.
- S: Yeah
- D: She's suggesting, she said, we should do some more procedures before we jump to IVF.
- S: Yeah, procedures or test are right just to figure out, I have heard that if your tube is blocked and there is fluid in there that that does lower the success of IVF.
- D: Yeah
- S: But umm, I forget what it is called, hydrohypoex or something like that, where that you know, just in my own research, but then...
- D: That is interesting to know, cuz that's the thing I was like well we are going to have to go find out about this, what's she's talking about, (Deanne 8/12/2004).

Both Becker and Franklin discuss how the use of language is key to explaining and understanding narratives surrounding infertility. However, Becker adds that not only the narrative and language used are of value, but also the interpretation of these stories by these women must be examined. The narrative and the language used to describe an infertility experience alone do not present the entire picture. The interpretation and understanding of these narratives gives one the ability to control and navigate one's way through this experience.

The infertility process is constructed and heavily dictated by the medical community. Because the medical community holds the knowledge necessary to proceed, the privileged terminologies and abbreviations (IUI, IVF) that are intrinsic to the process become barriers to a woman's ability to have some control over the experience. The same lack of knowledge that can create the feeling of isolation for women facing infertility can also impede her ability to take some control back, and make informed

choices as to how she would like her treatment to proceed. Finding narratives that closely resemble one's experience are key to removing this feeling of isolation. Not only can narratives help women identify with others, and reduce the stigma attached with the process, but it can also help them make choices they may not have known were available to them, simply by having access to knowledge sources in a process in which the medical profession has such a stranglehold on information and it is for sale.

*Driving Forces in Consumer Culture*³

Technology itself is driven by consumer demand, and reproductive technology is born out of the need and desire to achieve pregnancy. "Technologies derive from and are created by cultural priorities. Parenthood is one such priority. It is easy to see why new reproductive technologies have caught on so quickly: they hold the potential to allow people to reproduce themselves by having a child" (Becker 2000:11). From my own experience, the cost of *in vitro* fertilization was a very large factor in determining whether or not we would do the procedure. At the time, early 2004, the total cost of the procedures involved, and the medications totaled more than \$18,000, none of which was covered by insurance. How these technologies are utilized and who has access to these new reproductive technologies points again to normative and non-normative discussions of infertility, and who and what is socially privileged. Employed by Rapp and Ginsburg, the term "stratified reproduction," (developed by Shellee Colen) a true class system exists within the world of the infertile couple, where financial means determines access to

³ This heading was taken from the book by Gay Becker. 2000: *The Elusive Embryo: How Women and Men Approach New Reproductive Technologies*. Pp. 10-13, University of California Press. Berkeley and Los Angeles, California

available technologies. “Infertility, and especially the infections that lead to tubal closure, are particular problem for black women and women on low incomes in Britain and the United States, but these are precisely the women who have the least access to new conceptive technologies like *in vitro* fertilization” (Stanworth 1987:14). From my interviews, this point became very clear:

“Cuz I mean, when we came home from our wedding night, one of Jerry’s aunts had left us all kinds of baby toys on the table. Because everybody knew that we wanted a family right away, that was important to us. So, I mean, to have to go through the *whole process*, I’m glad it’s out there (referring to IVF). I wish it was more attainable and that you didn’t have to make a decision based on if you can afford it,” (Samantha 7/16/2004).

For a majority of those I interviewed (nine out of ten), access to the procedures that can help them achieve pregnancy is determined by their ability to fund the procedure, and many find that the combination of the risk of failure combined with the cost of the procedure is a fundamental issue in deciding to proceed or continue treatment. This point is made clear in my interview with Samantha, who relied on her extended family to help pay for her *in vitro* procedure, only to have her pregnancy with triplets fail in the 21st week. She then went through the process again, only to have it fail once more. Left with two remaining embryos, the financial burden became too much:

S: You still have the 2 embryos, Ok.

Samantha: But um, we actually are due to pay for the storage fee this month and we’re not going to do it. It’s because like now, when are we gonna have basically \$5,000 minimum (to do another IVF cycle). \$5,000 is flushed down the drain.

S: How much is the storage fee?

Samantha: It’s like \$200, \$250 or it was, I don’t know. I haven’t gotten the bill yet. But \$5,000 for an embryo transplant, a minimum of \$5,000. And it’s like, do I really want to go through all of those shots and now they know I have to be on bed rest and we don’t even know if I can carry a baby full term, (Samantha 7/16/2004).

Elle also spoke to the high price of the infertility procedures:

E: Yeah, yeah, my husband has a – I'm with Kaiser under my insurance and my husband has a PPO. So, it allows me to go see this other doctor. There's a, you know, co-payment when you go in and then—any of the specialized tests like the immune tests, those are not covered at all. And neither is the IVIG treatments—those are very – pretty pricey.

S: And the IUI's--are they covered?

E: No, none of that's covered actually. No. So, yeah, as with anybody going through infertility or fertility, trying to improve their fertility, it's a pricey thing, (Elle 8/07/2004).

Unfortunately, finances play a dominant role in both the decision to pursue infertility treatments, and the decision to continue when previous treatments have failed. In many cases, the reality of assisted reproduction comes down not to, “Are you willing to endure the strain?” but, “Can you find the cash?” “Consumer culture revolves around specific objects of consumption that are meaningful because they reproduce social identities. For Laura, IVF held out the hope of motherhood, an identity for which she longed” (Becker 2000:130).

Parenthood is for sale, and this theme was echoed in several of my interviews. The better your financial resources, the better the treatment you can find, and the longer you can continue to pursue additional or alternative treatments should the initial ones fail. Viewing medical practice as a business had significant consequences for interactions between patients and physicians. People became mistrustful of physicians and were angered by what they viewed as the “salesmanship” of IVF and its underlying profit motive. Lea and Deanne spoke of this in their interviews:

“I'm getting older and at least 39-1/2 by then. So, um. Then what happened next? Then we start shopping around for different IVF clinics and we hear about Dr. Z. Dr. Z the circus man. Just from marketing himself. So, he's acting like this one man marketing team and he'll put a baby in anybody's arms, you know,

he'll make it work for you. So we go through him and we start all the tests," (Lea 7/12/2004).

"For me when I was looking, when I finally got serious about it, I looked at statistics, and like I have friends who went through the effort and (this hospitals) statistics were less than Dr. W and the RS Center, but I understand now that they will work with anybody and so they aren't taking just the cream of the crop where Dr. W and his team is like OK, I am going to be honest with you, you don't have a shot or you do have a shot, and your chances are, so they try to keep their stats higher, right, by weeding out people who have less of a chance of becoming pregnant," (Deanne 8/12/2004).

So we can see in these interviews that sometimes, not even finances are enough to ensure you get a shot at being treated by the top infertility professionals. While some can say that these doctors are protecting patients who they know have a very slim chance from having to endure difficult procedures that have very little chance of working, they are also protecting their own results by excluding patients who have a very small chance of succeeding using *in vitro* fertilization, improving the statistical results that are key in attracting new clients.

By examining the narratives of "people's experiences with new reproductive technologies (it) can tell us much about how the consumption of technology evolves as a cultural process: that is, how it emanates from social forces. This process is occurring at a time when technological advances are appearing in quick succession, when cultural meanings are in flux, when gender is in a state of continuous negotiation, and when technology itself can be seen as culture" (Becker 2000:11). As medical technology continues to advance exponentially, it is having an increasing effect on the society that requires its use. It is medical technologies that originally threw into flux the black and white separation of the fertile and the barren, and with every advance in reproductive medicine, each of these extremes becomes grayer.

However, there is still an element of shame that is attached to those who undergo fertility treatments. For example, when explaining this project to someone I worked with it felt like we automatically went into the debate of whether or not medical insurance should not have to pay for infertility costs, he said that he felt that it was not a medical issue, echoing the sentiment that this issue is not the norm and should not be covered. “For example, the United States, a highly organized political lobby on behalf of the American Society for Reproductive Medicine is pushing for insurance coverage for infertility procedures, and for reclassification of the now mundane procedures such as IVF from “elective” to non-elective (involuntary childlessness is being made into a medical problem, so that its treatment is therapeutic, rather than voluntary/cosmetic) (Cussins 1998:73). Whether real or perceived, this shame plays an important role in defining the infertility experience, and continues to serve as one of the key barriers between the world of the fertile and the world of the infertile.

The Stigmatized Culture

Shame is a cultural phenomenon, not simply a psychological one. In the United States people are shamed by others when they do not fit into societal ideologies” (Becker 2000:45). When a woman finds herself outside of the “normative human reproduction” group, the predominant culture, there is a sense of isolation from the mainstream culture of “high” or normal fertility (achieving pregnancy without difficulty). This feeling of separation or of not feeling “normal” was identified often in my interviews. As exemplified by Ally, a white 30 year old woman:

“Peer pressure – it’s “the norm”. That’s why when I left the doctor’s office I was so disappointed that I’m not the norm. You know, I’m not the twenty-eight day cycle everybody talks about... I mean, I know medical science says certain things are normal, but if twenty-eight day cycles are rare, then why do they, then why do they harp so much on twenty-eight day cycles? Why do they teach it in schools?” (Ally 10/10/04).

While there is a very real social stigma attached with undergoing fertility treatments (or with simply having difficulty becoming pregnant), women may also attach stigma to themselves, branding themselves as different. A woman may attach this stigma as she learns that she has fertility issues, creating a *felt stigma*, as defined in the following quote:

“Scambler (1984) has made a distinction between *enacted stigma* – stigma that stems from intentional discrimination... and *felt stigma* – the shame felt by the stigmatized because of their internalization of societal evaluation of their condition and the resultant sense that they have failed to live up to the standards of “normality”...It would seem that for these infertile women, felt stigma was the source of more anguish...a “secret stigma” hidden from outsiders, but nevertheless deeply felt,” (Greil 1991:101).

The women I interviewed address “felt stigma” in a variety of ways. One of the ways most commonly identified in my research is through sense-making activities. They serve to empower these women to take control of their infertility experience, while others seem to reinforce the shame or “felt stigma” associated with infertility. Consider the following excerpt from one of my interviews with Ally:

“Even though I am at the beginning stages, I am not even at the next couple of stages, but initially when I left the doctors office, even though she seemed like a very nice person, doctor, I was very disappointed and kind of doubted myself I guess. I kind of left there thinking what was wrong with me” (Ally, 10/10/04).

By internalizing the inability to conceive naturally, and feeling that something is wrong with them, women place a felt stigma upon themselves. A woman breaks down this

stigma and begins to understand her experience better through sense-making activities, as demonstrated by the following quote from Ally:

“But when you really think about the little things that can occur or not occur that can keep you from getting pregnant, you go, “Wow! OK, so maybe I’m not so strange,” (Ally, 10/10/04).

As found in several of my interviews, sense-making is a normal process that is a part of the infertility experience, in which women will try to reason the cause of their fertility issues. They are basically looking to explain or justify the problem to themselves. Sense-making helps to define the experience and alleviate some of the “felt stigma”. When one stigmatizes oneself as not feeling normal, or not feeling like a woman, in actuality, she is trying to make sense of the betrayal she is feeling by her own body. I have categorized these sense making activities to help facilitate a better level of understanding of this process into the following categories: Religious Explanation (God), Punishment, Body Betrayal, and Scientific Explanation. Thoughts such as, “God, what did I do? You know, you know. Why are you punishing me?” (Tessa 10/09/04), “if it’s not meant to be, it’s not meant to be” (Nessa 09/17/04), “Oh, my whole life is work. I’m traveling all the time—it must have been the reason I wasn’t getting pregnant” (Ally 10/10/04), were found throughout my interviews. At the heart of the infertility experience is a battle that each woman forges to maintain her own sense of gender identity in the face of a society that equates the ability to reproduce with feminine identity. The knowledge base for couples dealing with infertility needs to begin with the idea that there may be something medically going on that is causing difficulties, and that it is a scientific issue having no reflection on the morality of the individual.

Gender and Normalcy

These non-normative experiences actively involve and call into question *gender relations*. “The portrayal of bodily experience--the connection between how people talk about their bodies and how they experience them--is so closely linked to people’s perceptions of societal expectations for parenthood. It is therefore possible to see links between the personal body, the body of experience, and cultural dialogues about normalcy” (Becker 2000:28). It is through these gender dynamics that we began to see how and why this non-normative reproductive culture exists.

Gender plays a key role in understanding the dynamics of the infertility culture. Gender is particularly relevant to a discussion of infertility, because of its organization around women’s bodies. Traditional gender roles and power relationships are both reflected in the infertility culture and constructed anew by it. This can be seen in the gendered division of labor used to manage the infertility experience and in the ways that men are somewhat able to opt out of certain aspects of this experience. The culture of infertility also calls into question the social constructions of masculinity and femininity. Infertility challenges each partner’s gender identity, throwing our very sense of self into question.

“The body is a bearer of multiple cultural meanings about gender, and these meanings are enacted, or performed, as people go through their daily lives. Judith Butler differentiates between gender *expression* and gender *enactment* because expression conveys that there is something natural, or essential, about gender, while gender enactment stresses its social and cultural aspects. When culturally derived bodily knowledge is disordered by infertility, women’s and men’s understanding of themselves and their world are thrown into chaos, affirming Judith Butler’s contention that “performing one’s gender wrong initiates a set of punishments both obvious and direct” (Becker 2000:28).

Gendered work helps shape this infertility culture. It gives individuals a framework, which then shapes the choices they make and the ways in which they approach this issue.

The following are examples of this division of labor:

“I have to say at this point, probably all of the appointments I had, my husband never came to one except the Endocrinology one. Because the Endocrinologist needed to assess his sperm, um, and so, that was, that was something he did. ...Um, so we took the injection clinic. But up until then, all of the testing I’d had—all of the doctors, all of the testing, all of the research I had done—it was up to me. And for most of the women, I would guess that would be the thing. (Pause.) Um, I’m not sure if it’s that men are kind of—I was fearful that my husband was not understanding,” (Ally 10/10/04).

“You couldn’t give it to yourself (the injection), it’s just physically (impossible), even if you could get the needle there yourself, trying to get it in...my husband would have to just push, and push, and push. And, it’s hard, because you don’t want it to go in too fast, because that’s going to put more pressure, right? ‘Cause you can just tell, right, that it’s not mixing in well with your system. Um, and sometimes, it just felt like, you hit a nerve. So it was like the one that was probably the hardest on him because he knew how much I hated it,” (Tessa 10/09/04).

As in the case of Ally, she felt personally responsible for managing the process, upset that her husband was not sharing the infertility experience along with her. In my interview with Tessa, a division of labor can clearly be seen in the giving and receiving of the injections. Here we see that although she is the one receiving the injections, she minimizes her own role by saying it is more difficult for her husband, and focuses on the fact that he does not enjoy being the one to deliver the pain that comes with the injection. Because the experience of infertility is constructed around and on women’s bodies, men have the agency to choose their level of participation. It appears that they have the ability to opt out when women do not have that opportunity, as was the case for Nessa and Ally:

“...What I noticed is most of the lobbies had men with their wives... and I was generally the only woman in the lobby who didn’t have a husband with her. But, I also didn’t feel it was necessary to yank him out of work to do it. My

frustration was that my husband wasn't doing the research that I was doing" (Nessa 09/17/04).

"...He helps looking at the charts, and things like that, and actually I showed him a couple of, um, paragraphs in the book. "Hey, you need to read this!" You know, I would circle it for him, or give it to him, and say, "Hey, read this." Um, so he's there, he's learning with me, just not (pause), not, "Hey, give me that book. I want to read it!" You know? He's not a hundred percent gung-ho, even though he wants children, and we've agreed, "Yep, we want to have children." I think it's just, I don't know if you could call it male ego maybe, or not? "Well, if it happens, it happens..." (Ally 10/10/04).

In these passages we see that the women feel responsible for doing the preliminary infertility research to both situate and understand their experience. Men on the other hand are "just along for the ride" until they are asked or their physical bodies were needed. Rather than having both parties go in for testing from the start, in almost all cases, the woman begins her testing long before the man is asked to go in for testing.

By taking a closer look at the division of labor and the roles that both men and women assume in this process one can see both masculine and feminine roles more closely, and further examine the ways in which this infertility experience conflicts with traditional constructions of gender. The biggest issue that seems to come forward during the infertility process is the threat that infertility itself poses to a woman's femininity and a man's masculinity. Consider the following examples that demonstrate how the infertility process can highlight the difference between both femininity and masculinity in the eyes of each partner. First, I will show several interviews that highlight a more feminine role or view of infertility:

"I mean, it's very primitive thought, but you know that, it's kind of one of the basic things that we're here to do, right? To carry a child. Now, some choose not to, and some do, but, and some don't have a choice. But I had never, I had never, I don't think you ever think about that" (Tessa 11/09/04).

“I just think sometimes men won’t deal with things until they’re absolutely—we’re faced with our biological clock and age. You know, men just aren’t, you know, not as much as we are” (Ally 10/10/04).

And second, these interviews highlight a more masculine role in the process:

“So that was the big joke. Um, but we didn’t see, I don’t think there was ever any big issues, because, whatever, his count was like “ten times that of the average man”. So I had to hear that for I don’t know how long...”Ten Times!”, “OK, whatever...” (Tessa 10/09/04).

“Dan’s been going through Dr. C for all his results, and he has a general Urologist. And when both of his results came back, he was like, “I’m shocked!” Which didn’t make him feel very good” (Tessa 10/09/04).

Infertility creates a conflict between the sexes and calls into question our ability to fit into mainstream ideals of what masculinity and femininity are. There is a disjuncture on the way we have come to define masculinity and femininity, and the infertility experience calls into question the ways in which we look at gender. Infertility actually confuses the notions of femininity and masculinity, attacking the core difference between the sexes: man gets woman pregnant, woman carries child.

The infertility process disrupts the affected individual’s sense of normalcy.

Almost instantly, the person finds themselves in a category separate and distinct from the rest of the population. There is a social stigma attached to a diagnosis of infertility that is compounded by any felt stigma that woman attaches to herself (by viewing herself as different from the fertile norm). Because infertility attacks gender identity itself, it truly attacks the core of how we understand ourselves as women or men. But through shared experiences, and identifying with others who have gone or are going through the process, this stigma can be greatly reduced, and the damage caused by this self-questioning can be minimized.

Managing Infertility

Gender issues that arise during infertility treatments can cause women to work to find moments of agency in a disempowering experience. The search for and the production of knowledge became one such way that women sought power in these situations. However, it should be noted that knowledge is the empowering tool, while at the same time functioning as a mechanism of control. Finally, I will look at the ways women attempt to re-locate themselves within the fertile norm.

Fertility Knowledge Experts

It is important to examine who generates, communicates, and privileges knowledge over other accounts in this culture. Whoever has the ability to define and communicate the infertility experience has the power to construct this culture. I found in my own personal experience that the act of conception, typically an intimate moment shared by the couple, becomes a public event with doctors, labs, nurses, and others all playing a role in my child's conception. In a televised documentary, "18 Ways to Make a Baby," James Grifo echoes the same idea:

There's, like, 18 different ways to make a baby now, because of the technologies. And, you know, that makes us have to rethink, "What is a family?" Well, the fact is, what it means to be a family is to have a parent or two parents raise a child, and care for the child, and have an attachment to that child that nobody else has, and a responsibility to that child that no one else has. And that's really what matters (Holt and Williams 2001:11).

Many pieces of infertility knowledge co-mingle, leaving me to make sense of it all. "In the context of assisted reproduction, successful conception and procreation have become achievements, realized through teamwork and the helping hand of technology" (Franklin

1995:327). This experience generates the questions: what types of knowledge count, who are the knowledge generators, and who has the ability to construct this “culture of infertility”?

I found throughout my observations and interviews several types of knowledge, produced by different experts. I have identified what I feel are the three most significant types: 1. The Medical Experts, including doctors, geneticists, reproductive endocrinologists, and any other persons from the medical profession who offer up technical knowledge, 2. The Professional Experts, this is made up of those who are serving as a counselors, adoption advocates, and/or social workers who offer therapeutic knowledge and professional advice, and finally 3. The Experiential Expert, or those that are or have gone through the infertility process, offering up their stories or experience as knowledge.

The Medical and Professional Experts – Technical Knowledge

When going through the infertility process certain types of knowledge can sometimes be, and most often is privileged over others at the expense of the individual undergoing treatment. Rapp and Ginsberg point to this idea in the following quote:

“Indeed, to focus too finely on the technology itself is to miss what anthropologists discover in their research more generally: the control and distribution of knowledge and practices concerning reproduction are contested in every society. For example, in some societies, older women are gatekeepers for knowledge surrounding fertility and childbirth; only after initiation can young women have access to such information and participate in reproductive support (Bell 1983, Llewelyn-Davies 1979, MacCormack 1980). ...When we analyze how knowledge of reproduction is distributed and controlled, both large-scale and local forces are always at play. At the local level, healers, for instance, whether physicians or other kinds of cultural specialists, play critical roles in the experience of reproduction in daily life” (Rapp and Ginsberg 1995:5).

Rapp and Ginsberg discuss how in diverse societies various types of knowledge specialties are highlighted and distributed with regards to reproduction. However, when under going infertility, frequent visits to physicians (IVF doctors, infertility specialists, etc.) are almost inevitable, thus these doctors play a “critical role” in defining these individual’s experiences and help re-shape their bodily knowledge. “People undergoing this experience sometimes find themselves subsuming their own bodily knowledge to that of medical knowledge or trying to balance the two” (Becker 2000:49). Consequently, medical treatment throws into question the bodily knowledge of women, as seen in the following example in my interview Ally:

- A: And I think, too, is that the knowledge of females about this, too, is very low. You talk to people—I mean, some of my family members, that do know— ‘cause I haven’t told the whole family yet, you know, that we’re trying. And they’re like, “Oh, you know, the tricks that you have to do, you know, in order to get pregnant, you have, you know, positions, you know the pillow trick, you know, you know that.” I’m thinking, “How do you know what’s true and what’s now?” I read that book, but how do I know that the book’s true, you know, you can’t believe everything you read, either. So, I’m sure you have a lot of good explanations for stuff, but, you know, sometimes it’s joking and stuff, when they say, “Oh, you have to try different things!” And you know, they’re all kind of teasing you—picking on you, but, you also hear that from other people.
- S: You also just have to ask, you know, just ask, and ask your doctor, and if you don’t know something, just ask, and have him explain that, talking with different people that are going through it, um, that helps...
- A: It’s amazing to me, um, how much females really, really don’t know about their own bodies! I had no idea, I mean, with some of this stuff, for awhile I believed whatever anybody told me (Ally 10/10/04).

This interview with Ally demonstrates the lack of knowledge women really have about their own bodies, and this became evident for Ally once she really had to get to know her own body, after she was diagnosed with infertility. Ally’s lack of awareness regarding her own body, affirms the gendered division of knowledge. “Thus the triumph of the male medical profession is of crucial significance for our story: it involved the

destruction of women's networks of mutual help –leaving women in a position of isolation and dependency –and it established a model of expertism as the prerogative of a social elite” (Ehrenreich and English 2005:38).

When initially diagnosed, women find themselves in uncharted waters, and must learn to instantly navigate their way through the infertility process. Due to this “newness” women must look to medical professionals for a road map. Thus, medical terminology quickly becomes the vehicle through which these women understand and describe their experience, rather than looking within themselves for the answers as well. Rapp (1995) points to this idea, that language used by women to explain their own bodies derive in fact from medical technology used by medical experts rather than their own terminology to explain their own bodies. Rapp argues that when medical science is taken as the authority in matters of reproduction, women's bodies are no longer the sites of experiential knowledge. I found this to be the case as well, that a woman who goes through the infertility process is heavily influenced by the use of medical terminology, “the language of infertility.” Those undergoing infertility treatments quickly adopt terms like IUI and IVF into conversation.

However, in addition to women utilizing these new terms I found that they not only adopted this new language as their own to describe their own body, but also utilized these terms to communicate their experience. Complex medical terminology and procedures were bantered back and forth between the participants and me to describe our own experiences, and it was almost a game of who knew more, as seen in this excerpt from my interview with Deanne:

- D: She's (*Dr. E at Kaiser*) suggesting, she said, we should do some more procedures before we jump to IVF.
- S: Yeah, procedures or test are right just to figure out, I have heard that if your tube is blocked and there is fluid in there that that does lower the success of IVF.
- D: Yeah
- S: But umm, I forget what it is called, hydrohypothenix or something like that, where that you know, just in my own research, but then...
- D: That is interesting to know, cuz that's the thing I was like well we are going to have to go find out about this, what's she's talking about. (Deanne, 08/12/04)

These medical terms were not only used to describe their own body, they became a part of their personal narrative, which they used to describe their current life experience.

"One of the abiding frustrations of those seeking social change is the resilience of certain dialogs within society that maintain cultural ideologies and thereby impose a limited view on life possibilities" (Becker 2000:25). The utilization of these medical terms continues to reinforce medical expertise, thus re-inscribing medical power relations.

Given the medical experts ability to shape a women's reproductive experience through language and knowledge, one of the ways I found that women were able to regain some control in defining and explaining their infertility experience was by becoming an active participant in the process. I found that eight of the ten women I interviewed sought out multiple doctors and opinions on recommended courses of treatments by simply just going to another OBGYN that they felt listened to them better or who they felt provided a better service. As Lazarus discussed, women can become passive participants in their own pregnancies, allowing the medical experts to dictate the experience for them. But by seeking multiple medical opinions, women are accessing differing knowledge sources, and gaining power in their experience by not allowing one single doctor to dictate their experience, as was the case with Carrie:

- C: ...Dr. C, who I was using, he wasn't very—he said he was an infertility specialist but really didn't know much about it.
- S: Dr. C wasn't really doing anything
- C: Yeah, so he was with (named specific medical group) and supposedly specialized in infertility. Well, not really! So, then I moved to Oregon.
- S: What process did he walk you through?
- C: Just the removal of the endometriosis.
- S: So he did that surgery?
- C: He would tell me to relax
- S: Um huh.
- C: He did that surgery.
- S: So he'd tell you to relax.
- C: Yeah. And I was having a bunch of problems with my hormones; they were all out of whack. I was having hives. I had hives like for the first two years of my marriage. So something hormonally was going on with me and nobody could figure it out. I went to allergy specialists, I went to everything, but I never went to an endocrinologist.
- S: Hmmm.
- C: So when I moved to Portland in '93, I went to an infertility doctor/endocrinologist.
- S: Ok.
- C: Dr. M, I think was his name. And he found out that I had hormonal levels that were all off. Like I had a high hyperprolactant, which is the hormone you need to nurse. I had a hyperprolactant level (that was high) and I was going through an adult issue with acne. And so I couldn't figure all this stuff out. Well he ended up putting me on this stuff called Alvactone for the acne and Parladel for this other thing. So he kind of regulated me. So when I moved to Oregon I had no more hives. I was so happy. And so, he put me on Clomid. Even though I was consistently every 28 days, Clomid is for women that don't have regular periods. Why he put me on that, I never knew why. And he was, I was like "what are you doing" and I remember feeling like a psycho on Clomid. I went to Puerto Rico with my family, my whole family—my parents and my brothers and sisters, my husband. And I remember feeling so crazy, I felt like I could kill everybody and get away with it. [laughter] Because they were driving me crazy. But the Clomid I didn't like. I was on it for like, I think I was on it for a few months and I was like this is not working; I don't need this. This is not working for me. And it wasn't working for me. It wasn't helping me produce any more eggs, it wasn't helping my follicles get bigger.
- S: Did you do ultrasound –
- C: Yeah, they did ultrasound but then that's as far as it went. Nothing was working and I felt really led astray, besides the hives being gone, I felt like "oh, this isn't working" so somebody referred me to a really good doctor, Dr. S in Oregon and he was fabulous. He had a very, he had a pretty big practice but it was, he was intimate in his nature. He was so much better than any doctor I ever had here in California.
- S: What was the difference between him and the process he put you through and how he worked with you versus what Dr. C and the other doctor did?

C: He was so much more thorough about my overall body. He took my blood. He took all my blood work, like thoroughly. He did more, like he even got through the levels of things that people didn't see, like for example, your ovulation. I mean, he, this other guy was just telling me to watch the days and yeah, ok, take the medicine and let's see what happens. But they weren't as aggressive as far as all the different tests that they were doing. Then they started testing "Alan", you know, my husband. They started putting him through tests. And then he discovered that I just don't produce eggs period. That my infertility is very low and that at my age I am at the age of a woman that should be, at the time when I was trying to conceive, I was 34, well 33. They told me I was of an age of a 40 year old woman. My eggs were the consistency of the eggs of the age of a 40 year old woman. So, then I worked with all that and what we did is we went right ahead into the drugs. What is it called? What are the drugs called? I didn't study for this. (Carrie 07/14/04).

This interview with Carrie shows that her infertility experience was not only mediated by her doctors, but that she did not play into the feminine role of passive participant, and sought another direction for her treatment. My interview with Lea demonstrates women taking a more active role in their fertility treatment as well:

"So we had—I had a very, very difficult decision as to what we were going to do next. And, so it took a long time for me to think that one through. And I did eventually have the surgery. I might be getting things out of order here. But anyway, we had—yeah. I did have the surgery and then it wasn't successful. It was only partially successful. So, then we had to find an IVF doctor who's willing to try to get me pregnant using my uterus that still had some fibroids in it, but they were all kind of out of the way, supposedly. So, we finally found another IVF set of doctors and they were willing to try and we went through—we went through our second round of IVF with them and—oh, we gave up on Dr. Z, because of his opinions and the marketing circus around him," (Lea, 07/12/04).

As these examples show these women actively sought out new doctors in order to gain back control of a situation that they felt did not have any. They wanted to go to a doctor who they felt listened to them, and made them active participants in their experience. As with any complex medical situation, the ability of the physician to have a dialogue with the patient has a dramatic effect on the quality of the treatment.

Each one of these experts plays a role in how those experiencing infertility come to understand what they are going through, and to help them make sense of it all. “In the local practices of “lab talk,” for example, geneticists may reveal the ambiguity of their findings; nonetheless, these findings are quickly codified as absolute knowledge in the language of counselors responsible for transmitting knowledge to patients” (Rapp & Ginsburg 1995:8). At its best, each class of expert (both medical and professional) lends knowledge to the other, as seen in the following excerpt taken from my field notes when observing Resolve’s Family Building Symposium:

Dr. Z talks about how he has come to embrace Eastern medicine and its ability to contribute to the work he has been doing at his IVF clinic. He began by talking about how Eastern and Western medicine has not always come together, but how he thinks that the combination of the two may hold the secret for a woman’s ability to get pregnant. This is a very westernized, foreign-born doctor, who is completely vindicating the Eastern teaching proposed by Mr. K (who is proposing the alternative technique) (field notes 9/20/04).

Here, Dr. Z is embracing aspects of eastern medicine in combination with his western medical approach. When multiple sources of information are given a voice, it encourages exploration into the subject, and creates an atmosphere more like a partnership than a strictly doctor-patient relationship. “The modern women’s liberation movement had arrived en masse to reject all the reigning stereotypes of femininity, from subservient mom to seductive single, and even more importantly, to challenge male domination itself, in medicine and every other authority structure” (Ehrenreich and English 2005:341). This exploration helps to give some control back to women, and instill the notion that they too are in control of the situation, and the more they know about the topic, the better informed their decisions will be.

The Experiential Expert

In my quest to discover everything I could regarding the topic of infertility I found that experiential knowledge is not always appreciated. There are quite a few books where women wrote about their personal infertility experiences to share with other women who found themselves in similar circumstances. Some of these books include: *Laughin'fertility: A Bundle of Observations for the Baby-Making Challenged* by Lisa Safran (1999), *Girlfriend to Girlfriend: A Fertility Companion* by Kristen Magnacca (2000), and *A Few Good Eggs: Two Chicks Dish on Overcoming the Insanity of Infertility* by Julie Vargo, Maureen Regan (2005). What I found particularly interesting is reading the reviews that other women wrote about these books on Amazon.com, a web site where one can purchase books. Although all books received good reviews, women noted in their comments that they did not know the book would cover only the author's experience, and expressed a desire to see more approaches included. One such comment noted that with Clomid, a common infertility drug used to produce eggs, some wrote that they were angry that all the author suggested to do was to "relax and it will work, as it was in her case," others wrote that that they would only take advice from women who have gone through IVF themselves or that these women's stories were void of medical content, for example "Bottom-line, if you need a book on infertility, 'A Few Good Eggs' ain't it. The hard evidence to back up the Two Chicks opinions on why women are infertile relies more on their limited personal opinions than on solid research from a medical standpoint" (Spotlight Reviews, Retrieved 01/09/06).

Reading these reviews made me wonder why these women's narratives were not taken within the context that the authors were merely trying to share their own experience to help other women. Why is medical and professional knowledge deemed so much more valuable than experiential? Is this expected? Well, yes! As previously discussed in the literature review, the historical development and decline of the use of midwifery within the United States points to why science is a valued commodity, and looked up to within our society. The collective book, *Our Bodies Our Selves*, helped open the door to women centered knowledge – as knowledge creators and contributors.

The doctors are the experts in the why and how of what to do, and which procedures to follow based on test results. However, experiential knowledge still seems to be hiding behind medical and professional knowledge types as they are more socially privileged, and women look to them as the experts as opposed to each other. "Science was well on its way to becoming a sacred national value, and any group which hoped to establish itself as the "experts" in a certain area would have to prove they were rigorously scientific," (Ehrenreich and English 2005: 76). This was observed at the Resolve Symposium where I found that there was a privileging of medical experts and medical knowledge, resulting in the exclusion of the knowledge of the experiential expert, "She (the doctor) spends the rest of the time going through some of the stress strategies above, and before we know it time is up. I feel too much time is spent on the physical side of stress. I would like to have an open discussion, but there is no time," (field notes 9/20/04). At the same I found it amazing that there were so many other women out there dealing with infertility, and so did the women I interviewed:

“For me, going to the fertility center and really starting to see people coming through the door and, I started going, “Wow! This is a much bigger problem than I ever realized!” And people just don’t talk about it. And I think that, in itself, helped me a lot,” (Tessa, 10/ 09/04).

“She (the doctor) gave me all of the infertility pamphlets and told me about Clomid, the drug Clomid. ...I told her I was not interested, because I really didn’t want to have twins. And so that’s when I kind of started thinking, ok the doctor is not really going to give me any more information from here, so I have to kind of have to let it occur naturally on its own...and that’s why I was kind of disappointed when I left there (the doctor’s office) I thought all I have is these fertility pamphlets. You know, it was kind of disappointing,” (Ally, 10/10/04).

There do not seem to be enough support mechanisms built to link those who have had to go through the experience, and are truly in a space to lend aid to those who are in its earlier stages. An example from my field notes on how the experiential knowledge expert can lend a hand in providing information to others going through the infertility process is as follows:

“He says to my husband and me, ‘There is a big difference in care when we go to someone that specializes in infertility vs. someone who does not.’ He encourages us to go to Urologist that specializes in infertility. The other man joins the discussion and shares how much finding a good doctor have made a difference in his outlook on the chances of conception for him and his wife,” (field notes, 9/20/04).

I am arguing that experiential knowledge is important, as seen in the following interviews:

- S: So, and I think that’s important, too, having that motivation along the way.
- D: Yeah. It could have got, I know it gets really hard for people, you know, like I met, I did meet this one woman in San Ramon while I was doing that, we were on our second time, she was like on her sixth time. And she was using the same doctor and I was like, Oh, I don’t think I could do that (Deanne 8/12/04).
- C: We have to educate our children, our daughters because, you know, sex education at school you don’t hear that if you have sex with boys, unprotected, not only can you get a sexually transmitted disease like HIV or herpes or gonorrhea, but now you can get Chlamydia. And Chlamydia can prevent you from having babies when you are ready to have babies.

- S: Exactly. Or if it lays dormant in there for a long time.
- C: Exactly. And you know lots of girls don't know that. Maybe that would make them think twice about doing it for peer pressure or for whatever reason. You know what I mean?
- S: Well, I student taught at San Jose State. And at the end of the class it wasn't my intent but a lot of the girls were just, they never heard of it (infertility) before, and were so freaked out. You know, and it was like, that's not my intention, but you do need to think about your fertility health.
- C: And what about the fact that little girls that you hear about now in adolescence and their teens are saying that oral sex is the best.
- S: Yeah.
- C: They have no idea what sex is (Carrie 7/14/04).

As echoed in my interviews, through experiential knowledge we all can benefit and learn. I have found through my own experience with infertility that what I have craved most is the chance to connect with other women, to know how they make sense of their infertility experience, how they have come to define their own situation, and how they have learned to deal with the chaotic mixture of experts now involved in their act of baby-making. For me I feel that what I craved most was to learn about infertility from those that have been there before.

I found that when I interviewed women who had more experience in this world of infertility, I asked a lot more questions, and was much more intent on learning about their experience. This is in contrast to my interviews with women who were more in the beginning stages of the process, where I found that the interview got turned around, and they began interviewing me and asking me questions about my experience with infertility. In my interview with Tessa, who had already gone through IVF and subsequently gave birth to twins, warned that working on this thesis project, while at the same time going through the infertility experience myself, might be too much:

- T: I think that when you are going through something challenging in your personal life, it really helps for you to be professionally challenged. I think

you can get too caught up in (pause) the issues you have. And I think for you especially, with you interviewing people, you're really focused on it, and in the beginning it might be really cool, but the point will come when you've had enough of it. When you are going through the process, it gets very stressful. It really challenges you as a person, you know and um, you know, depending on your personality, and how you communicate, and you know, handle that extra stress. All of those little things that kind of annoy you about yourself really annoy you a lot more.

S: Yeah

T: Because you are under a lot more stress, but I think it, you just need to stay in touch with it, and just be aware that, OK, I'm going to be more emotional and I'm sure that you are already aware of that now with all of the stuff you are going through. But you have to stay in touch with it, and say, "OK, I need balance. OK, I've got too much going on here, now I need to look at this a little bit more" (Tessa 10/9/04).

In the end she was right; I had to stop working on this project while undergoing IVF as the stress proved to be too much. In contrast, in my interview with Ally, who was just beginning the infertility process and was frightened of what the test results might say, I try to encourage her to move forward:

S: You know what? I mean, my husband went to Dr. C for everything, and he treated us as a couple, he didn't just treat me. Um...

A: That's good, that's important.

S: Also, though, so I think you should both go, I don't think that all OB/Gyn's—I'll just say this, when you are treated for infertility, you should be treated as a couple, and not as an...

A: Right.

S: An individual. So, and that's what we did. When we learned that there was a male factor involved, um, we went to an Urologist who specializes in infertility. Um, which made it easier for us at this point, you know, easier than knowing just what's going on with my doctor.

A: Right.

S: So, um, and that, I mean, that that's where I would start. And in fact when I went in, and then, "Can you take this? And then, Dave, you need to go take this test. Come back when you get all of the results, and we'll talk about it."

A: Right. We should do that, I mean, I need to get that blood work done. I mean, I, I literally get dizzy and sick to my stomach (laughs), when I get near needles, so usually when I just go get normal blood tests, because I also have high cholesterol in my family, so I usually have to give blood at least once a year. And I'm all like, "Can I lay down?" You know? (Laughs.) (Ally 10/10/04).

What these examples also show is a need for experiential knowledge, and the ability for women to network and story tell, making this experience hopefully an easier one. There is a huge stigma attached to the inability to get through the “baby making process” without aid of technology, and there should not be. When infertility is first diagnosed it is crucial for women to connect with other women who have gone through the process.

Undergoing infertility treatment is a very isolating experience for women, as it separates them from popular reproductive accounts, which are often privileged within mainstream society. This isolation is keeping women from gaining access to the knowledge they need in order to take some control of their treatment. There needs to be a more consistent way for these separate knowledge experts to share information, to add multiple perspectives to the existing knowledge base, combining information from the doctors’ initial testing, with alternative treatment options, and finally, offering resources of previous patients willing to share their experiences. I am arguing that experiential knowledge sharing needs to occur at the beginning stages, when infertility is first diagnosed. Providing information and knowledge to women during the assisted reproductive process is as vital as providing women information during pregnancy.

When infertility issues arise, knowledge—and who is controlling the dissemination of information—becomes crucial, as this knowledge is used to chart the path to pregnancy. Therefore is important for women to utilize and be aware of information from all three sources: medical knowledge, professional knowledge, and experiential knowledge. Professional knowledge (that of midwives, and others not directly related to medicine) has been minimized by the medical community, as the result

of an honorable attempt to improve sanitary birthing conditions at the expense of generations of experience. In fact, women going through the infertility process often disassociate with their own bodies, and willingly become passive patients, letting their doctors dictate their course of treatment without truly examining their own preferences. A balance needs to be struck between the three knowledge centers (medical, professional, and experiential) so that women can take ownership of the process, empowering themselves in the process, rather than being mere subjects of constant testing and monitoring. Losing control of the reproductive process can damage a woman's sense of control over her own body. It is knowledge gained from multiple sources (not just from medical sources as is so common today) that can help empower her to take back control, and to have a more informed role in the decisions made in attempting to achieve a healthy pregnancy.

Seeking the Fertile Norm

Once pregnancy is achieved, women almost instantly rejoin the culture of the fertile norm. Sarah Franklin, points out that once infertility issues have been resolved and a pregnancy achieved, women instantly become a part of the normative culture, and the infertility experience is left behind, and almost ignored. I argue that this is not necessarily the case; that women constantly call into question their acceptance back into the fertile world once they are in fact pregnant. A pregnancy does not necessarily produce a resolution to infertility and a ticket back into the fertile world. As seen in the following quote taken from a myth and fact section of the Resolve Web Site (a national

support group for infertility) the struggle between these two cultures does still exist even after infertility has been “resolved”:

Myth: "You will feel welcomed into 'The Fertile World,' getting support from family and friends, so you won't need RESOLVE."

Fact: Although many couples do enjoy sensitive and empathic support from family and friends, isolation is not automatically overcome by the news of pregnancy. Pregnancy, achieved after years of testing and treatment, remains a different experience. One RESOLVE member, pregnant with twins, reflects, "It feels so strange to be catapulted into a world of fertility after struggling with infertility. I go to Mothers of Twins Club meetings, LaLeche meetings, exercise classes for pregnant women, etc., but I find it difficult to identify with other mothers...I'm disturbed at the number of times people express negative comments to me about having children...Early on I used to explain to them why these twins were so dearly wanted by us but now I'm growing tired of explaining" (Dunnewald, Retrieved July 17, 2006)

Also, consider the following example with my interview with Jan. Here she shares that although she has “resolved” her infertility and ultimately had a child through adoption she still feels like an infertile woman:

“Adoption does not really end infertility, though, you know? I still feel a tug when I see mothers and daughters who look alike, and on days when my son is challenging, I wonder whether I’d be better able to connect with whom I had common genes. I feel very fortunate to have successfully adopted, but I would never do it again though,” (Jan 7/10/04).

Jan went on to say that she thought “being thought of as normal is nice, once you are pregnant” (7/10/04). However, she never experienced pregnancy and therefore never felt “normal.” I argue though that the experience of infertility is part of the reproductive experience as a whole, and that it is not necessarily beneficial to society for women to leave their infertility experience behind should they become pregnant.

After two and a half years of trying to conceive, and ultimately becoming pregnant through IVF, I could not wait to rush out and buy pregnancy books. This was what I had been longing for, and now I could focus on the fun of baby planning.

However, what I found in the pregnancy books that I purchased or received is that most chapters surrounding the early stages of pregnancy centered on, “Preparing for Pregnancy” and how “Pregnancy Begins” all of which privileged normative discussions of conception. “Traditionally defined as a natural sequence of biogenetic events, conception in the context of technological assistance is increasingly seen as an *achievement*. The narrative of the facts of life is consequently changed by the advent of assisted conception technologies, or ARTs, as they are often dubbed” (Franklin 1998:103).

However, the “standard conception story” did not apply as I did not need to read a whole section on determining my due date or when I conceived, I had a picture of the two embryos that were implanted with their fertilization date attached. To name a few of the pregnancy books I looked at, *Keep It Simple Series: Guide to Pregnancy* by Felicia Eisenberg Molnar, *What to Expect When You’re Expecting* by Eisenberg, Murkoff, and Hathaway, and *The Mother of All Pregnancy Books* by Anne Douglas. Although both pregnancy books by Eisenberg, Murkoff, and Hathaway and Anne Douglas discuss infertility and IVF they do so not in the way that one who is pregnant through these methods can follow the book from the beginning to end. They discuss it in passing, and the book by Douglas has a chapter titled, “Missed Conception,” geared to those that are having a hard time trying to conceive. However, when I was struggling to get pregnant the last thing I wanted to run out and buy was a pregnancy book! However, what I did find is that women who “quietly dismissed” their infertility experience did so not because they then wanted to be perceived as part of the normative group, but did so to forget an

experience that they deemed as painful and stressful. This is indicated in my interviews with both Carrie and Tessa:

S: It will make you feel better, I find out a lot that women have gone through IVF and it's been a few years out, you know, it's like I don't remember any of this. And part of me thinks that just through thinking about it that you don't want to go through this all the time. You don't want to remember.

C: No. You don't want to really talk about it over and over again because you've done it. You felt, you've had the pain (Carrie 7/14/04).

T: I think that when you are going through something challenging in your personal life, it really helps for you to be professionally challenged. I think you can get too caught up in (pause) the issues you have. And I think for you especially, with you interviewing people, you're really focused on it, and in the beginning it might be really cool, but the point will come when you've had enough of it. When you are going through the process, it gets very stressful. It really challenges you as a person, you know and um, you know, depending on your personality, and how you communicate, and you know, handle that extra stress. All of those little things that kind of annoy you about yourself really annoy you a lot more.

S: Yeah

T: Because you are under a lot more stress, but I think it, you just need to stay in touch with it, and just be aware that, OK, I'm going to be more emotional and I'm sure that you are already aware of that now with all of the stuff you are going through. But you have to stay in touch with it, and say, "OK, I need balance. OK, I've got too much going on here, now I need to look at this a little bit more (Tessa 10/9/04).

In the same way that people subconsciously forget physically painful experiences, women distance themselves from their own infertility experience, and spend little energy trying to resolve issues left unresolved as a result of the experience. Pregnancy does not transform members from one culture to the other. What I found in my interviews is that the experiences are remembered, although not discussed due to the pain of having to utilize non-normative methods to achieve conception, and the stress of having to go through the process itself. The experience of infertility becomes a defining point where once experienced, women clearly identify with non-normative reproductive accounts and this new culture.

Through the personal narratives of these women one can gauge feelings of being different most notably through the use of technology to “achieve pregnancy.” Assisted reproduction for women experiencing infertility is part of the reproductive experience itself, despite the fact that technology was used to help achieve pregnancy.

“Hence, the state has a “parental” interest in the origins of all new individuals born through the use of assisted reproductive techniques; the clinic becomes the site of procreative acts, and the clinicians the actors in the achievement of conception. The important symbolic conjunction of conjugal and procreative activity and the equally important opposition between acts undertaken for love and those undertaken for money is breached. What was once a private act of love, intimacy, and secrecy is now a public act, a commercial transaction, and a professionally managed procedure” (Franklin 1995:336).

The concept that children are born from the love of the parents is directly challenged, and replaced with the concept of children being born from the financial resources of the couple. According to my respondents, love is still the core motivator for reproduction, and even more so given the strain infertility can cause on the individuals and the couple, is not given enough emphasis, as obtaining the financial resources for the various procedures and exchanging them for services take a front seat. The cost associated with assisted reproduction adds another dimension to the stress that infertility can cause for a couple. As with all the best new technologies, there is a price to pay for its use, and many times that price alone can be the determining factor as to whether a couple can explore assisted reproduction or not. For those who discover that they have fertility issues, the costs associated with working around those issues are unavoidable in a culture where “achieving” pregnancy is the ultimate goal in “achieving” normative status.

CONCLUSION

Introduction

As I have shown, the social construction of infertility involves many actors, each of whom plays a role in shaping and defining the infertility culture. In this culture, a class-based system emerges where wealth, access, and power (knowledge creators) have a major impact on shaping the culture. When a woman first discovers that she will require medical assistance to become pregnant, she becomes a member of a unique culture of infertility that is separated from the normative world of natural reproduction.

Women initially experience infertility through medicalized experiences, which are controlled in large part by the knowledge providers, the medical community, who dictate the language and decide who can seek what types of treatment, and when that can happen. Through this experience gender and their sense of selves are under constant negotiations with technology, their doctors, partners, and themselves. Women manage this experience by understanding the level of influence that medical, professional, and experiential players have in defining this new world. They also become more aware of the possibilities in front of them, and become more of an active participant in their treatment.

The culture of infertility is increasing with technology, as more and more women who previously could not seek treatment are now able to participate due to medical advances. My argument is that all women who suffer from infertility immediately experience a “sense of difference” that transports them into a non-fertile world that they now must learn to manage. Although I have already presented several examples of how

the infertility process is socially constructed throughout my analysis, I want to review three major findings, which indicate *how a culture of infertility is created*, and how women both *experience infertility (paying specific attention to how stigma and gender is negotiated)* and *manage it* by understanding who generates, communicates and privileges knowledge over other accounts in this sub-culture in their efforts to become part of the fertile norm.

A Sub-Culture of Infertility

The infertility process creates a “sense of difference” between the normative fertile world, and the non-normative world of infertility, as demonstrated in my interviews. “By using reproduction as an entry point to the study of social life, we can see how cultures are produced (or contested) as people imagine and enable the creation of the next generation, most directly through the nurturance of children” (Ginsburg & Rapp 1995:1). Traditionally, marriage has been viewed as a move from adolescence into adulthood. But “with cohabitation becoming more and more common, marriage has become very closely linked with the decision to begin having children, and less of a move to adulthood” (Greil 1991). When fertility issues occur, they not only threaten one’s ability to have children, but hasten the move into adulthood. We see this concept echoed in my interview with Samantha, who came home from her wedding night to find baby toys placed on the table (Samantha 7/16/2004). Producing offspring is a major societal benchmark, and when fertility issues arise, they can transport those into a non-normative world of infertility, where they become outsiders to the fertile norm.

Rapp and Ginsburg's examination of reproductive experiences, highlight work underscoring the dilemmas of "disrupted reproduction" in which the "standard linear narrative of conception", birth, and the progress of the next generation is interrupted by pregnancy loss, reproductive pathology, abortion, and childlessness" (Ginsburg and Rapp 1995:3-7). Rapp and Ginsburg's approach to looking at women's reproductive experiences beyond "standard" or normative accounts, and highlighting "disrupted reproduction" or non-normative reproduction allowed me to add to this concept by defining "normalcy" to include those who have the ability to reproduce "naturally" and non-normative reproduction to include the many alternative paths available to bring a child into the world (*in vitro* fertilization, adoption, foster care, etc.). The experience of women who think they can reproduce naturally--only to find out they need medical intervention--carries with it a narrative as important to the reproductive sub-culture as the more widely known stories of normative reproduction. Pulling the curtain on this isolating experience for many women (and couples), and demonstrating that this non-normative reproductive cycle has in itself many shared experiences, that are worthy of being examined.

I also argue that infertile accounts needs to be examined through a cultural lens. Adding to the work of Ginsburg and Rapp in which they apply "reception theory" to seek understanding of the power relationships involved in determining who is encouraged and discouraged to reproduce within a society by seeking to provide a cultural framework around women's personal experiences with infertility. Reception theory, a theory based on ethnomethodology, which states that images, technologies, and representations that

are both produced and consumed provides cultural and social meanings (Ginsburg and Rapp: 1995:6). I extend their work to include the non-normative reproductive accounts. It is through these accounts a culture of infertility emerged.

During my observations and interviews, I was able to see the complex social arrangements that make up this culture through social interactions, language, and meaningful symbols through the narratives that these women shared. For example in my interview with Jan, who found that others did not appreciate her joking about her “barren” status, and in another interview, Lea finds that the infertility support group she attends is the only place where she feels understood on the topic. And again from the interview with Jan, I found it most poignant when she complained that only one way of producing children or creating a family is discussed in school’s sex education classes. It is through my interviews this idea of a “sub-culture” of infertility became alive, where marked differences between those that were able to reproduce naturally and whose narratives were privileged (sex education classes, baby books, etc.) and non-normative accounts that are typically not discussed socially. By knowing that there is a whole “sub-culture” of women out there going through infertility allows these women to share experiences, and identify with others who have gone or are going through the process. “Women and men strive for normalcy in their daily lives; infertility disrupts that sense of normalcy. When conception does not occur as planned, women and men experience a sense of difference. Feeling different provokes a reexamination of cultural assumptions about fertility, gender, and family” (Becker 2000:33).

Experiencing a Sub-Culture of Infertility

A women's medicalized experience within a sub-culture of infertility is centered on a feeling of difference from the fertile norm; I found in my interviews a re-examination of these differences, specifically issues surrounding stigma and gender. The medicalized process of infertility is dictated by the medical community from the moment women begin to ask questions about their difficulty in getting pregnant, setting time frames for when it is acceptable to begin testing, and what testing will be done, sometimes with no regard to what the patient wants. The process of constructing meaning about infertility begins once a couple suspects a problem, even before treatment is sought (Greil, Leitko, Porter 1998) and it is through their interpretations and choices that the infertility process takes shape. Infertility is a socially constructed experience that occurs through our daily social interactions with the outside world, how we have come to interpret medical definitions of infertility (Western/US definition of infertility), meaningful symbols or narratives ("achieved pregnancy"), and technology (*in vitro* fertilization or IVF). Becker and Franklin discuss how the use of language in narratives is key to explaining and understanding narratives surrounding infertility. In all of my interviews, we were communicating in terms unique to the culture of fertility such as IVF, ICSI, and IUI. Not commonly recognized by the normative culture of fertility, these terms are common and used freely among those in the non-normative culture of infertility. Through my interview process I discovered the ways in which these women take ownership of these terms, and the ability to use and speak this new language generates power by giving those who speak it the ability to frame fertility issues, and

define their own experience. In addition to women utilizing these new terms I found that they not only adopted this new language to describe their own body, but also utilized these terms to communicate their experience. In my interviews with Deanne, Tessa, and others a complex medical terminology and procedures were bantered back and forth to describe our experiences--it was almost a game of who knew more of the terms and procedures.

Medical definitions seek to identify and categorize women into a medical process that may or may not fit their individual medical situation and tends to wipe away these women's ability to create meaning about their own infertility experience and intentionally leaves them out in the cold when it comes to socially constructing their own reality. My interviews with Elle and Nessa revealed that both women had to endure a set number of miscarriages before their physician would refer them for genetic testing or to begin fertility treatments. Their doctors were actually requiring the pain and grief of additional miscarriages in order to gain access to further treatment. This medicalized process dictates these women's experiences, which can be seen in the collection of narratives that resulted from my interview process. I agree with Riessman, Franklin, and Becker that the use of narratives provides a window into the use and understanding of the infertility process, and that they represent identity, language, and interpretation. What I add to their research is the application of personal narratives, and how through the examination and connection of these narratives, the process of infertility emerges. By application I mean that a women's infertility narrative must always be a point of reference and examination when studying infertility. Socially constructed narratives and symbols play

a role in defining women's infertility experiences as it creates social meaning. One theme that did seem to run throughout my collections of narratives was that through infertility treatments and other non-normative ways to have children, parenthood was for sale. Sometimes, this was a financial cost, and sometimes women were denied treatment because of low likelihood of success, a statistical marketing cost their infertility specialist was not willing to pay. Lea, who spoke of the marketing aspect of her infertility specialist, felt that women were excluded from treatment because they had a high chance of failure, and that would damage the physician's statistics, which are a key marketing tool to attract new clients. Deanne also found that statistics played a role in her treatment as well, where "high likelihood" candidates were encouraged to seek treatment, and women who had a small chance of success with *in vitro* were discouraged from continuing, and in some cases, simply denied treatment.

This sub-culture that I have identified seeks to find and understand what it means to live "outside" the norm. At the core of this gender difference between the sexes is the simple notion that the man impregnates the woman, and she carries the child. Tessa made this very clear in our interview when she said, "It's very primitive though, but you know that, its kind of one of those basic things we are here to do, right? To carry a child." Fertility issues threaten this primal concept, bringing into question gender identity. "Women and men who struggle with infertility confront cultural ideologies surrounding gender norms...they have been forced to work intensively with cultural dialogues in order to reconcile their experiences with cultural expectations," (Becker 2000:237). Infertility creates a non-normative group of women trying desperately to get

back to normalcy—to re-establish themselves as women. Stigma has an important influence on a woman's infertility experience. And while societal stigma does play a role, my research indicated that felt stigma is far more dominant during the infertility experience than is societal stigma, and this is backed up by Greil's findings, "It would seem that for these infertile women, felt stigma was the source of more anguish...a 'secret stigma' hidden from outsiders, but nevertheless deeply felt," (Greil 1991:101). It is the sense of being different, separate and apart from other fertile women that feeds this felt stigma.

Gender is important to take up via its connection through normalcy, because of its organization around women's bodies, and how when a woman has difficulty or cannot reproduce non-normative means, she calls into question her gender identity. The infertility experience challenges a woman's sense of gender by calling into question her ability to bear children. Infertility threatens how men and women fit into traditional gender roles, causing them to look for ways to make sense of their social differences, reconciling their experiences with cultural expectations (having children) – performing gender. "Women and men who struggle with infertility confront cultural ideologies surrounding gender norms" (Becker 2000:237). For example in my interviews, gender plays a role in the division of labor between men and women during the infertility treatments. In my interview with Tessa for example she minimized her own role of receiving hormone injections by telling me how difficult it is for her partner to give them. Because infertility treatments are centered on women's bodies, men have the ability to choose their level of participation. This was discussed in my interview with Ally, whose

husband did not join her for any of her doctor's appointments, and who did all of the infertility research on her own. The infertility experience and gender are closely linked simply because of the core implications that fertility issues have in what makes us men and women.

Managing Infertility

The knowledge experts that have the most influence in the infertility process are the medical experts (doctors, geneticists), the professional experts (counselors, support groups), and the experiential expert (women who are or have gone through infertility treatments). Of the three, the medical experts have a dominant role in the dissemination of information, and control over how the process will proceed. How women manage this experience, specifically through relations of knowledge power or "knowledge experts", and how they make sense of it are particularly relevant to the study of the infertility sub-culture.

I argue that women who seek fertility treatment are experts in the construction of infertility, as women are co-equal with doctors because of our experience, although on different scales, and for different reasons. The infertility process forces women to lose control of their own reproductive system. The medical community holds the knowledge necessary to proceed, and the privileged terminologies and abbreviations (IUI, IVF) that are inherent in this process, which become barriers between a woman's ability to have some control over the experience. "Here, a male dominated and quintessentially patriarchal system of power and knowledge was deployed to name, define, and control a

territory located inside a woman's body" (Franklin 1995:335). The same lack of knowledge that can create the feeling of isolation for women facing infertility can also impede her ability to take back some control, and make informed choices as to how she would like her treatment to proceed. Seeking knowledge is one way in which women are able to regain some control in their infertility experience.

There are several books that contain a particular author's personal experience with infertility, but there are not many resources that contain many infertility narratives. Identifying with a narrative reduces felt stigma, and returns some sense of normalcy to those undergoing infertility procedures. This further points to the need for these infertility experiences to be given a stronger voice. I found that a majority of the women I interviewed switched doctors in order to exert some sort of control. There needs to be a more consistent way for these separate knowledge experts to share their information, to create a wealth of knowledge from the onset, combining information from the doctors' initial testing, with alternative treatment options, and finally, offering resources of previous patients willing to share their experiences. I am arguing that this needs to occur at the beginning stages, when infertility is first diagnosed.

Providing information and knowledge to women during the reproductive process is vital. There is an entire industry built around pregnancy, and millions of resources on what to expect during pregnancy. This wealth of information, however, is severely lacking for women facing fertility treatment. When infertility issues arise, knowledge and who is controlling the dissemination of information become crucial, as this knowledge is used to chart the path to pregnancy. It is important for women to utilize

and be aware of information from all three sources: medical knowledge, professional knowledge, and experiential knowledge. In fact, women going through the infertility process often disassociate with their own bodies, and willingly become passive patients, letting their doctors dictate their course of treatment without truly examining their own preferences. A balance needs to be struck between the three knowledge centers (medical, professional, and experiential) so that women can take ownership of the process, empowering themselves in the process, rather than being mere subjects of constant testing and monitoring. Losing control of the reproductive process can damage a woman's sense of control over her own body, at a time when it is crucial that she take ownership of her body, preparing it for pregnancy.

According to Sarah Franklin, in undergoing fertility treatments, there is an urgent desire to get back to normalcy once pregnancy is achieved. Both Franklin and Becker point to the idea that once fertility issues are resolved, and pregnancy occurs, women immediately rejoin the normative culture of fertile women. My research points to just the opposite, in that in managing the infertility experience, pregnancy itself does not produce resolution to infertility--the struggle between the fertile and infertile cultures still exists. This is also demonstrated in my interview with Jan, who said, "Adoption does not really end infertility, though, you know?" I argue though that the experience of infertility is part of the reproductive experience as a whole, and that it is not necessarily beneficial to society for women to leave their infertility experience behind should they become pregnant. However, what I did find is that women who "quietly dismissed" their infertility experience did so not because they then wanted to be perceived as part of the

normative group, but did so to forget an experience that was both emotionally and physically painful and stressful.

A Look to the Future

While this research has yielded interesting results and valuable findings, the study of the “culture of infertility” is still in its infancy. If reproductive information, specifically regarding infertility, were more part of the mainstream teaching, along with sex education or a part of everyday dialogues of reproduction, this culture would not be so invisible or underprivileged. A further critical study of the ways different knowledge areas contribute to the culture of infertility and the role and responsibility they play in the infertility experience would help further this research. By offering a plan that identifies, defines, and outlines resources in all knowledge areas to doctors who deal with couples in the earlier stages of the infertility process would help women navigate around this new world of infertility of which they now find themselves a part. One way to significantly increase the value of this research would be to interview “fertile” women to understand how they also deal with the medicalization process in the ways in which I discussed, in order to be able to provide a more conclusive claim.

Other areas to focus infertility research could be in any one of the following: to focus completely on the experiential knowledge expert, and the importance of story telling and sharing personal experiences as a knowledge expert. Also, a study on homosexuals and their limited options (and typically only option) in the use of reproductive technologies would be a great research project to show the differences

between the infertility experience had by heterosexuals and homosexuals, and how society affects each. Another area within the literature that I found truly lacking was how infertility, and the treatments, affects men. Overwhelmingly, the literature focuses on women's experiences, but men are also treated for their own infertility issues, and even when they aren't, they are affected by their spouse's treatment.

By creating a cultural framework around the world of infertility, issues such as gender, use of language, cost, etc. begin to make more sense to one trying to take a peek in and understand how this world operates. However, there is a lack of critical sociological literature about infertility, specifically the ways that knowledge, gender and the issues that take form and are expressed in this space (the process). By uncovering both men's and women's thought processes throughout this ordeal, as well as their true narratives, a manual could possibly be developed to help guide both professionals and experiential experts through this experience of infertility. There is a wonderful medical community built around this lucrative area, but there needs to be additional support mechanisms developed given the sensitive and sometimes painful steps in the infertility process. My project is only an introductory contribution to the relatively new dialogue of infertility. I hope other voices soon enter the discussion.

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APPENDIX

Interview Guide

1. Tell me when you first started to try and get pregnant? (How long have you been trying?)
2. How long did you try before you started to question that something was wrong? What steps did you take at that time?
3. What did you do once you discovered there was a true underlying medical issue?
4. Did you work with your regular OB/GYN regarding this, did you try to find a new doctor, or did your doctor refer you to a specialist?
5. How would you describe those initial stages?
6. What medical processes have you gone through to identify the issue? Did they discover what was wrong?
7. Where are you at in the infertility process, i.e., testing, IUI, IVF, pregnant, or delivered, or out of the process entirely?
8. If you are out of the process entirely, did you adopt or decide to remain childless?
9. Do you or did you (and your partner) have any support going through the process of infertility? Who and what were the types of support you felt were helpful?
10. What was your experience with your traditional support mechanism (family, friends)?
11. What infertility treatments have you done? Describe the process and/or experience?
12. What have you gotten out of going through the infertility process?
13. How would you have changed your experience to make it easier? Did you feel anything was lacking in terms of support?
14. If you have completed all of your testing, and been given the medical recommendation that IVF: What, if anything, would you like to say to women who have just discovered that they will not be able to conceive through natural means, as they embark on this process?

15. Given what you have gone through with this process, would you do it again to have another child?
16. Tell me about your decision to have a child?
17. What led you to assisted reproduction?
18. Tell me about your experience with assisted reproduction?
19. Tell me about your experience with doctors, hospitals, insurance companies, etc. during this process?
20. How do you feel about assisted reproduction?