

# **The Social Construction of Infertility by Minority Women**

**Doctoral Dissertation**

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## **Abstract**

Infertility is a growing social problem. The population affected by the experience of infertility has increased dramatically in recent decades and is expected to continue to increase. Furthermore, the incidence of infertility is higher in minority and lower socio-economic groups. People affected by infertility often need the services of social workers. Despite this growing need, the phenomenon of infertility has been largely overlooked by the social work profession.

The contemporary understanding of infertility is too narrow. In the twentieth century, infertility has come to be defined almost exclusively as a medical condition. The psychological and social needs are not adequately addressed within the framework of such a medical model.

Modern day infertility needs to be interpreted within a broader historical and biopsychosocial theoretical perspective. New social work research is required to advance current understanding of infertility within this broader view and to encompass affected populations inadequately investigated until now. A deeper understanding of infertility in contemporary society can guide future public policy and determine directions for effective social work practice.

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## Chapter One: Overview

*Chapter One introduces the dissertation by providing an overview of the research and the document. It motivates the study of infertility among minority women as a biopsychosocial problem; summarizes the analysis of the interviews about the experience of infertility as fitting into distinct patterns of irresolution; proposes the interpretation of these results as the consequence of an inability to formulate effective autobiographical narratives of infertility within the cultural and social contexts of minority women; and suggests the necessity of providing social work solutions to this problem.*

Infertility has been a topic of interest to me for several decades. As an infertile woman, I have reflected long and hard on my own personal experience of infertility. I often wondered if my experience of infertility was similar to, or different from others' experiences. As I have progressed through the developmental life stages -- now well past my childbearing years -- my infertility has continued to accompany me. Having completed this study, I now realize that I have routinely revisited my own understanding and interpretation of infertility and I have often had to reconstruct my narrative about who I am in light of my infertility.

Given my personal interest, I have talked with many people, male and female, about infertility. Throughout my career as a child developmentalist and as a social worker, I have worked professionally with children and families within a variety of settings, including Head Starts, Indian Reservations, private and public education programs, and special needs populations. Through my work I met many people dealing with infertility. Some have remained childless while others took various routes to parenthood, such as becoming foster or adoptive parents or through conception via modern medical treatments. I have observed that infertile people come to understand their infertility based on their social backgrounds and cultural interpretations. Like everyone, infertile individuals construct an autobiographical narrative understanding of who they are on the basis of values and roles they find in their cultural and social contexts. Infertile individuals face a difficult task in constructing a positive self-understanding about their life experience because fertility is a deeply entrenched social value while infertility is a culturally shunned topic.

As a result of these observations, I was interested in understanding infertility in more depth. During a qualitative research class while in social work graduate school, I conducted a case study of an infertile woman who underwent years of painful and expensive high-tech medical intervention which eventually resulted in the birth of a son. What struck me about her narrative was that even though she achieved parenthood, she still considered herself infertile since her son was one of the first children in the world conceived from a frozen embryo. She made me understand that she would never be like the mothers on the playground who told stories of their natural conceptions and deliveries. Shortly after his birth, her son was dropped from their insurance plan with a thinly veiled excuse about the potential negative medical effects of the Assisted Reproductive Technology (ART) she had used to conceive. I still remember her laughing while saying "embryo freezer burn" was their concern. Yet, underneath I felt her pain of still being different due to her infertility.

The information gleaned from this case study motivated me to complete my comprehensive examination on infertility as a prerequisite leading to this dissertation. From the literature review, it was clear that only a narrow population of infertile individuals have been studied. These

individuals have primarily been female medical patients involved in advanced medical intervention to resolve their infertility. This is understandable because these women are easily accessible to researchers. These women represent the majority culture and typically are well-educated and from higher socio-economic groups. Despite documentation that indicates infertility knows no economic, racial, cultural, or ethnic boundaries, there have not been studies of infertile populations other than this narrowly defined population. Statistics also suggest that the incidence of infertility is higher within some minority populations and lower socio-economic groups. However, the available infertility research has virtually ignored these populations. The biopsychosocial consequences of infertility among the populations that social work typically serves have not been explored either quantitatively or qualitatively.

By this time my curiosity was piqued. What was the experience of infertility among women from minority populations? This question became the topic of my dissertation research. Considering the lack of information into their experiences of infertility, as well as a sense that they may lack resources needed to address their infertility, I proposed an exploratory qualitative study to better understand the experience of infertile women from minority populations. I succeeded in talking informally with many women who met the criteria, but who chose not to be in this study. In hindsight, I think this information was as telling as the data I did gather. These women felt a powerful need to tell their story. Interestingly, they all talked with me in detail, often spontaneously answering the questions I used in the official interviews, but they declined to formally participate. In some of these instances I spent as much time just listening to them talk as I did with the actual participants. All the women who decided against participation thanked me profusely for the opportunity to talk with me and encouraged me to tell their stories, but through other women. Despite their desire to tell their stories, they felt even stronger social and cultural pressures that kept them from being full participants in the study.

Eventually, I did succeed in interviewing eleven infertile women who met the criteria for this study. One predominant theme emerged from a careful analysis of the interview transcripts: none of the participants are resolved about their infertility. Previous research on infertility and the practice of the major national infertility support group, RESOLVE, tend to treat the experience of infertility -- among upper middle class women -- as a grieving process that aims for resolution. However, analysis of this data indicates that "resolution" is a misnomer. Rather, the minority women I interviewed were at different stages of irresolution. For them, resolution is an elusive goal, never attained as a stable destination. Rather, the struggle for resolution is an on-going process of making meaning of one's personal experience of infertility at different stages of life and based on shifting cultural identities and social relationships. The eleven women in this study fell distinctly in three categories of irresolution. I call these categories: "defeated", "resigned", and "denying". These three categories represent different stances these women have taken in giving meaning to their infertility.

Reflection on this analysis and categorization of experiences of infertility led me to an interpretation of the fundamental hardship confronting infertile minority women. These women have had difficulty constructing autobiographical narratives about their experience as infertile. Faced with the shame, secrecy, and deep-seated taboos about the topic of infertility, they have not been able to talk openly about being infertile within their marriages, families, friendships, colleagues, churches or other support systems. These women have lacked safe places to tell their stories and to construct a positive meaning about their experiences. Within cultures that

perpetuate derogatory myths about infertility, it is absolutely necessary to talk with others about the experience of infertility in order to overcome the prevalent biases and articulate a positive identity. Turning inward, the women interviewed have had to choose between being overwhelmed by their situation (“defeated”), accepting it as a negative fate (“resigned”), or ignoring it and assuming an unrelated identity (“denying”).

The consequences for the social work field are obvious. A significant proportion of the low-income minority population that social work traditionally services consists of infertile women. Without supportive cultural norms, social structures, and resources necessary to narrate their story, these women have had to face their infertility in isolation, without a chance to develop positive self identities about their infertility. Social work can help to educate the general public and other professionals about infertility, while dispelling the anachronistic myths and taboos. This alone would make it easier for the infertile population to talk about their experience and to feel less alienated. Counseling can be sensitized to the issue of infertility, recognize cases where people are struggling with its biopsychosocial impacts, and establish safe havens where groups of infertile minority women can gradually feel safe about sharing their experiences. At the institutional level, social work can advocate for legislation and insurance practices that are in the interest of infertile minority women. By illuminating the experiences and needs of previously unstudied infertile populations, social work can become proactive in legitimizing this biopsychosocial phenomenon for all infertile populations. Additionally, this study identifies future areas of research, especially the need to include males in the research as well as other systems, like extended family members.

# THE CULTURAL CONSTRUCTION OF INFERTILITY

## INTRODUCTION

### Historical Background Information Supporting the Study:

Birth and death are the most basic of human events and reproduction transcends the boundaries of individual lives to signal the survival and continuation of the family and the species (McDaniel, Hepworth & Doherty, 1992). Fertility is revered in almost all cultures and the ability to reproduce is perceived as a milestone in adult development (Notman, 1990). Individuals who desire parenthood, often experience external or internal pressure to become parents (Greil, 1991; MCDaniel, Hepworth & Doherty, 1991; Monarch, 1993). Since the ability to reproduce is usually taken for granted, the realization of infertility problems, comes as a shock that has been labeled the “crisis of infertility” (Cook, 1987; Taymor, 1978).

Although statistical documentation of the incidences of infertility are difficult to determine accurately due to the very nature of infertility and the fact that many individuals dealing with infertility do not seek treatment, documented cases of infertility have continued to rise, although the statistics vary. According to RESOLVE, a national non-profit organization which offers education, counseling, referral, resource, and support groups to individuals dealing with infertility, 15% of the population in their childbearing years experience problems associated with infertility (Menning, 1980). Another study from the Division of Vital Statistics (Mosher & Pratt, 1990) estimated that approximately 8.4% of women deal with infertility and this translated into about 4.9 million or one in twelve women. Another prediction of infertility estimates the trend may result in 20% of the population over the next few decades (Stanway, 1980). Regardless of the statistic used, documented cases of infertility are significant and are predicted to rise.

Currently many stigmas and myths about infertility still exist. Although there is much more scientific information about the biological or medical aspects of infertility, understanding the psychological and social implications of infertility have lagged behind. One of the most prevalent myths about infertility is that since women ultimately conceive and become pregnant, infertility or the inability to conceive and become pregnant is perceived almost exclusively as a “woman’s” problem. Contrary to popular belief, however, statistics confirm that in fact, infertility impacts men and women almost equally: approximately 40% of infertility problems are male related, 40% are female related, 10% are a combination of male and female problems, and 10% are of unknown etiology (McDaniel, Hepworth & Doherty, 1992). Although one or the other partner or both partners may exhibit specific conditions which lead to infertility, typically it is ultimately the couple that is infertile.

Another misperception is that infertility is limited to specific populations, mainly the majority population. However, studies of infertility that include women from minority populations indicates that infertility is statistically higher within some minority populations: infertile women were significantly more likely to be black than fertile women, 13% being black compared to 7.5% of fertile women (Mosher, 1987, p. 620). Infertility also tends to impact lower-socio-economic groups (Greil, 1991; Monach, 1993). However, since women from higher socio-economic groups are more able to seek expensive medical intervention, these women also achieve more popular press coverage especially if treatment has resulted successful pregnancy.

Other frequently expressed myths like “just adopt” and your own children will follow evolve from misinformed supporters when there is no basis in reality for such a statement since those who adopt have no higher a fertility rate than those that don’t adopt. “Relax” is another of those expressions that also shows a lack of true understanding about the problem of infertility, but again is offered as helpful advice often in an already stressful situation.

Traditionally infertility has been seen within Western society as mainly a medical problem, although many medical, cultural, and social advances and changes have been responsible for the increase in infertility. For example, birth control has been well-documented as partly responsible for the increase in infertility rates (Greil, 1991; Menning, 1977; and Monach, 1993). Since abortions have been legalized, and theoretically are performed under more optimal conditions, side effects of abortions such as secondary infection have decreased, but side effects from abortions have been reported as responsible for between 1% and 5% of the future infertility problems (Evans, 1989).

Delayed childbearing, sexually transmitted diseases and environmental and lifestyle factors have also further contributed to the infertility rates. Additionally there may be other as yet unidentified variable that further contributes to the rising infertility rates.

Regardless of the causes, for those individuals who unsuccessfully seek parenthood, infertility comes to most as a surprise as the ability to conceive, one’s fertility, is usually taken for granted, unless there is a definitive reason to suspect otherwise.

#### Statement of the Problem of the Study:

The problem is that infertility is an increasing biopsychosocial problem that affects a significant population, particularly a segment of the population typically served by the social work profession. Currently the experience of infertility is not well researched and subsequently not well understood within minority populations. Therefore, this study is an attempt to better understand the experience of infertility within minority populations so so that social work can better address the needs of the entire infertile community.

Within Western society the incidence of infertility continues to rise. Historically infertility has been viewed predominantly as a “women’s” health problem which is often resolved through high-tech medical intervention. However, infertility is has not just a medical condition, but rather is a biopsychosocial phenomena (McDaniel, Hepworth & Doherty, 1992) . Additionally, not all those experiencing infertility seek medical intervention to resolve their infertility, nor can it be assumed that those experiencing infertility have the desire or resources needed to seek medical intervention as a solution to their infertility.

The purpose of this study is to understand the experience of infertility among women from minority or oppressed populations who have not previously been studied in the research. By answering the question: “What has been your experience of infertility?”, in addition to answering complimentary sub-questions, this study attempts to understand how women from these previously unstudied populations experience infertility and interpret that experience.

By better understanding the experience of infertility across all populations, social work can become better equipped to provide future research, education, and practice to the infertile community and those impacted by the infertility.

#### Significance of the Study:

It is important to answer this question and accompanying sub-questions for many reasons. First, there is virtually no information on the impact of infertility on minority or oppressed female populations. Infertile individuals from these populations tend to be invisible and have virtually been ignored. Current popular literature and scientific research has focused mainly on women from majority populations who have very homogeneous characteristics. Overall these women are already involved in medical intervention and therefore represent a convenient sample for research purposes. Additionally these women are almost exclusively from the majority Caucasian population. Overall these women are generally older and are from higher socio-economic and educational backgrounds thus affording them the luxury and resources to seek expensive, high-tech medical intervention. Often these women have delayed child bearing to pursue higher education or careers and are in traditional, committed, long-term, heterosexual marriages. And yet statistically we know that infertility impacts women, and men, with many diverse characteristics. But virtually nothing is known about women, or men, who do not have similar traits to the studied populations.

Second, “social policies” or “policies” related to infertility are sorely lacking and have been slow in being developed as they are fraught with controversy over one’s fundamental right to reproduce. Typically policy discussions related to infertility have been intricately intertwined with adoption or reproductive and procreative policies and thus have stirred legal and emotional debates which has stalled policy making.

Third, current documentation of the infertility populations already studied, even when parenthood has been achieved, indicates significant psychological and social impacts on those dealing with infertility, particularly women. Although there is more speculation than actual research on men than women, infertility is also assumed to impact men, although possibly differently than women. Because the nature of infertility is cyclic, infertility often triggers responses typically seen with other major losses. Thus, social work intervention could be beneficial to those dealing with infertility.

Fourth, the social factors leading to infertility can be ameliorated to some degree through better medical care and education. Sexually transmitted diseases (STD’s) have been attributed as a cause of infertility and can often go undetected, especially in women. Those lacking access to affordable medical care may go without appropriate treatment for resolution of STD’s, thus resulting in future infertility problems.

Fifth, the profession of social work has been absent in advancing research related to better understanding the phenomenon of infertility and thus has been negligent in advocating or providing social work intervention to those impacted by infertility. Social work has believed the myths related to infertility and has viewed infertility as not of significance to the population typically served by social work.

### Assumptions of the Study:

This study is based primarily on three assumptions or theoretical perspectives: general systems, biopsychosocial, and constructivist models.

First, understanding systems theory provides a broad foundation for understanding infertility. Although there may be a relatively simple medical explanation for an infertility problem, systems theory demands a deeper exploration of the obvious or presenting problem by analyzing multidimensional influences of a particular situation (Newman & Newman, 1991). Understanding human behavior is dependent on understanding, the person, the environment, and the interaction between them, thus resulting in a “person-in-the-environment” context (Greene & Ephross, 1991).

Second, infertility is a biopsychosocial phenomena. There are no biological problems without psychosocial implications, and no psychosocial problems without biological implications (Cook, 1987, Greil, 1991; McDaniel, Hepworth, Doherty, 1992). Within Western society, infertility has become medicalized since the medical model attributes pathology to biological and molecular processes (McDaniel, Hepworth & Doherty, 1992).

Although emotional factors were once thought to be responsible for between 40 and 40% of the cases of infertility (Eisner, 1963) current research indicates the actual number of cases of infertility caused by emotional or psychological factors is less than 5% (Seibel & Taymor, 1982). Yet psychological or emotional problems resulting from the stress of infertility may antagonize the existing infertility problem (Monach, 1993).

Third,

Personal Experience of Infertility:

Definition of Key Terms Used in the Study:

Infertility:

Primary Infertility:

Secondary Infertility:

Minority and Oppressed Populations

Assisted Reproductive Technology (ART)

Summary of the Importance of the Study:

Social work's hands are tied in dealing with the phenomenon

Organization of Remaining Chapters:

Personal Interest in the Study:

## ***SOCIAL ROLE OF FERTILITY***

Birth and death are the most basic of human events. Reproduction transcends the boundaries of individual lives to signal the survival and continuation of the family and the species (McDaniel, Hepworth & Doherty, 1992). Accordingly, fertility is revered in almost all cultures and pregnancy is seen as a milestone in adult development (Notman, 1990). Reproduction frequently stands as the marker of adulthood; consequently men and women typically experience both internal and external pressures to have children (Greil, 1991; McDaniel, Hepworth & Doherty, 1992; Monach, 1993).

Since most individuals take the ability to reproduce for granted, the realization of one's infertility usually comes as a shock. It sets the stage for a series of complex reactions that has been referred to as the "crisis of infertility" (Cook, 1987; Taymor, 1978).

## ***DEFINITION OF INFERTILITY***

In order to understand infertility and to measure incidences of infertility, an operational definition is needed. Naturally, infertility is closely related to fertility; thus both concepts need to be defined. One commonly accepted definition of fertility is as follows: for women, it is the ability to conceive and give birth to a live baby and for men it is the ability to impregnate a woman (Menning, 1977). Conversely, infertility is conventionally defined as the inability of a couple to achieve a pregnancy or to carry a pregnancy to term after one year of regular unprotected intercourse (Berger, Goldstein & Fuerst, 1990). These biological definitions of infertility are used when documenting infertility statistics.

Infertility can be broken down into primary infertility and secondary infertility. Primary infertility refers to problems with a first pregnancy, while secondary infertility is the failure to conceive following one or more births (Lauersen & Bouchez, 1992). It is more common for individuals to seek medical treatment for primary infertility than for secondary infertility (Greil, 1991). Women with primary infertility are twice as likely to seek medical services than women with secondary infertility (Hirsch & Mosher, 1987).

In reality, infertility is much more than just a medical diagnosis. Infertility is a stigma. For men, infertility is often taken as an assault on their masculinity (Greil, 1991). For women infertility is equated with barrenness, which history tells us is a curse (McGuirk & McGuirk, 1991). Since the interpretation of infertility is socially constructed (as elaborated in the theory chapter) its meaning has changed throughout history.

## ***PERSONAL EXPERIENCE OF INFERTILITY***

As the author of this paper, I have been able to draw on my own experience. Dealing with and making meaning of my infertility has been an on-going process over the past fifteen years. My personal experience with infertility is only one of the factors which has motivated me to examine

this complex and often misconceived phenomenon further. For reasons to be discussed, the topic of infertility has largely been kept secret, so that the breadth and depth of its impact has not been fully appreciated. Only with the emergence of the deep-seated ethical issues surrounding recent medical “solutions” is infertility becoming a hot social issue.

In hindsight, I now understand how I came to interpret my infertility almost exclusively through the medical model. As a couple, my husband and I had lost our power to control our reproductive destiny. The message we got from the medical community was, “if you just keep trying, eventually you will have a baby.” This kept us on the emotional roller coaster ride of trying the newest technologies. There was no end in sight to the physical, psychological, financial, and marital stress. Given our desire to reproduce, it was hard to get off the medical roller coaster when our infertility was viewed in purely medical terms. Not only were we deeply affected by our infertility, so were our families, extended families, friends, and other support systems around us, such as co-workers, even our insurance company. Our infertility created different meanings for those around us, depending on their values, beliefs, backgrounds, and life experiences. Looking back, it is clear that infertility is a social issue with complex implications.

As I listen to the experiences and stories of people currently experiencing infertility, directly or indirectly, I realize that their experiences are more similar to mine than different. I had assumed that people’s experience of infertility today is very different from when my experience initially began since there is now an increased awareness and understanding of the medical, psychological, and social aspects of infertility. However, recent medical advances appear to have shifted the focus of the infertility experience even further from the psychosocial context to a more narrow medical model emphasis. Therefore, from both my own experience and those of others, I believe that the experience of infertility has become even more complicated. It is increasingly defined within the confines of a medical model, more and more ignoring the broader psychological and social contexts.

## **ROLE OF SOCIAL WORK**

Another reason I chose infertility as my topic is because social work has largely overlooked infertility as a growing social problem requiring the expertise of social work. Traditionally, social work has not been directly involved with infertility except as an adjunct to medical interventions. However, social workers often come into contact with those dealing with infertility. Because of its emotional impact, infertile individuals may seek out counseling. Infertility is often not the presenting problem; but depression may be the predominant underlying theme (Mahlstedt, 1985). Social workers typically work with disadvantaged populations, and infertility is more prevalent in lower-socio-economic groups and in the black community (Greil, 1991; Hirsch & Mosher, 1987; Monach, 1993). Infertile women were significantly less likely to be in higher-status occupations and to have husbands in professional jobs (Mosher, 1987). Estimates based on findings obtained from studies by the National Fertility Study (NFS) in 1965 and the National Survey of Family Growth (NSFG) in 1976, found infertility rates were higher among black couples than white couples (Mosher, 1982). The NSF study was the first national study to include an adequate sample of black women. Infertility among the black couples rose from 16% in 1965 to 18% in 1976 compared with 11% and 9% respectively among white couples. Infertile women were significantly more likely to be black than fertile women, 13% were black compared to 7.5% of

fertile women (Mosher, 1987, p. 620). Accordingly, social workers may—unknowingly—already be working with individuals who are dealing with infertility. Therefore it is important that the social work profession take a more conscious and pro-active role in addressing the biopsychosocial implications of infertility.

Not only should social work address the needs of the infertile individual, but it should also address the needs of the social systems within which that individual exists. The values that social work places on understanding and accepting the person-in-the-environment can positively impact people's experience of infertility. Social work can provide the balance between the medical, psychological, and social perspectives that is frequently missed when infertility is only interpreted within the medical context.

## ***APPROACH OF THIS PAPER***

The argument of this paper is that infertility has become too narrowly defined within the medical model framework, thus primarily influencing how infertility is experienced and understood. The medicalization of infertility that currently exists within technical Western cultures ignores the importance of the psychological and social aspects of infertility. The rationale for writing this paper is to broaden the understanding of infertility from a biopsychosocial perspective so that the social work profession realizes the need for increased involvement with the growing social problem of infertility.

Chapter 1, history, will document the increasing statistics of infertility as a growing social problem in the United States. This chapter will show how the medical model, through the “medicalization” of infertility, has come to dominate modern interpretations of infertility, especially within the last few decades since high-tech medical interventions for the treatment of infertility have developed.

Chapter 2, theory, will discuss how three major theories prominent in social work literature—general systems, biopsychosocial, and social construction—can be applied to the problem of infertility. The rationale for the exclusion of other theories will also be included. The theories presented will serve as the framework for understanding the complex impact infertility has had, not only directly on a couple, but indirectly on the systems that surround them.

Chapter 3, policy, will describe the current state of infertility policy in the United States. This chapter will focus on the developing state of policy and analyze why infertility policy has been slow to develop. Policy from other countries will be presented as a potential model for future policy. Recommendations will be made for the implementation of policy in the United States.

Chapter 4, research, will identify, describe, and critique the three primary groups of infertility research that currently exist: medical, psychosocial, and popular. Social work's lack of involvement in this research will be explored. Future research recommendations will be identified, specifically as it applies to populations not represented in the contemporary research.

Chapter 5, application to social work, will elaborate upon the main themes from the previous chapters which support the importance and the need for increased social work involvement in addressing today's problem of infertility from both direct and indirect practice perspectives. Specific suggestions for social work's contribution will be made.

The conclusion is intended to bring the discussion of infertility full circle by highlighting the fact that infertility is a complex social problem which needs the expertise of the social work profession.

The paper is dedicated to those who have been touched or remain to be touched, directly or indirectly, by infertility.

More than two decades ago I was a new bride, content with my life, but knowing someday my husband and I wanted and would have children. After all, children were something we were seemingly destined to have as we had talked about wanting children long before we married and we both very much wanted to be parents. Having both finished college and having worked several years, our future looked bright and the decision to have children seemed right. Innocently, we assumed that once we were ready for children, the rest would be easy and the excitement of becoming pregnant and eventually parents mounted. But month after month, the disappointment of not conceiving also mounted, and the anticipation of pregnancy leading to parenthood gradually turned into frustration and despair.

After years of misguided trying and confusion, the medical community finally identified our problem as “infertility”, an unfamiliar word in the foreign world of medicine. Misled by the “promise” of a miracle cure, we endured years of unsuccessful medical interventions and treatments. Our embarrassment and shame of being infertile often prevented us from reaching out to those who loved and cared about us and so we often pursued our dream in isolation. As our financial investment in modern medical increased, our emotional resources dwindled until eventually we lost hope of having children. Adoption taunted us as it seemed a reasonable solution. But cruelly, at that time, adoption was also difficult as “normal” babies were at a premium and were frequently only available to an exclusive clientele. Thus, instead of helping us resolve our infertility, adoption was another disappointing dead end. Against doctors’ orders (after all we were told, the technology was there, as long as we kept trying), we finally exited the medical treadmill. However, the strain of infertility had taken a toll on our marriage and sadly, our relationship finally ended in divorce.

I now know many others who have experienced infertility and I have learned from talking and listening to them. But back then, as the “identified patient”, I could only relate to **my** experience and could only feel **my** pain. Although intellectually I knew I was not the first or the only woman to have experienced infertility, I did not know of any one else who was infertile. On the contrary, ironically it seemed, everybody I knew who wanted a baby was able to conceive almost immediately. It took me a long time to remember women, mainly in history, some famous like the barren Biblical characters and the artist Frida Kahlo, and some fictional and infamous, like Martha in “Who’s Afraid of Virginia Wolfe”, who were also infertile. However, knowing other infertile women existed was little consolation as I felt alone in a fertile world.

Many years have passed now and I personally and/or professionally know of many, many women, men, couples and families who have also experienced infertility. I wondered if my experiences of infertility was similar or different to their experiences. Through my research, I discovered that my experience of infertility was more similar than different with those women studied, but that they were similar in background and culture to me. Thus, I couldn’t help wonder if our interpretation of infertility was because we were all women or if it was more influenced by

how our similar backgrounds led to similar interpretations. After all, the population studied was the majority population and women from minority populations were virtually absent from the literature. Therefore my curiosity peaked. How similar or different were all women's experiences or were they dependent on their unique heritages?

This sense of wonder has sparked my personal interest in learning even more about the impact of infertility, especially in populations not yet explored. And as a social worker, I cannot help but wonder what contributions can be made to those dealing with infertility.

The stories of the participants in this study that follow are amazingly individual, although all are woven together by the often unspeakable thread of infertility. Their personal journeys are powerful in their own right, regardless of their collective experience with infertility. I am humbled to think that each participant was so willing, eager even, to share their incredible stories with me and hopefully through me. The trials and tribulations reflected in these pages are a meager offering to their true spirits and voices. I shall always treasure the opportunity this research gave me in coming closer to these women.

## **Chapter Two: Literature Review**

### ***INTRODUCTION TO RESEARCH***

Until recently, infertility research has focused on the medical aspects of infertility. From the previous history, theory, and policy chapters it is understandable why infertility has been researched primarily from a medical perspective. One practical reason is that the medical community has had almost exclusive access to the infertile population as medical treatment for infertility has increased. Medical research has had a willing audience of consumers available for research as they searched for solutions to their own infertility. Furthermore, because of the stigmatizing and private nature of infertility, research into other than medical concerns was restricted and more difficult.

As the understanding of the biopsychosocial nature of infertility has evolved, and the number of people impacted by infertility, directly and indirectly, has grown, so too has the public's awareness of the prevalence of infertility increased. This revelation has helped decrease the secrecy and stigmatization of infertility and has opened up opportunities for expanding infertility research into other dimensions. Expensive, dramatic and painful ART advances have further peaked professional and consumer interest. Questions of the efficacy of intervention are being researched. As more challenging moral and ethical decisions related to treatment arise and as more children are born via ART, many questions requiring research have been posed. The possibilities for infertility research have only recently been realized. Expanded research within the realm of infertility is becoming a new frontier of interest.

A review of the published infertility research indicates that it falls within three distinctive categories geared specifically to three separate and unique audiences. First, the largest body of research falls within medical research. This research is mostly geared to the medical factors related to diagnosis and treatment, although there is a smaller body of material which addresses the psychosocial reactions to infertility. Second, there is a growing body of literature which specifically focuses on the psychosocial factors of infertility, but is written within the medical literature. Third, there is an increasing wealth of popular literature targeted to the infertile population or to a non-professional audience. These writings serve as potential guides or self-help books for understanding personal infertility and infertility in general.

This chapter will identify and critique existing infertility research and literature from each of these three categories as it applies to the broader biopsychosocial theory of infertility advocated in this paper. Recommendations for future research which advance social work's knowledge base in understanding infertility will be articulated.

### ***MEDICAL MODEL RESEARCH***

#### **Identification**

Understanding the technical information in the medical research literature is difficult for those without medical backgrounds, such as many social workers. This body of information is written

for an audience that is sophisticated in the medical diagnosis and treatment of infertility. Obviously, research from this perspective is the most crucial ingredient for understanding infertility from the medical perspective. As ART has continued to advance, and the number of individuals seeking infertility treatment has increased, so too has research from the medical model perspective expanded. The journal, *Fertility and Sterility*, is a good example of this type of research. It is highly technical and it does fill a necessary role in documenting the efficacy of treatment.

Without a doubt, research within this category is the direct result of a medical model theory which strives to understand cause and effect relationships in scientific terms as evidence for medical interventions and more effective medical “cures”. Ironically, medical interventions have offered hope for the infertile population, but simultaneously have contributed to the psychosocial or iatrogenic stressors of the infertility experience as evidenced by the increase in marital distress exhibited by couples in long term diagnostic and clinical interventions (Berk & Shapiro, 1984; Butler & Koraleski, 1990; Cook, 1987; Ulbrich, Coyle, Llabre, 1990). Since the thrust of this paper is not meant to illuminate the medical understanding of infertility per se, this body of information will not be explored further. Suffice is it to say that its importance and valuable contribution to understanding infertility cannot be denied.

Another major contribution of the medical community is its observations of the psychosocial reactions to infertility and the initiation of much of the beginning research in this area. From clinical observations, descriptions of common psychological reactions to infertility have been documented within the medical journals (Bresnick & Taymor, 1979; Mahlstedt, 1985; Menning, 1980). This body of information corresponds and overlaps with other research from the psychosocial literature that will be elaborated upon below. Overall, this body of information suggests that infertile individuals experience similar psychosocial reactions to their infertility, although their individual circumstances and experience of infertility may not be the same.

## **Critique**

In perusing the medical model research one is struck by the technical and empirical nature of this research. Even for a non-medical professional familiar with some of the terminology, the material is so scientific and advanced it almost seems unreal.

Interestingly, not all the information appearing in medical journals is by medical personnel; some is by mental health professionals. Overall this information serves to reinforce the medical community’s role in the interpretation of infertility. Additionally, it acknowledges infertility from the psychological and, to some degree, social perspectives.

The psychological information available in this body of research dispels some of the myths that assume psychological causes for infertility. Previously, when only about one-half of all infertility problems were able to be medically diagnosed, hypotheses about psychogenic causation of infertility prevailed (Cook, 1987; Seibel & Taymor, 1982). Experts agree that infertility can be prompted or even exacerbated by emotional factors (Kaufman, 1970) and that psychological factors may contribute to some types of infertility (Cook, 1987). However, this is not the norm. Current evidence suggests that a direct cause and effect relationship between psychological

factors and infertility is generally illusory (Denber, 1978; McCartney, 1985; Seibel & Taymor, 1982), although current myths about this relationship persist (Cook, 1987).

The psychosocial research within the medical model lacks the rigor of the more scientific empirical medical studies. As explorative studies, the psychosocial information addresses some important questions, but is not convincing enough or thorough enough to answer specific questions. Generally, this data was gathered through informal methodology and not necessarily based on any careful plan or theories. Sample sizes were relatively small and there were no comparison groups identified which could help explain any discrepancies. Although the medical community may not be the best profession to investigate the psychosocial factors of infertility, their acknowledgment of its presence is a validation of its importance in understanding infertility from a biopsychosocial perspective. The empirical medical model also serves as a relevant research model for further research in examining psychosocial considerations.

## **PSYCHOLOGICAL RESEARCH**

### **Identification**

The psychosocial research on infertility has evolved primarily from medicine's observations of the psychological reactions to infertility and reflects the theoretical understanding of infertility already discussed in the theory chapter. Research on the psychosocial nature of infertility tends to be more theoretical than empirical, is more qualitative than quantitative, and often takes the form of individual case studies. It frequently overlaps with the findings reported from the medical community. Other mental health disciplines, mainly psychology, and to a limited degree social work, have also contributed to a growing body of psychosocial research on infertility. Only a couple of references in this paper have been authored by social workers. To date this body of information represents the experiences of heterosexual couples within traditional relationships, who have been involved with some level of medical, mental health, or support group intervention.

Two recent major research studies, Greil (1991) and Monach (1993), have been selected as representative of the current state-of-the-art research on the psychosocial aspects of infertility, although other studies will also be cited as support for these findings. It should be noted that Greil's study included twenty-two married couples who were all Caucasian and from above average socioeconomic levels, living in the Northeastern part of the United States. Snowball sampling was used and data was gathered from a series of "focused" interviews. Although Monach's research was conducted in Britain, findings agree with other studies completed in the United States. This study was selected because it provides some longitudinal data—although only four years after the couples initially entered treatment—regardless of their resolution. In Monach's study, thirty couples were recruited from a prominent university's infertility clinic. Both studies acknowledge that their samples may not be representative of the infertile population.

The research findings from these two studies and other studies support the theoretical foundations addressed in the theory chapter. Infertility is not only a medical problem. For most, it is a life crisis with serious psychosocial implications (Cook, 1987; Greil, 1991; Mahlstedt, 1985; Menning, 1980; Monach, 1993). The psychological stressors in response to infertility set the stage

for a series of complex reactions which has been labeled as the “crisis of infertility” (Taymor, 1978).

Loss is a dominant theme in the two identified research findings (Greil, 1991; Monach, 1993), as well as in numerous other studies (Conway & Valentine, 1988; Halman, Abbey & Andrews, 1992; Mahlstedt, 1985). Following the primary loss—that of a biological child—five groups of associated losses emerge: the experience of pregnancy; childbirth and breastfeeding; parenting; control over relationships; and one’s view of oneself as a fertile individual (Conway & Valentine, 1988). “Having no choice: this was one of the most common ways of describing the feelings of involuntary childlessness; it involved the loss of one of the most fundamental and taken-for-granted choices, the bearing of children” (Monach, 1993, p. 181). Even at their four year follow-up interviews, couples in Monach’s study who had not conceived were still experiencing loss and a lack of control over their reproductive selves.

Although infertility loss parallels other familiar losses, infertility loss is often perceived differently from other traditional losses. Since infertility is the loss of potential, it is an abstract loss. Thus it is seldom acknowledged as a real loss (Menning, 1980). There may be no recognized need to grieve, especially since grief, even after death, is still a difficult topic in Western societies. There are no societal rituals for acknowledging abstract losses, especially those related to infertility. Even the infertile couple may not see or understand the impact of that loss on their psychosocial well-being. There may be uncertainty about the finality of the loss, and support systems may be uncertain of what roles to play.

Research results have identified grief as the most pronounced “emotional” reaction to infertility (Conway & Valentine, 1988; Daniluk, 1991; Menning, 1980; Shapiro, 1982). Grief is the feeling which follows major loss due to the death of a loved one (Mahlstedt, 1985; Conway & Valentine, 1988) or in coping when diagnosed with a chronic illness (McDaniel, Hepworth & Doherty, 1992). Although the quality of grieving is documented as changing over time, the impact of reproductive loss never completely disappears (Conway & Valentine, 1988). The five stage theory of loss/grief proposed by Kubler-Ross (1969) in response to death also applies to dealing with infertility. It includes: denial and isolation, anger, bargaining, depression, and acceptance. However, infertility studies have expanded these stages to also include disbelief and guilt (Menning, 1980). Cook (1987) expanded disbelief to include surprise, and isolation to include anxiety. Realization of the possibility of not having a biological child sets the loss/grief cycle into motion, often before any medical intervention takes place. The treatment for infertility is likely to exacerbate loss/grief reactions.

Feelings other than grief that accompany infertility have also been identified in the research as being present in varying degrees and intensities. A consolidated list of these feelings from several different studies includes: disbelief and surprise; denial; anxiety; anger and loss of control; isolation and alienation from others; guilt, inadequacy, and low self-esteem; depression and grief; and resolution (Harrison, O’Moore, O’Moore & Robb, 1984; Mahlstedt, 1985; Mazor, 1984; Menning, 1980; Shapiro, 1982). Reproductive loss not only results in feelings of anger, shock, unfairness, fear, and sadness, but in a sense of being different from others (Conway & Valentine, 1988). Infertile individuals report feelings of isolation and loneliness from the fertile world and elaborate on these feelings in different ways.

Depression is another common reaction to infertility, primarily among women. It may be more pronounced during the diagnostic and intervention phases of treatment (Mahlstedt, 1985). Depression often follows the sense of multiple losses associated with infertility and the prolonged stress and uncertainty associated with treatment. The depression and preoccupation from infertility can negatively impact one's effectiveness at work (RESOLVE, 1991). Depression is characterized by a sense of hopelessness and despair (Mahlstedt, 1985).

Although a couple faces infertility together, men and women experience the psychosocial reactions to infertility differently. Research suggests that gender differences exist, but more research is still needed in this area. Overall women tend to be more devastated and consumed by the experience of infertility. They give it "master status"; the infertility becomes the focus of the relationship (Greil, 1991). Women tend to think of themselves as inadequate.

Men may feel crushed, not completely a man, when diagnosed with the impairment, but men seldom described themselves as "spoiled identities" (Monach, 1993). Although men were disappointed by infertility, they did not perceive it as life threatening, but as something they could get over. Frequently men's feelings are in response to their wives' reactions to the infertility.

Understanding pronatalism is a prerequisite to understanding how infertility interrupts the developmental life cycle stages discussed in the theory chapter and confirmed in the infertility research. Pronatalism, the attitude that exalts motherhood and assumes or encourages parenthood for all, flourished during the 1970's and 1980's (Monach, 1993). In 1985, only 10% of American women between eighteen and thirty-four did not expect to have a biological child (McDaniel, Hepworth, Doherty, 1993). Although there is a popular assumption that choosing to be childfree is on the rise, this is not proven in the statistics since between 90-95% believe childlessness is an undesirable state for themselves and others (Greil, 1991). Typically, a couple is likely to discuss the question of when to have children, rather than whether to have children (Menning, 1980).

Another theme which permeates the psychosocial infertility research (and was described from a theoretical perspective in the theory chapter) is that infertility disrupts the normative developmental life cycle, thereby creating additional psychosocial stresses on infertile individuals (Greil, 1991; McDaniel, Hepworth, Doherty, 1992; Menning, 1980; Monach, 1993). Greil (1991) asserts that parenthood is the norm, but that biological parenthood is the most desirable. This explains the incredible thrust toward medical resolution. In our pronatal culture, not having children is often interpreted as not moving on to the next stage of adult development (Mahlstedt, 1985). Pejorative terms are typical: "For those who are unsuccessful in confronting the psychological tasks presented by their infertility, the result is not only a failure to meet a crisis, but also a failure to come to terms with the issues related to parenting as a developmental step in the life cycle" (Kraft et al., p. 620-621). Research confirms that the interruption of the normative stage of parenthood because of infertility creates additional psychosocial stressors (Greil, 1991; Monach, 1993) which may potentially have life-long effects on infertile individuals. Thus, it is not surprising to find research results that confirm the impact of infertility on interrupting the life cycle stages and on one's sense of belonging within a normative cycle.

Infertility is reported as a social stigma by many infertile individuals for three primary reasons: the belief that infertility is psychological rather than physical, the association that infertility is equated with sexual incompetence, and the assumption that infertility is a woman's problem (Greil, 1991). Infertile individuals report an invasion of their privacy, a trivialization of

their problem, and an insensitivity of taking fertility for granted. There is some indication that isolation from the fertile world protects the infertile couple from unnecessary painful experiences (Jones, 1991; Menning, 1977). However, the high incidence of suicidal behavior among those without children may indicate the isolating impact of childlessness (Monach, 1993). Suicide rates have been reported to be twice as high for infertile couples (RESOLVE, 1991).

Infertility is an intergenerational crisis which threatens the family and the extended family's future. Anecdotal reports describe the interruption of the normal stages of development of other family members. The inability of family members to understand and discuss reproductive loss is pervasive, possibly because family members themselves are experiencing their own losses, such as the parents of the infertile couple never becoming grandparents (Conway & Valentine, 1988). Bierkens (1975) found that childless couples experience continual discomfort as other family members have children. The discomfort increases when family members do not talk with childless couples about their pain. Friends, too, were perceived as non-supportive, possibly due to their own feelings of discomfort (Conway & Valentine, 1988). Friends and family members' responses further influence the infertile couple's reactions and interpretation of their infertility and their ability to cope with the circumstances.

The discovery of infertility can provoke a complex biopsychosocial crisis which involves an interaction among physical conditions predisposing infertility, possible medical interventions addressing the infertility, social assumptions about parenthood, reactions of others, as well as individual psychological characteristics (Cook, 1987; Taymor, 1978).

## **Critique**

Research about the psychosocial factors of infertility is relatively recent, but has been growing. It is a valuable contribution to the understanding of the devastating psychosocial effects of infertility as well as to dispelling commonly held myths and assumptions about the psychological and emotional make-up of the infertile individual. However, the research described here has narrowly focused on the psychosocial factors of those directly impacted by infertility, with only an introductory understanding to those systems indirectly impacted, such as the extended family.

Although the samples studied in the research have been relatively small, the research designs, repetitive nature, and sampling would indicate high reliability and validity of the findings. However, the samples are not representative of those impacted by infertility. For example, in one study, all but one couple in the sample was Caucasian and all but one couple had at least an Associate's degree (Conway & Valentine, 1988). Samples were generally from those already seeking medical intervention or referred through an infertility support group. Again, they cannot be considered representative of the infertile population. Additionally, since most couples were traditional married couples, the samples have ignored other groups such as non-traditional couples, same sex couples, or single individuals. Those lacking access to expensive health care, such as lower-socio economic groups, were not represented. Current research has not been able to make comparisons between groups of individuals affected by infertility.

Another drawback to this research is that it is not longitudinal and only looks at one slice of a person's life, primarily during the diagnostic and treatment phases of infertility. Understanding

how the impacts of infertility change with individuals over time and across developmental life stages has not been investigated. Additionally those not directly impacted by the infertility experience, such as extended family members, have only barely begun to be studied. Research looking at possible needs of the children born via ART has not yet been undertaken.

Finally, although the research presented represents couples, the emphasis still tends to be on the woman since ultimately it is the woman who becomes pregnant or not pregnant. While differences have been reported between men and women's interpretation of infertility, these differences are only minimally understood.

Although the interest in psychosocial research associated with infertility has increased, it's importance in understanding the experience of infertility is in the infancy stage.

## **POPULAR LITERATURE**

### **Identification**

Although this category is on the borderline of the main scope of this paper, it is important to acknowledge its presence in the literature for two reasons. First, its mere existence speaks to a need. People want more information about infertility. Because of the secret nature of infertility, information has not always been available to the general public. This explains the explosion of recent publications in this category, especially as the rates of infertility have escalated. Individuals want information to assist them in dealing with their personal infertility as well as in understanding infertility in general. Second, this body of information is another avenue for the social work profession to become informed about the intensity of infertility and the problems faced by many infertile individuals.

This grouping of writings is important because it combines both medical and psychosocial aspects of infertility. This section on popular/self-help documentation is to provide an overview, not an in-depth assessment, of the material that falls within this category.

A survey of one of the largest private bookstores in the Denver Metro area and two other nationwide chain bookstores was conducted by this author. Interestingly, all three bookstores had a specific section where infertility literature was housed: within the women's section. Information present in these sections ran the gamut, from case histories written by infertile individuals (Liebmann-Smith, 1987), to self-help resources and reference guides for seeking treatment (Menning, 1977), to books geared only to a specific topic such as surrogacy (Andrews, 1989), to books questioning the moral and ethical dilemmas of ART (Evans, 1989), to those documenting new relationships between technology and conception (Hotz, 1991). The earliest copyright date was 1977 (Menning). Information in this book is still relevant today even though it lacks information about many of the most recent ART developments.

### **Critique**

About twenty books were present among the stores surveyed and several of the books were available at all three stores. Since women seek out treatment more than men, their appearance in

the women's section, instead of general health, was not surprising. Although, most of the material could not be considered scientific strictly speaking, it does provide a form of descriptive information from individual case studies which could be considered qualitative research. The works are not based on theory, nor representative of specific research designs. Much of this information is self-help oriented, in understanding and compassionate ways.

Perusal of these books suggests their intentions are to provide a sense of normalcy to the experience of infertility, partially by bringing it out in the open and demystifying some of the stigmas that have historically shrouded infertility. Additionally this information provides a realistic representation of infertility and its treatment. It shows that not everyone is cured and underlines the emotional and financial costs. It presents not only the miracle cures, but the disappointments of infertility and related medical interventions. It presents realistic stories, whether they result in a baby or not. At the same time it provides hope and some feeling of control to know what options are available.

Clearly, this material addresses the needs of an audience starved for details and coping with the psychosocial reactions of infertility which are documented within these pages. It normalizes the secrecy and stigma of infertility by presenting insightful data that may be more difficult to access via the medical community or directly from someone who has gone through infertility personally. It also provides legitimate well known resources from which additional information can be gathered. It does an excellent job of showing the biopsychosocial components of infertility. This information may also be more readily available to those with limited access to such information, due to geographic considerations or restricted access to medical personnel.

## **RECOMMENDATIONS**

Considering the biopsychosocial nature of infertility, future research should try to integrate the biological, psychological, and social factors inherent to infertility. Historically, medical research has tended to focus on the diagnosis and treatment of the patient. As ART advances, there will be an on-going need to determine the safety and efficacy of new technologies through rigorous and empirical studies. In that sense, medical research has its work cut out for it in immediate research as well as future research needs.

The possibilities for additional research from a psychosocial viewpoint are endless, even when viewed only from a medical model perspective. From a social work perspective, one of the most critical aspects of research that needs immediate attention is to understand infertility from the point of view of those populations not included in the research to date. That is, we need to study lower socioeconomic, minority, and special populations. Current research has primarily focused on the populations already involved with medical or psychosocial support and has ignored the needs of other groups of infertile individuals. Research has confirmed a lot about the infertile medical patient, but not about the infertile non-patient. Since relatively well educated individuals seeking medical intervention have usually been the subjects of research, little is known about disadvantaged populations. Future research must focus on the other groups traditionally served by the social work profession: poor, under-educated, minority, disadvantaged, and special populations.

In addition to research directly addressing the infertile individual or couple, more information is needed on understanding the impact of infertility on other social systems, including family members, extended family members, friends, co-worker, agencies, even communities.

Since infertility is defined by its cyclic nature, future research must also address how infertility may or may not impact individuals once they pass through the developmental stage of child bearing. Current research only assesses one specific period within the infertile individual's life and does not yet understand the effects of infertility over time. Even among individuals who seemingly have resolved infertility (e.g. through adoption) little is known about how other types of resolution come to be and their impact on one's social construction of infertility. Interestingly, popular beliefs among many mental health professionals indicate a higher incidence of emotional problems among adopted children than biological children and question if this may somehow be related to unresolved infertility (Kraft et. al, 1980). Additionally infertility research may be able to contribute to the existing body of information on adoption. Another population also related to infertility is the new generation of children born via ART. It is feasible that their needs are not yet completely understood. Research which addresses infertility has an obligation to understand these children's potential needs. The concerns of reproductive medicine should not end at conception or delivery.

The medical community has been criticized by the infertile population—to some degree behind its back—of not always addressing more of their psychosocial needs. Patients often expect more from physicians than physicians themselves believe they can give. Frustrated, angry patients sometimes want to get back at their physicians, while frustrated physicians often feel: "I can't be all things to all people" (Mahlstedt, 1985, p. 335). The medical community's focus on the patient has been a distracter in understanding how medical personnel can address the psychosocial needs while treating the medical condition. Medicine's motives and procedures of working with the infertile population need to be investigated. Research could assess the medical community's influence, overt or covert, on their patients' decisions regarding medical intervention, especially with regard to continuing or discontinuing treatment.

Regardless of technological advances, medicine alone cannot resolve all cases of infertility. Future research must also learn about the course of these individuals who are the involuntary childless. There has been little follow up of infertile individuals once they leave the medical system. Perhaps they may show up for mental health services which initially seem unrelated to the crisis of infertility. For instance, depression has been reported as being linked with infertility and may be a precipitant to seeking counseling (Link & Darling, 1986).

As technology advances, many infertile individuals and medical professionals treating infertility, have expressed concern regarding moral and ethical considerations related to treatment. This has become the topic for much discussion among medical personnel (Chen & Wallach, 1994; Kempers, 1994). Research which targets understanding how these dilemmas impact and are resolved by infertile individuals, would be a logical next step.

## **RESEARCH SUMMARY**

Some of the highlights of current research studies have been presented here. Additional knowledge from research which addresses the biopsychosocial perspective is needed if social

work is to be effective in supporting those directly and indirectly impacted by infertility. Social work must become more active in initiating infertility research that represents populations not previously studied. Research today lags far behind the need for understanding infertility from a biopsychosocial perspective.

*Chapter Two reviews two main sources of literature about infertility which guided this study: 1) non-technical literature, and 2) technical literature. As a result of this review of available literature, this chapter also discusses the theoretical foundations which provided the framework for this study. The three theories most salient to understanding the experience of infertility are: 1) biopsychosocial, 2) general systems, and 3) social construction.*

## **Non-technical Literature**

Non-technical literature includes biographies, diaries, documents, manuscripts, records, reports, catalogues, and other materials that can be used as primary data (Strauss & Corbin, 1990, p. 48). Non-technical literature can also include information from popular media, television and magazine articles. Much of this literature has sensationalized the experience of infertility by focusing on positive outcomes of Assisted Reproductive Technology (ART) such as the recent birth of octuplets. Other examples include the personal stories of celebrities who have either eventually given birth or adopted. Since these stories generally have happy endings, the general public does not have a realistic impression of the true dynamics of infertility. These isolated stories do not represent the real stories of the majority of individuals adapting to their infertility. Such publicity gives a false impression of the outcomes of infertility treatment and makes ART look like the miracle cure. Due to the expense, usually not covered by insurance, ART is only available to a select group of the infertile population. Many infertile individuals do not choose medical intervention as a viable solution due to personal, financial, religious, or moral reasons. Unfortunately popular literature does not realistically represent the biopsychosocial impacts of infertility on individuals and the systems that surround them. Rather it serves to further alienate the infertile population from the fertile world.

Non-professional written documentation about infertility focuses on how to get pregnant, how to choose a medical specialist or personal anecdotal accounts of one's journey with infertility. Within this body of information there are references made to the psychological and social implications of infertility, but usually within the context of medical intervention. Again, these sources of information tend to focus on outcomes that include parenthood and not on any alternatives other than medical intervention.

## **Technical Literature**

Technical literature includes reports of research studies, and theoretical or philosophical papers characteristic of professional and disciplinary writing (Strauss & Corbin, 1990, p. 48). Technical literature clearly has a different agenda from non-technical literature. Since most of the research on infertility emanated from the medical arena, the original focus of the literature has been on medical diagnoses and intervention. Although the sole emphasis on medicine has slowly been changing, addressing the psychosocial implications of infertility is not the main focus of the medical community. Essentially infertility research has been dominated within the medical community. Again, even though statistics document that men and women are equally affected by infertility, the medical research has focused on women. Since women are the ones who ultimately conceive, they are more likely to seek medical treatment, even if the male is determined to be infertile. Therefore, infertility is erroneously perceived as predominantly a woman's condition.

Women who enter the medical community for infertility treatment are convenient samples for research subjects. Typically women seeking intensive medical intervention such as ART are more likely to be white, college-educated, and affluent. Therefore these women make convenient research subjects. Thus, current research studies do not include a representative cross-section of infertile individuals, even of women. Infertile individuals from other populations, particularly women from minority populations, have been ignored despite higher incidences of infertility in those populations.

Since the focus of this study is on the psychological and social implications of infertility, strictly medical findings will not be reviewed here. Rather findings that address the more biopsychosocial implications will be addressed.

Preliminary research findings indicate women and men typically react differently to infertility. Although gender differences have not been adequately explored, since women have been studied more than men, overall women are more negatively impacted by the experience of infertility than men.

Involuntary childlessness places additional stresses on the infertile couple's relationship. Infertility triggers the loss-grief cycle and in women is often accompanied by depression. Due to the cyclic nature of infertility, each month reinforces the roller coaster nature of dealing with infertility and can make absolute resolution more difficult since the progression through the typical developmental life stages is interrupted. Infertility tends to deepen women's sense of isolation and chasms develop between the fertile and the infertile worlds. Additionally negative overt and covert pressures are put on the infertile individual and the couple from the systems that surround them, despite others' seemingly positive intentions.

## **INTRODUCTION TO THEORY**

As evidenced in the preceding history chapter, current understanding of infertility in the United States is primarily constructed through its *medicalization* or from within a medical model perspective. However, there is much more to understanding infertility than understanding its medical component. This chapter will focus on the most relevant social work theories that support

a broader understanding of the complexity of infertility. The theories to be discussed include: 1) general systems theory; 2) biopsychosocial theory; and 3) social construction theory.

The theories presented here were deliberately selected as the most salient ones for increasing the understanding of infertility while providing an integrated overview of the complexity of infertility. Admittedly, other social work theories are also relevant to understanding infertility. Their exclusion from this paper is a factor of both space and focus. Feminist theory was omitted because an emphasis from this perspective runs the risk of further delineating infertility as a “women’s problem”. Infertility impacts men and women almost equally, although differently, and this paper’s focus is on those impacted, directly and indirectly, by the experience of infertility. Since social construction theory is included, feminist theory can be viewed as an extension of that theory. Similarly, communication, role, empowerment, and cognitive theories could also all be applied to this topic, but critical aspects of each theory are represented or alluded to within the theories presented. Ecological theory may have been another appropriate approach, but was eliminated since systems theory generally encompasses ecological theory and this paper’s emphasis on the biopsychosocial is grounded in general systems theory.

General systems theory (also referred to here as systems theory for ease in reading) has been selected as the primary theory since it is the skeletal framework for applying a biopsychosocial framework in understanding infertility from a broader perspective. Additionally, general systems theory is the contemporary foundation of much of current social work practice (Turner, 1974). Systems theory will be used to explore how infertility impacts many different systems, even when only one person has been identified as the “infertile patient”. More specifically, the use of systems theory will focus on the biological, psychological, and social subsystems.

Within this biopsychosocial perspective, the medical model will be elaborated upon as a particular form of biological theory. It is important to situate the medical model since it has come to dominate current understanding of infertility. It will serve as a comparison for the other theories presented, specifically as a contrast to the psychosocial theories. The psychosocial perspective will be examined by seeing how developmental or life cycle and loss/grief theories pertain to infertility.

As seen in the history chapter, the meanings given to infertility have changed depending on the beliefs and values of a particular society within a specific historical period. The social construction of reality theory makes the assumption that one’s unique interpretation of infertility is based on the experiences of an individual from within his/her personal environment and culture. It therefore provides a theoretical framework for analyzing the historical development of the current understanding of infertility, including the medical interpretation.

These theories were chosen because they represent a comprehensive understanding of infertility from the broader biopsychosocial perspective. By examining these theories, it is hoped that the reader will come to appreciate infertility from several different and complex, but complementary theoretical bases.

## **GENERAL SYSTEMS THEORY**

Overall, general systems theory is most relevant to understanding infertility since it lays the foundation for understanding infertility from a broad perspective. Systems theory originated from

a biologist's, von Bertalanffy, understanding of organisms as systems (Rodway, 1974). It has subsequently been generalized to apply to social systems, such as groups, families, and societies (Payne, 1991). Systems theory invites one to look beyond the obvious or presenting problem. It does not focus on simple cause and effect relationships, but rather analyzes the multidimensional influences of a particular problem (Newman and Newman, 1991). Systems theory and ecological theory have formalized the idea that understanding human behavior is dependent on understanding the person, the environment, and the interaction between them. From this, the person-in-the-environment concept, a central premise to social work practice, has evolved (Greene & Ephross, 1991). Within social work practice, systems theory can be implemented at three different practice levels: micro, mezzo, and macro (Zastrow, 1992). Using these levels as a framework, the person-in-the-environment assumption can help to clarify current understanding of infertility.

### **Micro Level**

In thinking about infertility, the micro system level is key since a married couple comprises a micro system. Traditionally a couple seeks parenthood as a couple. Whether one partner or the combination of the two partners is physiologically responsible for the infertility, it is the couple that is affected since the medical diagnosis of infertility impacts men and women almost equally (Greil, 1991; Menning, 1984; Monach, 1993). Infertility embroils a couple in the gender politics of marriage (McDaniel, Hepworth, Doherty, 1992).

One of the problems frequently reported by infertile couples is the invasion of their privacy and intimate areas of their relationship, primarily their sex lives (Greil, 1991). This in turn can create a host of additional problems around trust and intimacy (Monach, 1993). Women may adjust better to infertility if they have a confiding relationship (McDaniel, Hepworth, Doherty, 1992), while men often are stigmatized by the experience and seek to maintain privacy through secrecy (Greil, 1991). Greater emotional and marital difficulties have been reported by both men and women when the underlying cause of infertility is attributed to the man (Connolly, Edelman & Cooke, 1987).

### **Mezzo Level**

On another level, mezzo systems that include family, friends, church, groups, and work, to name a few, are also impacted by a couple's infertility. Infertility is an intergenerational crisis since it threatens the loss of the family's future (McDaniel, Hepworth, Doherty, 1992). Couples may experience pressure to have children to extend the family tree. Often potential grandparents may question if somehow they caused the infertility. This is especially the case for women who took the drug diethylstilbestrol (DES) to maintain their own pregnancies (Greil, 1991; Menning, 1977).

Numerous case studies report the "split" between the fertile world and the infertile world as being a painful alienation and isolation for the infertile individuals (Greil, 1991; Monach, 1993). Because of the secret nature of infertility, friends or co-workers may not know specifically about the infertility, but sense something is wrong or different. They may be unsure how to go about supporting a couple (McDaniel, Hepworth, Doherty, 1992).

## **Macro Level**

On the macro system level, even larger social systems such as governments, agencies, and organizations experience the societal effects of infertility (these will be elaborated on in the policy section). Federal and state legislators are under pressure to more directly address statutes and policies related to infertility. For instance, the advocacy group RESOLVE has worked diligently to bring the concerns of the infertile population to the attention of national and state policy makers. Insurance companies have also experienced the need to adjust policies related to infertility. Federal and state legislators are under pressure to more directly address statutes and policies related to infertility.

In summary, systems theory stresses that a change in one part of the system naturally impacts other parts of the same or other systems. Three key concepts of systems theory are: wholeness, relationship, and homeostasis (Zastrow, 1992). With these concepts, systems theory can help deepen our understanding of infertility at all three levels of social work practice.

*Wholeness* means that the sum is more important than each of the individual parts. Thus in a married couple, the family unit is the critical level of analysis. If one person is identified as infertile, the couple, is in many ways more affected than the particular infertile individual. This means that the *relationship* between the parts, the interaction and communication between two individuals within the couple, is more important than the problem element itself, the infertility of one, the other, or both partners. How infertility is interpreted and communicated about is more critical than the specific physical cause(s) of the problem. *Homeostasis* implies that systems seek to maintain balance in order to preserve themselves. By its very nature, infertility upsets the previous balance in a couple's relationship regardless of how stable that balance may or may not have been. Attempts to maintain or regain that established sense of balance can create additional disequilibrium. Often, an outside observer, such as a social worker, can recognize the destabilizing behaviors and aid the homeostatic function.

## **BIOPSYCHOSOCIAL THEORY**

Biopsychosocial theory is an integration of several other theories: biological, psychological and social theories. The term biopsychosocial refers to the idea that problems are at once biological, psychological, and social. Essentially, there are no biological problems without psychosocial implications, and no psychosocial problems without biological implications (Cook, 1987; Greil, 1991; McDaniel, Hepworth, Doherty, 1992). The medical model is an instance of a purely biological theory. Although there may be simple or complex medical reasons to explain infertility, other psychosocial factors, such as familial, gender, and cultural, also impact and influence one's interpretation of the infertility experience. Until recently, psychological or social factors have not been adequately addressed within the medical model. Additionally there has been less than an ideal professional interaction between the medical and mental health communities (McDaniel, Hepworth, Doherty, 1992).

Biopsychosocial theory provides a framework for understanding the complex interactions between all the systems affected by infertility. The biopsychosocial approach, also referred to as medical family therapy, is founded on the premise of systems theory as developed in family therapy, but applied to the modern medical model (McDaniel, Hepworth, Doherty, 1992). This

approach is characterized by conscious attention to the medical condition and its role in the personal life, not only of the patient, but of the interpersonal life of the whole family and other impacted systems.

In examining the biopsychosocial theory, it is important to understand the influences of the underlying theories that comprise it: biological or medical model theory and psychosocial theory.

### **Biological or Medical Model Theory**

The history chapter has documented the evolution of present day understanding of infertility as rooted within medicine or the medical model. Infertility has become medicalized. The medical model attributes pathology to biological and molecular processes (McDaniel, Hepworth, and Doherty, 1992). In approximately 90% of the cases referred for infertility treatment, a physical reason for the infertility can be diagnosed (Greil, 1991; Monach, 1993). If emotional or psychological problems are deemed to cause a medical condition, such as infertility, the medical model identifies these instances as mental illnesses (Zastrow, 1992). At one time, 40% to 50% of infertility cases were thought to be caused by emotional factors (Eisner, 1963; Seibel & Taymor, 1982). Although mental illness is still linked to some cases of infertility, current research would indicate this accounts for less than 5% of cases (Seibel & Taymor, 1982). However, infertility has been well documented as leading to psychological or emotional problems that may antagonize the pre-existing infertility (Monach, 1993). Both men and women undergoing prolonged and extensive clinical investigation and treatment for infertility report increased emotional and marital difficulties (Connolly, Edelmann & Cooke, 1987).

Within the medical model framework, it is an unspoken assumption that clienthood and autonomous selfhood are mutually exclusive concepts. Clienthood has far-reaching effects on clients, their families, and society as a whole (Holmes & Saleebey, 1993). Holmes and Saleebey contend that medical professionals come to “own” the client, giving or withholding services according to how well the patient plays the role in terms of dependence and acquiescence. Thus when a patient plays the role well the possibility of self-management and decision making is diminished.

Infertility is commonly identified as an illness, mostly a chronic illness, since it is often long-term, is shrouded in uncertainty, and can dominate and intrude on one’s life. However, it may be more appropriate to consider infertility as merely analogous to illness, rather than to say it is a type of illness. It differs from illness in three significant ways (Greil, 1991). First, infertility typically impacts more than just the identified patient. It primarily affects the couple, as discussed above in the section on systems theory. Other illnesses primarily affect the patient who has the illness; thus other systems are impacted only indirectly. Second, infertility is not necessarily the result of a pathological condition. Rather infertility is the absence of a desired condition. Thus, it is theoretically impossible for an infertile woman to be diagnosed as normal, even when there is no pathology. Infertility can be considered idiopathic in nature. Third, infertility does have solutions other than biological resolution. That is, infertile individuals have choices other than biological conception, such as adoption or childfree living. (These potential alternatives present their own social work issues, which will not be explored further since they are beyond the scope of this paper). Since fertility is cyclic, whether naturally or medically regulated, there is often hope that conception might occur. Infertile individuals are seldom told by the medical community that they

have no chance for conception (Greil, 1991; McDaniel, Hepworth & Doherty, 1993; Monach, 1993; Taylor, 1990).

Despite the differences from chronic illnesses, infertility has come to be understood through a medical model theory. It is now perceived as a medical condition or an illness. Infertile individuals seek out medical advice and expertise to resolve their infertility. This further reinforces a medical framework. As a practical consequence, office visits for the medical treatment of infertility almost tripled during the period 1968-1984 (Greil, 1991).

The medical interpretation of infertility is part of a larger social trend. The medical profession has substantially increased its power over women's health in general. In 1981, 61.9 % of all visits to gynecologists were for reasons other than illness (Greil, 1991). A statistical indicator of the growth of this trend is that membership in the American Fertility Society, the major organization for physicians specializing in infertility, more than tripled during 1968-1984 (Greil, 1991).

The medical model's focus on highly technical medical solutions has guaranteed the medical community's dominance in the field of infertility. ART's response to the treatment needs of the infertile population further assures the prominence of the medical model as the primary framework for interpreting infertility.

### **Psychosocial Theories**

Infertility is not just a problem which may require medical intervention. For most infertile individuals and families it is a life crisis with serious psychosocial implications (Cook, 1987; Mahlstedt, 1985; Seibel & Taymor, 1982). The emotional reactions which develop as a result of realizing one's infertility has been called "the crisis of infertility" (Seibel & Taymor, 1982). Erikson's developmental theory provides a framework for understanding how infertility interrupts the normal developmental and emotional stages of life and for understanding how infertility triggers the loss/grief cycle theory of Kubler-Ross. These two theoretical views will be elaborated on in this section.

#### *Eriksonian Theory: A Developmental Approach*

Erickson understood human development to be the interaction between the individual (psychological) needs and abilities and the societal (social) expectations and demands (Erickson, 1950). One of Erickson's major contributions is his conceptualization of a developmental approach to ego mastery, which must occur before passing on to the next life stage of development (Greene & Ephross, 1991). Erickson's focus on a biopsychosocial view of development has contributed to social work by providing a less fatalistic and medical model view of an individual's unique personality (Newman and Newman, 1991).

Although Erickson's original work only proposed eight stages of psychosocial development, subsequent theorists expanded those initial eight stages to reflect a changing culture where adults are living longer. Infertility is not considered an interruption of the normal developmental cycle until Erickson's Stage VI, Young Adulthood. Here, child bearing is considered the norm. Although child bearing can happen in the earlier Stage V, Adolescence, this is not the norm. Stage VI encompasses ages 22-34, the time when the focus shifts from self to other. Typically partners are

selected and intimacy becomes the focus. Families and children are created during this stage (Newman and Newman, 1991). Reproduction is seen as a prominent marker of this stage, so infertility is seen as an interruption of normal development (Butler & Koraleski, 1990; Kraft, Palombo, Mitchell, Dean, Meyers, Schmidt, 1979; McDaniel, Hepworth, Doherty, 1992). Developmentally, infertility represents a failure to achieve one of life's milestones. Erikson (1974) believed that young adults were moving toward the stage of generativity and that having children was "the first, and for many, the prime generative encounter" (p. 130). Failure to produce children can be a block to ego development (Lindell & Dineen, 1986). For some, the lack of children may make their life seem pointless (Corson, 1983).

The discovery of one's infertility results in an identity crisis since the normal societal expectation of parenthood has not been achieved (McDaniel, Hepworth, Doherty, 1992). Infertility not only interrupts Stage VI, but to some degree it impacts all the remaining stages. Each subsequent stage of development has some link, although not necessarily primary, with being a parent. In addition to interrupting the current life stage of the infertile couple, future life stages (e.g., being grandparents) are also interrupted. The couple's parents may feel robbed of the opportunity to interact with grandchildren (McDaniel, Hepworth, Doherty, 1992). From the psychosocial developmental perspective, unresolved infertility can potentially disrupt one's entire adult life.

Family loyalty is based on biological hereditary kinship (Boszormenyi-Nagy & Sparks, 1973). Couples may feel internal and external pressure to become parents. Parenthood is an extended family event that immediately changes the new parent's relationship with their parents (McDaniel, Hepworth & Doherty, 1993). Emotional and biological continuity from generation to generation helps form family identity, legacy and myths which further pressure young adults to reproduce. Society also reinforces personal feelings of inadequacy since the value systems of others treat childlessness as inappropriate (Matthews & Matthews, 1986a). Couples receive messages that somehow they are "unfulfilled, lacking in adult adequacy, immature, or selfish" (Valentine, 1986, p. 66).

Although delayed childbearing has become acceptable and the perception may be that couples are choosing to be childfree, the "norm" is still on marriage and children. The number of young adults who plan or intend to remain childless has not increased significantly in the twentieth century (Newman and Newman, 1991). In 1987, only about 5% of married women expected not to have children and of those who anticipate marriage, only about 5% expect to have no children by choice. However, some of these may in fact be infertile and thus would have had "no choice" had their infertility been identified (Monach, 1993). Even a conscious decision to delay childbearing or to remain childfree means potentially addressing issues of fertility. This still disrupts the developmental stage as adults and makes even the transition to voluntary childlessness stressful (Ulbrich, Coyle, Llabre, 1990). The general unacceptability of childless families in society (Lalos, Lalos, Jacobson & von Schoultz, 1986), jealousy toward family and friends with children, and the isolation felt by the infertile couple (Butler & Koraleski, 1990) contribute to their difficulty of adapting to the life stages that traditionally include children.

Not only does infertility impact each individual's developmental stage, infertility disrupts the couple's developmental stages as well. The transition to non-parenthood has been well documented as different for males and females (it will be elaborated on below within the social construction theory section). Matthews and Matthews (1986b) describe this transition as a

“status-passage” which poses a threat to the couple’s shared realities and necessitates the construction of new shared realities (Greil, Leitko, Porter, 1988).

One’s ability to reproduce is taken for granted and infertility is an unexpected disruption in most peoples lives (Butler & Koraleski, 1990; Menning, 1982. When that expectation is lost, it creates a series of psychosocial reactions. The loss of one’s reproductive self can prevent one from moving into the next developmental stage. The experience of infertility is most commonly described as not having choice since it involves the loss of one of the most fundamental and taken-for-granted choices, the choice to bear children (Monach, 1993).

### *Loss and Grief Theory*

One of the most prominent themes surrounding infertility is the profound sense of loss, which dominates the infertility literature (Cook, 1987; Mahlstedt, 1985; Menning, 1977, 1982, 1984). Adapting loss/grief theory, developed from Kubler-Ross’s (1969) work with death and the dying, to infertility has provided insight into the losses experienced with infertility. Obviously, infertility’s major loss is that of having a biological child (Conway & Valentine, 1988). The feelings associated with this loss have often been equated with the feelings at the death of a loved one. Five stages of grief from this loss/grief theory include: denial and isolation, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). Experts in the field of infertility have expanded these states to include disbelief and guilt (Menning, 1980) and surprise and anxiety (Cook, 1987).

Grief is the internal process of re-establishing emotional and cognitive equilibrium after the disorganizing effects of experiencing a loss (Cook and Dworkin, 1992). It is a natural response to loss (Bowlby, 1980). Grief can also be a reaction to non-death losses such as infertility (Shapiro, 1982). Grief in response to infertility is unique since the process of dealing with infertility tends to be cyclic and may be recurring with each menstrual cycle (Monach, 1993). Overall there is not just one significant event which triggers the loss/grief cycle, but a series of losses, even on a monthly basis. Thereby, grief is triggered on a recurring basis.

Other losses related to the loss of the “hoped for child” include: loss of the experience of pregnancy, childbirth, and breastfeeding; loss of parenting; loss of control; loss of relationships; and loss of the view of oneself as a fertile individual (Conway & Valentine, 1988).

## **SOCIAL CONSTRUCTION THEORY**

The social construction of reality theory is rooted in sociology. The basic premise of social construction theory is inherent in its title: “reality is socially constructed and the sociology of knowledge must analyze the processes in which this occurs” (Berger & Luckmann, 1966, p. 1). Translated to infertility, the existence of a physiological impairment in one or both partners (the medical condition) does not in and of itself determine the course of the couple’s experience of infertility. Rather, the process of being infertile is dialectical; spouses interpret, respond to, and give meaning to physical symptoms and psychological conditions (Greil, 1991, p. 6). Thus the most important decisions about infertility—whether to pursue treatment, stop treatment, initiate adoption etc.—are not medical decisions at all (Greil, Leitko, Porter, 1988). Interpretations of

infertility are socially constructed from the ideology and social structure of the society in which people live. Greil (1991) says it well:

... it [infertility] is influenced, among other things, by the nature of medical technology in a given society, by the function of marriage and the family in that society, by role expectations for men and women, and by the social value of children. It is also influenced by beliefs about the importance or non-importance of blood relationships, by ideas about the relative contributions of men and women to the processes of conception and child rearing, by general theories about the causes and cures of health problems, by societal beliefs about the nature of moral action and the causes of suffering, and so forth. (p.7)

From the perspective of social construction theory, infertility is not a static condition with predictable psychosocial outcomes, but rather a dynamic, socially conditioned process that changes as individuals struggle to deal with and to make meaning of their unique experience of infertility. Often the process of constructing meaning about infertility begins once a couple suspects a problem, even before medical treatment is sought (Greil, Leitko, Porter, 1988). Socially constructed definitions of infertility include: the absence of a desired state (Greil, 1991) or the failure of conception within a specific timeframe (Monach, 1993).

Social construction theory is critical for understanding how different people interpret infertility. In particular, it can help to expand current thinking about how infertility impacts minority and special populations since their ideology and social structure may be significantly different from that of the majority population, but are living within a dominant culture. As will be seen in the research chapter, more work needs to be done about understanding possible differences. However, to provide a flavor for the importance of socially constructed interpretations, three variables which influence the interpretation of infertility will be presented briefly: culture, gender, and socio-economics.

### **Cultural Differences**

Cultural differences are a poignant way to show how different interpretations of infertility evolve from particular social contexts. Although most cultures do not attribute a single cause to infertility, there are fundamental ideas or beliefs which influence the meaning given to infertility. The following example was selected from many examples since it depicts a similar value, but reflects opposite practical applications (Greil, 1991).

Korea and Taiwan provide good examples of cultural differences. Many values are similar, but other related values are the antitheses of each other. In both Korea and Taiwan, a son is traditionally required to perform ancestor rituals and to insure family continuity. Therefore, having no sons is similar to being childless. The lack of a son is equated with being childless or essentially infertile. Yet, within these two cultures where such a similarity exist, there is a vast difference in how blood relatives are perceived. In Korea, one can solve being sonless by adopting. However, in Taiwan blood relations are considered more important and it is more feasible to adopt a daughter in the hope that she will “call in a younger brother.” Not only do cultural differences exist for the causes of infertility, but also for the remedies. Both must be understood when evaluating how culture impacts the interpretation of infertility. Adoption is not a universal answer to infertility.

This example may not seem representative of understanding diverse groups currently residing in the United States. However, from the history chapter it is clear that even erroneous historical beliefs influence modern day thinking. The influence of past socially constructed interpretations may be subtle and an individual's degree of identification or acculturation may temper a particular interpretation. Even in industrialized societies, the understanding of infertility is not based exclusively on scientific evidence or logic. In the United States, a highly technical society, many traditional infertility myths are still prevalent. The following are a few of the more common myths (followed by the scientific facts in parentheses): 1) Infertility is a female condition. (Infertility affects males and females almost equally). 2) Infertility is all in the individual's head; it is a psychological rather than a physiological problem. (The psychological impact of infertility is the result of the infertility, not the cause). 3) Infertile people have no right to get pregnant in an already overpopulated world. (Zero population growth allows each couple to produce 2.11 children) (RESOLVE, 1993). Other anecdotal advice is reported by the infertile population and supports cultural differences about infertility and resolution. Many infertile people are advised: adopt and pregnancy will follow, relax, or go on a vacation (Monach, 1993; personal communications, 1994). These are just a few on the list of advice, but the list is endless and depends on one's cultural beliefs and values.

### **Gender Differences**

Infertility as a medically diagnosed physiological characteristic of individuals (often called reproductive impairment) must be distinguished from infertility as a socially constructed reality. One of the biggest differences in interpretations of infertility is related to gender. Infertility impacts women differently than men (Connolly, Edelmann & Cooke, 1987; Greil, Leitko, Porter, 1988).

Essentially, the biological drama of infertility, regardless of the root cause, is played out in the woman's body since she is primarily the subject of medical interventions. Even if the infertility problem is male related, there is still a tendency for a woman to perceive the situation as her problem (Greil, Leitko, Porter, 1988). The medicalization of infertility impacts the woman greater than a man since women become accustomed to medical intervention in managing other aspects of the couple's reproductive life, such as birth control (Monach, 1993). Socialization and biology combine to teach women that they are the childbearers and childrearers (McDaniel, Hepworth, Doherty, 1992). A women's recurring menstruation serves as an on-going reminder that something is amiss. Since women typically utilize medical services more than men, it is no surprise that women initiate medical intervention for infertility treatment more than men, often under pressure from their husbands (Greil, 1991).

Women may be more emotionally impacted by infertility and have more negative outward psychological responses than men. Women experience infertility as a serious crisis, whereas husbands perceive it as disappointing, but not an emergency (Lindell & Dineen, 1986). Women's medical visits for infertility have risen substantially while men's have remained virtually the same (Greil, 1991). There is an underlying, usually unspoken, assumption that being childless is the women's fault, which is bound to impact a couple's interpretation of infertility.

In America there is not the same mandate for fatherhood as there is for motherhood. Nevertheless, infertility may be more stigmatizing for a man than a woman since infertility

becomes associated with male impotency (Greil, 1991). Men are expected to carry on the family line, and traditionally children signal a man's virility (Stotland, 1990). Furthermore, men often experience the emotional aspects of infertility based on how they perceive the impact on their wives (Monach, 1993).

Cultural difference also impact a specific gender's interpretation and response to infertility. In African Dogan society, when children are not present in a marriage the man is encouraged to divorce and remarry. Some cultures support the man in taking a second wife (Greil, 1991).

### **Socioeconomic Differences**

Currently there is more speculation than documentation about potential differences in interpretation of infertility related to socioeconomic status. The socioeconomic debate is important when applying a socially constructed theory. What is known is that the incidence of infertility is higher in lower socioeconomic groups (Hirsch & Mosher, 1987), while treatment of infertility is positively correlated with higher socioeconomic status (Greil, 1992). Women from middle class or higher economic classes seek treatment more often than women from lower socioeconomic groups, but this is true of all reproductive medicine (McDaniel, Hepworth, Doherty, 1992). Are these current statistics indicative of one's interpretation of infertility or simply the result of financial resources? In order to fully understand socially constructed interpretations of infertility, this question must be more adequately addressed (it will be elaborated on in the research chapter).

## ***THEORY SUMMARY***

As those impacted by infertility continue to interpret and re-interpret their experience of infertility, social workers with a strong knowledge of the underlying theories will be in excellent positions to support the infertile population and other impacted systems. These theories are the basis for social work's interest in future research, policy development, and integrated practice to be discussed further in the following chapters.

### ***Biopsychosocial Theory***

Instead of viewing infertility as only a medical condition, biopsychosocial theory is a more accurate description of infertility since there is a biological component as well as psychological and social implications. Although science has created a broader knowledge base for understanding the physiological roots causing the infertility, the medical community has been lacking in addressing the psychological and social needs of the infertile population. Yet these non-medical

needs are critical, especially when advanced medical treatments turn out to be long term or unsuccessful.

### ***General Systems Theory***

General systems theory sets the stage for understanding infertility from a broader perspective and invites a deeper look at infertility as not just a biological problem. The person-in-environment concept, central to social work practice, serves to explain how when one system, the infertile individual, is impacted, so too are other systems. With infertility, not just the infertile person is affected, but also other systems, such as the partner relationship, immediate and extended families, friends, colleagues, and the surrounding systems, are also impacted.

### ***Social Construction Theory***

Many factors influence how infertility is interpreted. Considering all the variables that contribute to one's understanding of infertility, social construction theory is pertinent. Factors such as gender, religion, relationships, culture, race, ethnicity, age, economic status, education, medical intervention all contribute to how infertility is perceived and attempted to be resolved. Although the characteristics of the experience of infertility may be similar, each individual has a unique experience and interpretation of their own journey with infertility.

Social construction theory emphasizes the importance of the human capacity to tell narratives that give meaning to life. Geertz (1973) argues that human life would be too chaotic if our culture did not provide narratives about what it means to be a productive member of society. Bruner (1990) stresses the role of autobiographical narrative in the individual's construction of identity within their social context. More specifically, Lave and Wenger (1991) argue that a crucial role of support groups like Alcoholics Anonymous is to provide a safe community in which members can learn how to construct their own stories. This social construction perspective analyzes the constraints on autobiographical narration imposed by the social context.

## **Chapter Three: Methodology**

*Chapter Three provides detailed descriptions and discussions of the procedures used in this study. Included in this chapter are purpose and research question, research design and approach, theoretical perspectives, researcher's role, responsibilities, and presuppositions, data collection and analysis, and assessing the quality of the research*

### **Research Purpose and Question**

The purpose of this study is to understand the experience of infertility in women from previously unstudied populations. Thus, the research question of: "What is your personal experience of infertility?" was the grand tour question which was followed by a series of subquestions.

### **Research Design**

Considering the exploratory nature of this study, a qualitative design was implemented. A qualitative study uses a constructivist or naturalistic approach (Lincoln & Guba, 1985). The only reality is that constructed by the individuals involved in the research situation (Creswell, 1994, p.4). This research design was used so that the data would speak to the researcher and subsequently to the readers.

### **Theoretical Perspective**

Although several different theoretical perspectives were appropriate for this study, and pieces of other approaches were utilized to some degree, the heuristic approach was most fitting for two primary reasons: 1) The heuristic approach focuses on discovering the nature and the meaning of the experience and 2) heuristic inquiry assumes the researcher has some personal experience with the phenomenon being studied and is able to go beyond description to capture the essence.

Heuristic research is a journey not only of the participants, but of the researcher. Through exploratory open-ended inquiry, self-directed search, and immersion in active experience, one is able to get inside the questions, become one with it and thus achieve an understanding of it (Moustakas, 1990, p. 15). Unlike phenomenology which encourages a detachment from the phenomenon being investigated, heuristic inquiry emphasizes connectedness and relationship. The main research question develops from an intense interest in a particular topic. Implicit in heuristic inquiry is the notion of tacit knowledge, we can know more than we can tell. In heuristic inquiry, the researcher bridges between the explicit knowledge and the tacit, creating almost an intuitive level of understanding. Having personal experience with a particular phenomenon facilitates that depth of understanding.

Heuristic inquiry places the emphasis on the researcher's internal frame of reference, self-searching, intuition, and indwelling to portray qualities, meanings, and essences of unique experiences (Moustakas, 1990, p. 12 & 13). Data generated is dependent upon accurate, empathic listening; being open to oneself; being flexible and free to vary procedure and to respond to what is required in the flow of dialogue; and being skillful in creating a climate that encourages the

participant to respond comfortably, accurately, comprehensively, and honestly in elucidating the phenomenon (Moustakas, 1990, p. 48).

## **Research Approach**

Raw data needs to be developed into useful information. Therefore, a grounded theory method of analysis was utilized in this study. Grounded theory, the discovery of theory from data, systematically obtained and analyzed, is inductively derived from the data (Glasser and Strauss, 1967, p. 1).

## **Research Process**

The information necessary to understanding why this study was undertaken and the framework for implementing the study have already been discussed. The purpose of this section is to provide insight into the nuts and bolts methodology of the study. Thus, sample, interview guide, interviews, ethical considerations, role of researcher, and research quality will be elaborated upon.

### **Sample**

In keeping with a qualitative research study, purposeful sampling was implemented. Purposeful sampling relies on selecting information-rich participants for in-depth study (Patton, 1990). A form of snowball or chain sampling was implemented by contacting well-situated people in an attempt to secure an intensity sample which is often used with a heuristic approach. An intensity sample consists of information-rich cases that manifest the phenomenon of interest intensely (but not extremely) (Patton, 1990, p. 171). With intensity sampling, some prior information and judgment must be executed to determine the appropriate sample. Extreme cases do not lend themselves to the reflective process of heuristic inquiry and thus were not part of the sample.

From the literature review, it was obvious that only a specific group of infertile women had been studied. These women were predominantly from upper middle class, educated, and white populations. They had sought ART in resolving their infertility. Women from minority populations had virtually been ignored in the infertility literature. Thus the first criterion for my sample was women from minority populations who identified as being infertile.

Other criteria that emerged as relevant from the review of literature was accessing some diversity with regard to education and socio-economic backgrounds.

Chapter Four further describes the sample in more detail.

### **Interview Guide**

Based on a review of the literature, professional experience and personal experiences, an initial interview guide was developed. Although a heuristic approach is open-ended, an interview guide was determined an important tool so that the same information could be covered with each

participant. However, the guide, was only intended as that, a guide, so as not to stifle the open-ended nature of this study. See Appendix H.

Once the guide was developed, an expert panel was asked to review the guide and provide input at several different stages of revision. The expert panel consisted of an infertility nurse, a professor of social work who specializes in qualitative data, and an infertile woman from a minority population who was willing to support this project, but who did not want to be a direct participant.

Subsequently the revised guide was used with a “mock” participant who was not part of the formal study, but who was infertile. Essentially, a grand tour question asking the participant to describe their experience of infertility in their own words is followed by several sub-questions. The final interview guide can be seen in Appendix . Throughout the interview, participants were asked to clarify certain statements and probing questions were asked for more details. The interview guide did not hinder the quality of the interaction, but rather focused on assuring all participants had ample opportunity to address certain concerns garnered from the literature review.

### **Data Collection**

Finding appropriate participants was more challenging than initially thought, but in the end, women were recruited from a variety of sources. The original research proposal planned to access participants by placing flyers in critical locations and by placing information in publications that served the targeted population. In reality, these recruitment attempts were futile. Next, well-situated individuals were contacted. Finally, after months of following false leads and failed contacts, I connected with a private practice physician who saw patients through Denver General Hospital’s Women’s Clinic. For months I assisted him while he provided access to women who met the research criteria. Although many women from the clinic qualified for the study and wanted to participate in such a study, there was a language barrier. Some of the women spoke only Farshie, Spanish, African or Asian dialects. Considering the heuristic approach of this study and the importance of the ability of the researcher to understand the participant’s story from a unique perspective, using a translator to interview these women was not deemed a viable option. The risk of losing the richness of the data was simply too great to use a translator.

Word of mouth also became an ally and contributed to the snowball effect as women began to self-recruit. Potential candidates came forth from unlikely sources and there was constant scrutiny to assure women met the criteria, while maintaining a heterogeneous sample.

Interestingly, during the recruitment phase, many women who wanted to be in the study, but eventually who chose not to, contacted me, mainly by phone. During those conversations, these women shared with me much of the same information gathered in the interviews with the participants. However, these women shied away from being in a study because they were afraid their husbands would find out they had talked to someone and they perceived that as betrayal. Despite understanding the confidentiality, these women worried that somehow their “secret” would be exposed and they did not want to take that chance. Overall, these women thanked me for listening and expressed gratitude that some women were willing to tell their stories.

## ***Interview Process***

In all, I ended up talking with over twenty-five women who qualified for the study, twelve of whom were interviewed officially for the study. Many others were automatically eliminated because of the language barrier. I was encouraged by a committee member to recruit an infertile lesbian as representative of the minority population. One of the twelve women I did interview was an infertile lesbian woman. However, that woman is excluded from my study as her data would be considered an outlier. Also, according to Heuristic research protocol, she would be considered at best an “extreme” and would therefore be excluded from the data analysis. The population of infertile lesbians should be considered as a separate future study as her story which was rich with data was conceptually different from the other infertile women in my sample.

Although several women in the study did want to participate in the focus groups, their geographic locations, sometime hundred of miles apart, made that an impossibility. To recruit a diverse population for my study I traveled over ten hours one way to reach some of them in person. The population was clearly there to be studied, but more difficult to access than I had anticipated. Once accessed, these women were more than willing to share their stories and intimate details with me. All the participants expressed in one way or another their appreciation for the opportunity to participate.

There is no definitive number of participants required for a study of this kind. The number of participants interviewed is determined by saturation which was reached with the ninth interview, but to assure the accuracy of saturation, three more participants were interviewed with one being identified as an outlier or in the heuristic approach as an extreme and therefore eliminated from the data. Overall these women represent a diverse population of women from minority populations and they will be described in detail in the next chapter.

## ***Researcher’s Role: Ethics, Responsibilities and Presuppositions***

The role of researcher is a critical aspect of the success of implementing a qualitative research study. Particularly when a heuristic approach is utilized, the researcher does not take an impartial back seat, but rather becomes an integral part of the research.

### **Ethics**

This study was approved by the Institutional Review Board (IRB) at the University of Denver. See Appendix for a copy of the IRB application and approval. As part of the approval process, the rights of privacy and confidentiality of the participants had to be guaranteed. To assure anonymity, each participant was assigned a letter in the chronological order in which they were interviewed so nobody knows their true identity except the researcher. Each participant received a participation letter which outlined the whole research study and the procedures in place to protect their participation. Audio and videotapes and any additional identifying information, such as field notes and research journals, would only be viewed, other than by the researcher, by the dissertation chair if necessary.

Additionally, participants were informed in writing and again verbally prior to the interviews that participation was voluntary and they could withdraw from the process at any time. As a

trained social worker, my experience would help identify undue stress and if the participants warranted, they would be referred to outside sources if necessary.

All participants rights and protections were listed in the information letter. Letters of consent for participation and audio and video taping purposes were signed by all participants. See Appendix for copies of the letter and consent form.

### **Researcher As instrument**

The responsibility of the researcher to the participants is monumental especially since qualitative research is interpretive. Therefore, it is imperative that the researcher be aware of personal bias and values during all stages of the investigation. Not only should the researcher be sensitive to the intimate nature of the research topic, the researcher should also be competent to conduct the study and inform the participants of that competency.

As an infertile woman, I have had personal and professional contact with many infertile individuals. Although the focus of my professional career was working with young children and their families, infertility was not a stranger to some of these families. As a graduate student I have had the opportunity to participate in many discussions about women's issues and am familiar with the arguments that infertility is a medical problem and not of concern to the social work profession. Even professional social workers have fallen prey to the myths that shroud infertility.

The key similarity I have with the participants is that we are all infertile. But, the main difference I have with the participants is that I am Caucasian and do not come from a minority group. There are other differences, mainly education status and economic background of childhood.

### **Presuppositions**

Without acknowledging the presuppositions and biases I bring to this study, I cannot be an effective heuristic researcher. First, I acknowledge that not all women desire or pursue motherhood, although all the women in this study desired parenthood at some time in their lives. And for those women who wanted to become mothers, infertility poses a unique dilemma to their womanhood. Second, women assume the responsibility of infertility since it is women who ultimately conceive. Third, infertility is a sorely misunderstood phenomenon that is plagued with myths and misconceptions that isolate the infertile population from the fertile world. Fourth, the medical community has not adequately met the needs of the entire infertile community. Fifth, the infertile population and their needs have virtually been ignored by the social work profession.

### ***Assessing Research Quality***

Validity has long been a key issue in debates over the legitimacy of qualitative research because of the absence of "standard" means of assuring validity typically found in quantitative research (Maxwell, 1992). While Wolcott (1990) questions if validity is a legitimate concept in qualitative research, Lincoln and Guba (1989) substitute the concept of "authenticity" for validity.

Although Wolcott's critique that understanding is a more fundamental concept for qualitative research than validity (1990, p. 146) is understandable, specific measures were taken in this study to increase validity or authenticity.

### **Descriptive Validity**

The first concern of most qualitative researchers is factual accuracy as other questions of validity are dependent on these facts (Maxwell, 1990). "Description is the foundation upon which qualitative research is built" (Wolcott, 1990, p. 27). To assure factual accuracy, all face to face initial interviews were audio and video taped. Tapes were transcribed verbatim and rechecked for accuracy. Videotapes were reviewed to capture features omitted in the verbatim transcript such as non-verbal communications which are essential to the understanding of the interviews and these observations were also noted on the transcripts.

### **Trustworthiness**

Trustworthiness in qualitative research increases the validity of the study. Philosophically, the researcher must believe and trust that the research participants are in fact the true experts on the topic under investigation. Without a doubt, this is my belief and this is the first step to trustworthiness. Prior to initiating this study, there was no preconceived ideas of where the data would lead. Since I had identified my own biases and presuppositions before the interviewing took place, I was able to refer to them and reflect on them to determine if they were influencing my understanding and interpretation of the data. Through careful and systematic analysis of the raw data, themes and categories began to emerge which were subsequently confirmed with the participants at different stages throughout the analysis. By checking back with the participants (member checks) for validation of the preliminary findings, triangulation of the information begins. Further triangulation took place in comparing the verbatim transcribed interviews, with field notes, research journals, and other observations.

### **Credibility or Truth Value**

Credibility or truth value in qualitative research parallels internal validity. Ultimately credibility answers the question of logic and common sense: Are these findings in keeping with the data? Prolonged engagement, persistent observation, and triangulation are activities that increase the probability that credible findings will be produced (Lincoln & Guba, 1985, p. 301). All three activities were present in this study. Additionally, there were member checks with all the participants. Peer debriefing sessions were held with other colleagues and graduate students as well as with committee members. Also the use of videotapes served as referential adequacy by capturing and holding episodes that could then be later critiqued for accuracy (Lincoln & Guba, 1985).

### **Transferability**

Transferability or applicability corresponds with external validity. Since the goal of this study was not to generalize to other populations, but rather to explore findings specific to the sample population, controlling for transferability was not a major priority. However, because there was

some diversity within the sample, this does allow for some generalizability, more so than would a homogenous sample.

“Thick description” (Geertz, 1973) was also used at various points and for different purposes in this study. Through such interpretation of the meaning of the participant’s direct words and quotes, a reader is given some understanding about the context of the study and its feasibility in generalizing to other scenarios.

### **Dependability**

Dependability pertains to reliability or if findings can be replicated in other similar studies. Through systematic and detailed analysis, the dependability of a study can be increased. By constantly examining the data, triangulating it between and among different sources, the researcher is more likely to uncover possible biases or values that have led to false findings. Through a careful review of the literature and the development of an interview guide, there was continuity between interviews.

### **Confirmability**

Confirmability refers to objectivity (which the lack of) has long been a criticism of qualitative research. To ensure objectivity, participants were informed of my own infertility. Throughout the interviews and during the member checks, participants were repeatedly asked to for more detailed explanations or probing questions were used to clarify particular points. As a researcher I was able to enter their world and suspend mine. Since there are lengthy descriptions as well as direct quotes and expressions from the participants, the findings can be compared back to the data. Also since there are detailed procedural notes, an audit of the analysis is also possible.

## Chapter Four: Description of Participants

*Wolcott's (1994) three step approach to qualitative research, description, analysis and interpretation, was used for transforming data into meaningful information. Chapter Four is the first step of that approach, description. This chapter describes the participants by providing demographic information as well as some personal facts that help the reader understand their individual uniqueness and similarities.*

Thus, this chapter focuses on describing the women interviewed for this study while subsequent chapters focus on analysis and interpretation. The intention here is to capture a snapshot of the uniqueness of each woman before integrating her experiences into a more definitive package through analysis and interpretation. To protect confidentiality, actual names and any substantially identifying information has been fictionalized. For ease in reading and so as not to diminish their voices, each woman has been assigned an alphabetic letter which represents something unique about her to the researcher, thus while maintaining her essence, instead of creating fictional characters.

Considering the vast amounts of description and information gathered for each woman, the details presented here are limited to what directly pertains to the phenomenon being studied, in this case infertility. Thus, information that answers the question, "Is this relevant?" (Wolcott, 1994, p. 14) is included while other less focused information, although potentially interesting, was excluded.

### **Demographic Descriptions**

Description treats demographic information as fact. Factual description of participants is a way to get to know them and personalize the data. Although descriptive information consists of facts, through detail, the uniqueness of each participant in the study is illuminated. Without clean and concise descriptions, a deeper understanding of the data gathered in the interview process would be difficult. Description sets the stage by painting a picture of what is going on and is derived from what the researcher is told as well as what is observed. Therefore, description provides the foundation for further analysis and interpretation, or deeper understanding. The information presented here is limited to what directly pertains to infertility and according to Wolcott (1994, p. 14) answers the question: "Is this relevant?"

Although all three guidelines overlap, description treats descriptive data as fact. Qualitative research typically starts with description as a factual depiction of the participants and as a way to get to know them and personalize the data. Description consists of demographic or factual information, yet through its detail, it describes the uniqueness of each individual woman who participated in the study. Without clear and concise descriptions, a deeper understanding of data gathered in the interview process could be more difficult. Description paints a picture of what is going on here and is derived from what is told to the researcher and what is observed by the researcher. Therefore description provides the foundation for further analysis and interpretation, the deeper understanding.

The following chart identifies each participant by the following demographic information: infertility status, number of years of known infertility, age, ethnic or racial identity, educational and marital status, amount of medical intervention, family income and personal occupation. To preserve confidentiality and protect anonymity, each participant was assigned an alphabetical letter (A-J) in the chronological order in which they were first interviewed. The following chart does not give the demographic information of the participant previously identified as an outlier.

	<b>Infertility Status</b>	<b># Years Infertile</b>	<b>Age</b>	<b>Identity</b>	<b>Educ</b>	<b>Marital Status</b>	<b>Medical</b>	<b>Family Income</b>	<b>Occupation</b>
<b>A</b>	Secondary	15	48	NAI	12	Divorced	Diagnostic	\$28,000	Nurse's Aid
<b>B</b>	Primary	14	45	Hispanic	MA	Divorced	No	\$29,000	Case Mgr
<b>C</b>	Primary	5	40	Hispanic	BA	Married	AIH	\$40,000	Health Worker
<b>D</b>	Primary	14	36	AfrAm & NAI	11	Divorced	No	\$15,000	Unemployed
<b>E</b>	Primary	4	21	AfrAm & Creole	13	Separated	Diagnostic & Meds	\$37,000	Security Guard
<b>F</b>	Primary	10	38	Hispanic	MA	Married	2 IVF's	\$70,000	Social Worker
<b>G</b>	Secondary	4	29	Hispanic	BA	Divorced	Diagnostic	\$23,000	Student
<b>H</b>	Primary	4	27	Hispanic & Moslem	12	Married	Diagnostic & Meds	\$10,000	Homemaker
<b>I</b>	Primary	6	41	Hispanic	BA	Married	No	\$140,000	Case Wker
<b>J</b>	Primary	9	37	Hispanic	MA	Married	No Hysterectomy	\$80,000	Mental Health Wker

All the participants are from minority groups. However, these participants represent diversity in many of the other demographic categories.

### ***Personal Descriptions***

This section will describe characteristics other than the uniform demographic data that personalizes the individual, such as the community they live in, hobbies, and self-professed descriptive traits that make them unique from one another and further defines their diversity.

#### **PARTICIPANT A:**

A is a forty year old single Native American (Crow) Mother of two daughters she had while still a teenager herself. A lives on a rural Indian Resevation and who works in the medical facility on the reservation. A has been trying to have other children for the last fifteen years. Initially A

sought medical intervention and was told that her secondary infertility was “all in her head”. Subsequently A was also told there was nothing medicine could do for her. A was encouraged by family and tribal members to consult a medicine man, but chose not to because she felt her belief in God was more important, although she reflects now and wonders if that would have helped.

A is now separated from her partner as she blamed herself for not being able to give him a child and wanted to allow him that opportunity and he also blamed her for not being able to have a child. A felt a responsibility to protect her tribe’s “bloodline” by having more children since women are of greater value if they have more children. A reports feeling guilty and depressed. While appearing strong on the outside, A often cried in secrecy and acts as a surrogate parent to prove that she is a more adequate parent so God will grant her more children.

A is concerned that her own worries and insecurities about her infertility have been transferred to her daughters, particularly her older daughter as A sees her as trying to get pregnant with any man as a way to prove her own fertility, although she has been unsuccessful thus far.

A received no formal counseling for her infertility and feels isolated from communicating with other women about her infertility.

#### PARTICIPANT B:

B is a forty-six years old, single, childless, Hispanic caseworker who lives alone with her three dogs, often referred to as her children, in a semi-rural community. Although unconfirmed by medical expertise, B believes herself to be infertile for over fifteen years during which time she was married several times and actively tried to conceive.

B’s initial response to her infertility is self-described as flippant, rationalizing that either the timing or the relationship weren’t right while questioning her ability to parent or her motives for wanting children. However, as she enters mid-life, B has begun to question her previous seeming acceptance of her infertility and has engaged in provocative exploration of her true feelings about her infertility through self-reflection and therapy. As B acknowledges the fact that she most likely will never experience biological parenthood, her inquiry into its true meaning has become a somewhat prominent interest in her life including possibly getting medical consultation.

After the initial interview, this participant expressed her gratefulness for the opportunity to talk about some things that had been obscured in her life and expressed her realization that how she dealt with her infertility permeated many aspects of her life and to some degree has kept her stuck and has forced her to deal with her loneliness and how she truly feels about her own childhood and most probably never having that sense of closeness that one has with a child.

Culturally B resented the pity other Hispanic women expressed to her and the stereotype that she should have children. B committed herself to betterment through education as a way out of the migrant life style she had experienced as a child.

#### PARTICIPANT C:

C is forty-three years old, childless, married Hispanic mental health worker who lives with her new husband (recently married her long-term partner) and their dog (who C refers to as their child) in a rural and predominantly Hispanic agricultural community.

Although known to be infertile for almost eighteen years, C actively sought unsuccessful medical intervention consistently over the last six years. The frustration of failed medical intervention and lack of unlimited financial resources has prevented C from pursuing the medical route more rigorously.

C's inability to have children within a Hispanic family where having children is the norm has put additional pressure on her and has alienated her from many family members who continue to make insensitive and hurtful comments. C's husband's command of English as his second language has made it difficult from them to find culturally sensitive support groups or appropriate counseling.

Having come from a devout Roman Catholic background and experiencing infertility has caused C to question her faith, particularly as she observes less capable parents have the ability to reproduce. C's guilt at not being able to give her husband a child led her to give him permission to leave the relationship (which he hasn't) and has further isolated her and made her feel less valuable than the fertile world.

As her biological timelock ticks away, C has never felt more ready and capable of being a parent, while the reality is very bleak for her to have a biological child, she has a difficult time reconciling that dichotomy and it makes it difficult for her to rejoice in other's ability to become parents.

#### PARTICIPANT D:

D is a thirty-seven year old, childless, single, half Black and half Native American (Cherokee) airport ramp worker who is currently on disability due to a work related injury. D lives alone in a metropolitan area and although she has no biological family close to her, D maintains a very close relationship with her Mother's best friend who is a foster mother and D often helps this woman care for her foster children.

D's income falls well below poverty guidelines. D is known to be infertile for over fifteen years. Initially she had a miscarriage at three months and subsequently miscarried a stillborn child at six months gestation. D reported that hospital personnel never let her see the child or even told her its gender. D had a difficult time losing her stillborn child, and years later was still crying a lot until an older woman from her church read her a passage from a Maccabee Bible that allowed her to begin to heal from her loss: her baby had one mission, to be born and was too good for this earth and that's why God takes them back, to be angels. D continues to experiment with her beliefs and has difficulty accepting family members advice that she's either overweight or that there are already too many children as reasons why she can't have children. D believes that God has a plan for her.

D is bitter about the medical care she has received and partially blames them for her ongoing infertility problems. D continues to receive medical treatment through a City Hospital which does not provide extensive infertility services.

D's depression and anger over her infertility have diminished over the years, especially due to the peace she has found from the one particular Bible verse, but she still has difficulty understanding "why me" when she sees so many other incompetent mothers have children so easily.

#### PARTICIPANT E:

E is a twenty-three year old, childless, Black Creole who currently lives alone in a metropolitan city. E is currently dealing with what she sees as her husband's virtual "kidnapping" due to their inability to have children and particularly his family's cultural belief that as the oldest son he needs to take another wife so he can have a child as fulfillment for his parents. E's family too has been unsupportive of her marriage to a man from a different ethnic, racial, and religious background, so E is essentially alone in her incredible grief. E and her husband had believed that love does conquer all and E is learning a cruel lesson about the hardships of life strictly brought on by her inability to have a child.

E has been infertile for over four years and has been frustrated with the medical community's casual attitude toward her problem and reassurance that she is young and therefore has lots of time to eventually conceive. E had been receiving medical treatment through the city hospital up until her husband disappeared and they both felt uncomfortable with all the pregnant and newborns in the waiting room.

Even coming from a family with a female history of infertility, E was essentially rejected by her parents' new found religion as it is unsupportive of her cross-cultural marriage. E also dismissed her voodoo background. Therefore, E has found little support among her family and from friends who are in their child bearing stage, so she feels alone and isolated. Compounded by her husband's recent disappearance, in her desperation, E has found herself in the emergency room and has also found some peace in talking with a phone psychic who just listened, didn't judge, and gave her some hope.

E describes her journey with infertility as "a war inside of you" as there is no control and no resolution.

#### PARTICIPANT F:

F is a forty year old married Hispanic social worker whose family lives in South America. F currently lives in a metropolitan area in the United States with her husband and their dogs who she says are accused of being like their children by other family members.

F's familial background makes it difficult to communicate with her family members about her longings for a child and her series of high-tech medical intervention attempts (all unsuccessful and financially devastating) to have a child over the last ten years of her infertility. F found it frustrating that the medical community assumed the infertility problem was hers alone and she

when through a series of painful testing until years later her husband was also tested and they both have medical problems complicating their ability to conceive.

Family members make hurtful remarks, including a niece who said she would act as a surrogate and when she got pregnant, then decided on abortion. Discussion of their options has grown difficult as E's husband will not consider adoption (much to his own Mother's surprise) and E feels alienated from him as far as other compromises except more painful and expensive medical intervention that was difficult physically, emotionally, and financially.

In her desperation F has secret fantasies of adopting a child on her own, but is conflicted as she loves her husband and feels they have a good relationship other than not having children.

F attended group counseling alone (without her husband) and she found it only to be mildly helpful, rather it stirred her up thinking how much they were all doing and F was feeling like she couldn't handle anymore. F thinks that most people have no clue how painful a process infertility is to go through and since you are continually surrounded by a fertile world, you become extremely isolated and alienated.

#### PARTICIPANT G:

G is a thirty year old single Mother of two girls who lives in a metropolitan area. After her divorce which was precipitated by their infertility, G returned to school and is now a graduate student completing a Master's Degree in Social Work.

G never considered herself infertile although the medical community initially focused on her. After over two years in treatment, and after minimal testing of her husband, G learned their problem stemmed from her husband. G was angry and frustrated with the medical community as she had endured years of physically painful and emotionally draining interventions at a great financial cost. Even knowing the problem, G continued to protect her husband from the humiliation of him being infertile so as not to lose his "Macho" image. Discussing their problem by themselves was difficult and although they agreed to go to counseling together, G's husband never showed up at the appointments and G was too embarrassed to return alone.

G's strategy was to hide their infertility from family members and friends because of the assumption that it was G's preference not to have more children, all the while G was considering desperate measures including secret sexual encounters or inseminations to conceive.

Few even close friends know of G's struggle with secondary infertility since she has two children and hopes eventually to have more. G prefers to keep her secret private and clearly did not want to participate in group settings to protect her animosity and says "...for some reason I don't want anyone to know".

However, as G told her story her eyes still fill up with tears as she never saw herself in such a humbling experience and losing someone she loved dearly in the process.

#### PARTICIPANT H:

H is a twenty-nine year old, childless, half Hispanic Moslem who lives in a metropolitan area with her husband who is an immigrant from Algeria.

Dealing with their infertility for over the past five years has been difficult for H as she was raised believing in Western medicine, but now her and her husband's religious faith and belief that Allah determine if you have children puts her in a Catch 22. Many of the necessary interventions and treatments goes against their belief system. As her motherly instinct has taken hold, H questions her faith in Allah which further upsets her husband. In order to deal with her depression and frustration, h admits to eating for comfort and ironically now her weight may be a possible factor in her inability to conceive.

H understands that her role as a woman is to have children and continue the bloodline. Thus her inability has isolated her from the community as different and H cannot help but feel resentful to those who seems to have children so easily. H worries that her husband may take other wives to fulfill the cultural expectation that once he marries, he father children.

Even the limited medical intervention has been a financial struggle and continually challenges them about what they can do without crossing the boundary with their religious beliefs. Adoption of family members is considered as a possibility, but since H is a Westerner, she is not seen as favorable as some other potential adoptive Mothers which alienates her from his family even further while already feeling somewhat alienated from her own family for marrying an immigrant.

#### PARTICIPANT I:

.I is a forty-three year old childless married Hispanic who lives in a metropolitan area. I lives with her Hispanic husband who has an adult son from a previous relationship. After unsuccessfully trying to conceive for over six years while assuming her husband was fertile, I then assumed and self-diagnosed herself as infertile. I has never sought medical consultation that support or negates her conclusion.

Since learning of their infertility, I has maintained a seemingly positive attitude about being childless until more recently when she entered mid-life. More and more I has wondered what life would have been like with a child. I's own Mother's comment that there is no greater love than that of a child has haunted I's thoughts and I questions who will take care of them as she begins to age.

While I continues to present the impression of having a blessed life, there is an underlying theme that she may in fact have missed out on something and not thoroughly examined her options when she was more vigorously trying to conceive.

I's strong faith in God and her belief that in all things, good and bad, there is a reason gives her peace when she begins to look too closely at her own true feelings about her infertility. I has an older sister who is also childless and I seems to find some solace in her closeness with that sister and the fact that neither of them have children.

I rationalizes that having a child puts a great deal of stress on a couple, emotionally and financially. At the same time I talks about possibly taking in children or working directly with them when she and her husband retire.

I also says that since she perceived as a stereotypical Hispanic female, when she feels pressure from others she tells them of her infertility as it takes her off the hook.

## PARTICIPANT J

J is a thirty-eight year old Hispanic who was divorced because of her infertility and is currently remarried and lives with her husband in a metropolitan area.

J struggled with medical problems, which eventually led to her infertility, since she first began menstruating. J often was in severe pain and frequently ended up in the hospital, sometimes life threatening hemorrhaging. Although J very much wanted a child and she did receive medical intervention over the almost ten years she was infertile, J refused to take fertility drugs due to concern regarding possible multiple births and often related medical problems with multiple births.

Despite J's desire to have children, medically she was essentially forced to have a hysterectomy which ironically made her feel better both physically (alleviated her pain) and emotionally (hormones were in balance and she was no longer up and down with her infertility status). However, as a result of their on-going infertility problems which subsequently resulted in surgery as well as the fear of cancer, J's marriage ended shortly after her surgery.

Although J is still saddened that she did not have children, she has a strong faith and belief in God. J has dealt with her infertility by trying to turn something negative into something positive. J sees bad things that have happened to her a growth potential and feels her spirituality has been strengthened through her experience of infertility even though J still has a hard time going to baby showers or being in the children's section of a department store. J also worries who will care for her as she ages and may need assistance.

## Chapter Five: Data Analysis

*Chapter Five centers on the analysis of these participants' comments. According to Wolcott's (1994) schema, analysis answers the question: How things work?. Analysis is the elaboration and expansion of data which develops from clear and concise description. Through a systematic and thoughtful examination of the individual participant's comments, common threads of similarities and differences emerge. By categorizing these into groupings, a collective voice of the participants emerges. Through analysis of their individual voices, a deeper understanding of their common experiences is illuminated. Analysis takes description one step further and sets the stage for interpretation.*

### **Resolution or Irresolution?**

Defining resolution as the solving of a problem sets the stage for understanding these participants difficulty with resolution. The central theme that resonates in each of these participant's experience is their lack of resolution about their infertility, thus their "irresolution". Participants talked about resolution as a goal, a positive destination that when attained, they could then put their infertility behind them and move forward as if they were never infertile. However, that has not been the experience of these participants.

Although each participant hopes for resolution and at times may feel resolved, it's temporary. Their infertility, and the feelings that accompanny it, continues to surface and resurface. As one participant so aptly summed up her struggle with infertility, she laughingly commented "...it's resolved for today" meaning tomorrow or the next day might be an entirely different story. That sentiment is echoed by other participants: "All of a sudden it [her infertility] comes up again and again." or "I think it [my infertility] will always come and go".

Due to the cyclic nature of infertility, resolution is difficult as there is always that hope, no matter how subtle, that something will change. After desperately trying to become pregnant for over five years, listen to what one participant said about the cuclic nature of infertility:

...I still watch my cycle very, very closely. I still sometimes use an ovulation kit. I still try to, you know, be sexually active during the days that I am fertile and hope and pray that some miracle might still come about. I still go to the doctor's on a regular basis and ask them what's my status, has it changed, is it worse, it is it better, is it the same and hoping and praying that I go in one day and there's no problem anymore. I try to convince myself that I am doing it [seeing doctor regularly] for medical reasons, but in reality I think that I still have a little glimmer of hope that [begins to cry] I just can't give up. (3)

Thus, this cyclic nature leads to a sense of ambivalence which was expressed by another participant.

I don't know what it would be like if I were resolved. I don't know. Maybe I wouldn't be so ambivalent about it right now. That wouldn't be present. I think I would just know that. I wouldn't be thinking well you know women my age have had children for the first time and that kind of stuff, I think that wouldn't be happening then [if I were resolved].

Although participants understand intellectually that infertility is going to be a part of them for the rest of their lives, emotionally the permanency and longevity of being childless is difficult to accept. For one participant the indeciveness of infertility and not being able to let go keep her infertility present.

...(laughs) I think that I am going to feel it's resolved when I am comfortable with...well, I don't know that I am ever going to resolve it really. If I am never going to have kids, I am always going to have that little, you know, that little hole inside of me. And if I choose to be childfree, you know, which I would never have chosen, you know I would never have kids. Sometimes I feel...I feel like I am trying to resolve it. I am trying to tell myself, okay, make a choice, so what are you going to do now. You are going to be childfree so adapt to being childfree. And I think that as time has gone by and I am kind of and I have processed all of this in my head, I realize that I may never resolve it. It will always be a part of me and my life. And if I choose to[pause], I guess what I am trying to say is that I don't feel like I have resolved it because I am getting close to a point where I might end up being childfree and that is still not satisfying to me. I guess there is a part of me saying that, it wouldn't be bad, but there's another part that I can't let go of. (6)

For another participant, the finality of her being childless is too hard and so she denies her infertility by holding onto some small hope:

...the final thought I have is that until I go through menopause, I am still going to have that glimmer of hope and I don't know if that's good emotionally or not. And after that I don't know what to expect, but I doubt it will be totally resolved, *ever* [italics added].

The reality of how ingrained infertility impacts these woman is summed up by one participant. Even if she allows herself to see herself with children, the infertility is still there and the reality of not having kids is still upsetting to her: "I think that even if I have children, I am still going to have, even if I were to have kids, it would, I mean, it would still be there. [long pause] It's still [voice quivers] so hard for me to imagine myself really without kids". (6)

Instead of resolution, dealing with infertility is an on-going process. One can read the following words, but one cannot hear the sadness in her voice. She know she will now never have children, but she cannot accept it. Listen carefully to her pain:

I don't think my infertility will every be totally resolved. I think I will have to touch base with reality at some point and that is getting very close. But hum [pause], I think that the only way I will ever resolve it, will be to put my energy in other areas, like my dog, that has helped me so much to even come to gripes with where I am at. But I don't think you ever can be resolved because it will always be there. I don't think I am going to wake up one day and say it's over, no more [voice quivers]. Now, when I'm almost fifty years old and I'll never have a child, I know that, I know that, intellectually, but in my heart, and in my soul, I will still grieve [tear rolls down her cheek]. (3)

At different points in their lives, participants have rationalized their thoughts and feelings about their infertility to keep it under control. Participants have been modifying and reconstructing their understanding of infertility to accommodate their changing circumstances. An

explanation that previously worked, may no longer fit. For example, one woman explains: "I was convinced at the time [when I was actively trying to get pregnant] that I just didn't want kids that badly. But it wasn't true then and it isn't true now." Essentially, at that time, she had fooled even herself into believing that she didn't want children that badly.

At other times, participants maintain hopeful attitudes to avoid deny the reality of their infertility. One participant had easily gotten pregnant and had two children as a teenager, but is having trouble with the reality of secondary infertility. Despite evidence to the contrary, she still emphatically relates that: "I still want a child and if I really can't get pregnant, I don't know what the future holds, but deep down inside of me, I know I can still get pregnant." Another women dealing with primary inferility for over fourteen years has a similar fantasy that if she keeps trying she will eventually conceive: "I'm still going to keep trying to get pregnant."

As these women have opportunities to tell their stories and not be judged, they develop new awareness about their infertility and are able to construct more realistic interpretations about that experience. During one participant's interview, she seemed to have a revelation about how she has dealt with her infertility, basically by thinking something other than what she was feeling, thus making her very conflicted about her situation. The day after the interview, this participant called to express her gratitude. Talking about her experience allowed her to understand that being dishonest about how she perceives her infertility has negatively impacted other parts of her life. Having the opportunity to talk freely about her infertility without being judged, gave her the insight and the courage to pursue conseling which she had thought about in the past, but was reluctant to do and nows plans to initiate. Here are her words:

...there's been a lot I haven't bothered to look at. I mean even when I [pause], because I think last year when I actually realized that all of this time I had been always thinking about kids, names, etc., and I noticed how women really, other women, have been really affectionate with their babies, I wonder how that would be, even now. You know, so I've been noticing how I pay attention to that but choosing to think something else. I've done that a lot [laughs]. (2)

Turning their infertility into something positive allowed participants to minimize the negative aspects of their experience and have some sense of control. As one woman said:

Well, you know, I think I approach my whole situation with hmm, [pause] I have a lot of freedom and I have a fairly good life, I'm not saying it wouldn't be better if I had children, but I am the type of person that for years I never thought of me first and I do that now. And I don't know if all of this was a learning experience, it certainly was I guess. I approach it as sometimes it takes a negative to have a positive. And there were so many things that I had to deal with it forced me to accept that this was the way it was and some things I don't have control of and that's a good learning. (10)

## ***Categories of Influence***

From the analysis of data, four major categories which influenced the participant's construction and reconstruction of her narrative of infertility emerged from the data. These four

major categories of influence are: 1) Background and Culture; 2) Expectations; 3) Feelings About Self; and 4) Support Systems. Within each of these main categories, there are specific variables that contribute to these main categorical influences.

## **Background and Culture**

Background and culture define the conditions that form the setting within which something is experienced. According to the comments from the participants, specific factors from their background and culture which have been strong influences on them include: ethnicity, family, and religion or spirituality.

### **Ethnicity and Culture**

All of the participants are from minority cultures and received strong messages about the roles and importance of men and women to become parents. As a result of these values that were instilled, overtly and covertly, over many generations, the inability to fulfill an ethnic and cultural responsibility was difficult to accept for these participants.

For one woman, she was grateful she was living in modern society, otherwise she may have been an outcast from her Native American tribe as she reiterated several times during the interview:

It hurt a lot. I'd seen my Mother, my boyfriend now, his cousins and stuff having kids and stuff, all over. I figured I would be able to do that. In our culture, I guess men marry women because they want to have kids too. That's the culture I guess. If I was living in the older days, I'd be like an outcast cause [sic] I can't have kids and that would not be right either....My culture does not support people that cannot have a lot of children. If I was alive back then, I would have been thrown out by now, that is how the culture stays strong. Some of the things I have, I have a home, a boyfriend, I'm independent, but not having more kids is still a stigma. (1)

Participants were well aware of their prescribed ethnic and cultural roles to become mothers and knew they were seen as different in a negative way since they didn't fulfill those roles by having any children or enough children. These participants' comments demonstrate their sense of being different and isolated from women in their culture:

I think culturally speaking, children are a big part of Muslim and people of Islamic Arabic faith, that's a big part of their lives. That's a big part of the women's duty in life. So, I mean, you know, so to them they are probably thinking you are *nothing* if you can't have kids, you are a *nothing*. It's a big thing to them.

I always thought that I would have kids and I think well, that part of is well, that is part of the way I was brought up, that is what women do, they get married, they have children, they have a husband, you know....I think that in general people probably think, that's odd, a Hispanic women, not having kids, that very odd.

But it's been the culture that's influenced me. Just the way that [pause], the way that other women, other Hispanic women have responded when they ask me if I have children. And I

say no and they say you poor thing. And they make it sound like it's a really horrible tragedy and a loss. That's been my experience with all Hispanic women when they have ever asked me....I would feel annoyed that they would more or less stereotyped me that all women, especially Hispanic women, want children first and that all Hispanic women have children. It would make me kind of angry that I would be stereotyped. The pity, I hated that they would just look at me, oh your poor thing, you know, that would bug me.

It's a typical of part of my culture of society, Hispanic, to have kids. I would say that it's typical not only of the culture, but of my generation . Because you know my brother knows I am infertile and he has never ever said anything, neither have my brother-in-laws. So it's probably more generational and especially since my Father's generation viewed fertility as wonderful and everyone should be pregnant. We were Methodist, but it was more Hispanic to have children.(10)

Participants were also aware and sympathetic to the roles of the males within the cultures that their partners had grown up assimilating. In some cultures, the man is perceived as less than a man if he is childless. A wife reports: "The whole purpose [for the man] is to have children." Another participant in the study tells it like this:

So you know, I think if we come to the point where it's definite that I can never have kids, I will come to the point where I will probably divorce him because I know, in ten or twelve years, he's going to want you know kids, he's going to want kids. You know, I think there would probably come a point in my life, where he would say listen, I want to have another wife. So would you accept me in taking another women to have kids. I don't think I could handle it (8)

About three months ago he [husband] said, let's adopt a baby. And that kind of emotionally messed with my mind because I'm saying this isn't a good time, I'm in the middle of this infertility process, let's finish this first, then we'll think about that. You know, now that I am finished and it didn't work, now let's adopt a baby. Well, financially we are not able to do that right now. I know we are not and another thing is you know my husband's citizenship thing is still not established, he's going to school, financially, so that would probably stop us, but he's talking about having one of his sister giving us a baby as he wants a baby from a Moslem country, from his country." (8)

You know, most of the men and women in Islamic countries get married when they are older because that is when they are ready to have kids, around 27 or 28, in the middle east they get married earlier. But in North Africa where my husband is from, probably because of the economic situation, they get married when they are older and they want children soon. (8)

For one participant, knowing the sacrifice her husband was making for her made her feel guilty for not being able to conceive for him. As she said:

Knowing the culture of Mexico and being the machismo, knowing that a man is not a man until he has a child. And for a man who is a man to give that up for a woman that he loves [voice quivers]. The more I think about that and as I sit here I just can't understand how [voice is more shaky] I could even ask him to do that [cries] (3)

Well I think it was about his masculinity. Because coming from a Hispanic family, they kind of have that kind of Macho, you know, especially Spanish people are able to have lots of children and so everyone in his family had children and everybody in my family have children and so I was *able*. I already had two children and so he really saw that. And we did everything we could, he didn't go into the hot tub, he didn't do any of that, he quit riding his motorcycle anymore. He always wore tight clothing, well not real tight, but tight jeans and briefs or whatever, and he had to go to boxers, and he just hated boxers, and it was just awful, he hated it that he couldn't do it [be a Father]. (7)

Although the majority of these participants had grown up in cultures that participated in activities or rituals unique to that culture, participants were conflicted about pursuing them and were reluctant or felt guilty about refusing them or in seeking out alternatives that would be perceived as deviant from their upbringings.

One participant did not take the advice and visit the medicine man from her Indian tribe, but in hindsight questions if maybe she should have because maybe it would have helped and nothing else has helped:

Some people asked me why you should to and see the medicine man and get advice from him, have him take care of you. but I guess my belief in God is more important than, I guess I didn't believe in it really. I never did try. I just, but there were times I really did want to do it and to talk with them and have them actually help me out and maybe find a way to help me out. I guess I didn't have the courage. I was still grieving, thinking I still had a chance, but it never happened. (1)

One participant did take the advice of a family member and made contact with a curandaro, a healer from her childhood community. Her experience with the curandaro reinforced the difficulties she was already having with her husband to consider adoption as a possible resolution. This is what she had to say:

I did go to a curandaro. And her take on that there was this spirit of a child that did want to come through me, but didn't want my husband as the Father, which again was pretty painful, and you know she recommended some things to do which I did. And I did some Chinese medicine too. And I went through that part thinking something might work out; drinking lots of chamomile tea, and not walking barefooted, never having my abdomen exposed to the cold and then I did like two years of Chinese herbs. (6)

Although participants did not necessarily believe in seeking alternatives, they were desperate to find some relief from the discomfort of their infertility and were eventually willing to go outside their comfort zones to explore what might work. Interestingly, participants who partook of these alternative expressed some satisfaction, most likely because they talked with someone who listened. The following excerpts reflects some of these experiences:

This might sound strange, but, let's see, it was in the early 90's and I did a couple of regressions, you know past life regressions. I said I'll try anything because I don't want to go through that again...I saw myself in a big barn. I mean, my guess was it was probably back in the 1800's and there were three men standing there and they were dressed in black hats. I was struggling with one of them who had be by the arm and he was pulling me and I was pulling away from him and we were having this tug of war. I finally got away from

him and I was gone and I came to the end of the session. As I was driving home I kept thinking I'd forgotten something. I just simply had forgotten something important. I couldn't figure it out. What the heck was it so I called him up after the session and told him I feel like something is still missing and I don't know what it is. Something in the past that is still here now. When I pulled away from the last man [in the regression] I felt like I'd forgotten something and I had left something behind when I ran from him. Then a couple of days later, I don't know what I was doing, I think I was working and I said. 'Oh my god', I left my baby [begins to cry]. I left my baby when I left...I did another regression and I was talking about my issues with my Mother and I was feeling really scared and all this kind of stuff and he said let's go back to a time when you knew your Mother. I remembered sitting as a young girl in this one room house and my Mother was mopping the floor and I could even smell it. It ended up that I was pregnant and I started to cry. We moved forward and he said where's your baby and I said my Mother gave it away [cries harder] and that's just so hard for me to talk about. I don't know if regressions are real, but a part of me believes in them. I just don't know, but that's always stayed with me when I think about my own infertility. If those past regressions are real and why I have never been able to have children now. I think maybe I didn't allow myself the opportunity to have children because I couldn't even hold on to the other that I had. I've thought about that a lot, especially that last regression. I've always had a hard time knowing other women who give up their babies. That's been a real heartbreaker for me. When I see unsolved mysteries and I see children being separated and then reunited in their 50's and 60's, finally finding each other, it's just really hard. (2)

Squeezed between two cultures, her family of origin's and her husband's, one participant felt she had no place to get support and reverted to an unfamiliar place, a psychic, but she did find relief there:

I have spoken with other Creole women and they have had problems and also within my family, my grandmother, my sister, and my Mother all have had fertility issues.... A lot of Creoles practice voodoo white magic, consulting the starts and cards. In "voodoo", that's how we say it back home, they would have a ritual, more of a ceremony, to find out what the problem is by praying and chanting over you.... And the reason why I didn't anything with voodoo is my Mother and Father would frown upon that as they have separated from it now and went into Christianity. That's why I finally decided to call a psychic....It was a battle for me to just pick up the phone. I was like should I call or should I not call because inside of me are my Christina beliefs and on the Molem side, to consult any spirit medium or anyone like that is wrong. I finally decided talking to a stranger, someone who knew absolutely nothing about me, who couldn't judge the situation, who wouldn't have any bias or prejudice, or any knowledge of what is going on could sit and listen. So I called the psychic hotline and the man opened up and he did his leelte things. He asked me what my Zodiac sign was. He started talking with me and I started talking with him and it felt like there was a great burden lifted, and it just left. Because I had finally gotten to speak my piece and gotten to say what I was feeling inside and have someone listen and try to...they weren't trying to consult religion or culture, they were just looking to the universe for the answer, mother nature for the answer and speaking to me one to one. So it made me feel a lot better. It's like today. I am smiling because I can talk about it here. (5)

There are many myths and old wife's tales that were told to the participants. Despite knowing they most likely would not help, they still tried them almost as if to say I tried everything. Of all the remedies these woman related, none of them worked, but they still would try anything if there was the slightest chance it might work.

There are sisters [women from her religious community] who have told me to drink tea, parsley tea to not bring on the menstrual cycles. There is one women who told me to take Geritol to make the sperm and eggs strong and more fertile...I bought the Geritol, but it said to check with the doctor before taking it and I was too embarrassed to ask him, so I didn't do that. There is vitamins that I actually went and bought from Wild Oats {health food store}.(8)

In the Crow culture, they say if you have fertility problems, getting one of your sister's or brother's kids and keeping them for a while, they actually believe that helps them get a baby and get pregnant and that's the belief behind it." (1)

Education was an important component of these participants' lives. Participants valued education as a way to advance their family's status, including socio-economic. All participants have advanced further in their education than any of their parents and most of their siblings. Some of the participants were the first in their family to finish high school, while others were the first to receive college or advanced degrees. Regardless of their current educational status, all but two participants, aspire to completing at least a Bachelor's degree.

"I think education has always been important to me. I couldn't imagine myself not having an education and I had to get it one way or another because I saw my parents struggle, they were migrants. It [education] was just a necessity for me. I don't think I ever did it intentionally to separate myself from my culture and the women in it. It was something I had to do for myself because I've always been a curious kind of person, wanting to learn and wanting to know things. But I can see to some degree it was important to my family in terms of my folks not wanting us to have to work as hard as they did because they worked really really hard and they wanted to make sure we at least had a high school education."

Becoming educated was an opportunity to advance, but it also separated these women from the majority of women as this participant went on to explain:

"My background was somewhat different from other Hispanics in my area because we were educated Hispanic women. But my childhood was unlike so many of the kids in my community. Our parents wanted something better for us, even though they did not have an education, jobs, college degrees, these were the priorities, not having babies and getting married right away. They [friends] were all Hispanic, that's all I hung out with....That was what they were suppose to do. Like we were suppose to get a degree and better ourselves, that was the only expectation for those women to have value through having children. We were kind of lucky." (9)

## **Family**

All the participants' families as well as their partner's families have also influenced these women's experience of infertility.

For one woman, the shame of being childless led to her husband's disappearance, she suspected by his family, since as the oldest son his duty was to father children and hers was to bear them. Hear her pain as she tells of her dealing with his abduction:

I sat many nights and cried and wondered is he still alive? And at some point I even thought well are they fanatical enough to kill him just because he didn't have a kid or to tie him up or whatever? And then calling the psychic didn't help, they were telling me well I see him in a hospital somewhere, maybe in a coma and some type of incident, accident or whatever and they said that he is in critical condition there. So now my heart couldn't take it anymore. I was to the point to where I wanted to go to the emergency room where I was having chest pains because here I was, I was separated from my husband who I love so dearly, who was taken from me which was solely upon the fact that we didn't have any kids. And so he was basically snatched out of my life.... I've cried so many nights, and the crying, it just never stops....I feel that they wanted him to go back home [husband kidnapped by family and returned to Middle East] to give him another wife. That is what I believe and that is why he probably has not called. I can't imagine him not calling me because he has always been very protective and caring and loving. (5)

Her explanation for his disappearance was:

That it [infertility] was a disgrace to the Muslim culture that it was a disgrace to their family and the Muslim culture if the oldest son does not have kids, who is going to carry on the family business, so it's like a slap in the face. It's like he's (husband) telling his family, I love this woman so much, even though she is infertile, I am willing to sacrifice everything and make sure that our people don't have a name anymore. That's how they think. (5)

Despite growing up in the same culture as her husband, this participant tries to minimize her husband's family's value about children by finding it rather an absurd notion that children are so valued. Although her husband in fact had a son in a previous relationship, she also devalues that relationship by blaming the Mother. By discounting his heritage, she can better tolerate their inability to have a child:

Well you know in his family, all his brothers have you know juniors [voice quivers] and it's like to me, it's so ridiculous. My husband is not the typical macho Hispanic male and if he was, I would never have married him. He is very much his own individual, self-assured and he doesn't need to have any son to say I am a man. This woman got pregnant after telling him she was on birth control so he would marry her. She tried to trick him into marrying her and he wouldn't marry her, so he wished things would have been different. And he regrets that he wasn't more of a father to his boy, but he [the boy] had a father, a stepfather. But that's his biggest regret that he only was a monetary father.... My biggest regret was that I wasn't more understanding when I learned of this child and I didn't encourage him to nurture that relationship. I couldn't get past the Mother and her, whatever you want to call it, I could call it so many things, the way she would operate with him [husband], especially financially, her way to control, it was not a good feeling. (9)

## Religion and Spirituality

Religion or spirituality played a critical role in all the participants lives. Several participants have continued to be unwavering and devout to their religious beliefs and credit their faith in God as helping them cope with their infertility. Those participants who had no answers often turned to prayer:

“For me praying is a big thing as there are times when just about anything that makes me uncomfortable I pray about.” (10)

“Pray, my husband always says just pray and ask Ala, you know, and that’s it. Just pray and he will give you what you want *if* you just ask him...and that is something we do five times a day. Morning, mid-afternoon, sunset and then two at night.” (8)

“As far as spirituality, well I think, I pray about everything. I just say thank you all the time, that’s my way of [pause] because things happen that I don’t have control over those things and that God is doing his best for me. I also think thy will be done.” (10)

And we [husband and me] put our faith in God and we feel that he has a plan for us and this is his path for us.” (9)

“I think I always look for answers in my faith and I don’t know those answers, only my God does. I just pray for the strength to accept whatever had has planned for me. (9)

I prayed a lot. I prayed all the time, please, please, please. And I though maybe God doesn’t think I deserve to have a baby because I am so busy because of work and school and I already have two kids and some people can’t even have one and her I am asking for too much. Maybe I don’t spend enough time with the children I have now and maybe god is not giving me one because I don’t deserve it. (7)

For one participant, she and her husband struggled with seeking medical intervention as it goes against his religious beliefs. Therefore, there is tension between them about how to proceed and what will eventually happen in their relationship:

...the sperm should be used to impregnate the woman, not to check and see how high his sperm count is or to inseminate it *artificially*. So that part, kind of went against his morals, I don’t know against his religious beliefs...If you are going to be pregnant, you are going to be pregnant from the way that God wants you to be pregnant and if you’re not, they you’re not. And he’s accepted that also because I told him, if I can’t have kids, you know, I think that you should just find another woman, or you know, get divorced or something like that. But he just says it’s up to God, it isn’t up to us to choose whether I am going to have a baby or not. I think even a non Moslem man would still want children from his blood.

I mean you know, he’s given his sperm for insemination and had them check it and stuff. so he’s tried, and even being, you know being so strongly religious as he is saying that you know, God has, God is the only one, you know that determines whether I am going to get pregnant or not, you know, not me getting pregnant, you know, or the doctors....You know, he wants a baby and he knows how much I do, you know, I mean, he kind of , it’s the will of Ala, you know, it’s the will of God. If I’m going to have a baby, I’m going to have a baby and no one is going to say let’s help her do this or whatever. (8)

However, it was more typical for participants, even those who strongly identified with a particular religion to question their faith and not find answers to their questions in prayer. Doubting their religious belief system was troubling to these participants. Once again, participants found themselves alienated and isolated from what they had considered a safe haven. These participants are struggling with their previously held religious values and their disappointment that their faith hasn't given them relief in dealing with their infertility.

I mean so many different things, emotions that we have gone through us both. My husband and I were raised very strong devout Catholics and there have been so many times where you know you question your faith and question God and you say why did this have to happen to me. My sister who just came by has a daughter, my niece, who turned 21 years old yesterday and had her first baby when she was fourteen years old, and she is a very unstable parent and I see example of this all the time and I just feel like how could God have done that to me. Because I feel like I know I would have been a much better parent and I have so many more things to offer and I see people with their children in the streets and I have worked in the prison system and I have seen men that are there as a result of abuse and neglect and sexual abuse and sold as child prostitutes at three and four year old and you see that kind of life that these people have and I just [long pause] I just curse God, I'm angry, I feel like I have been singled out and I feel so much pressure from my family. Before we had a lot of information on the actual infertility, it was always why aren't you having a baby and culturally it is the thing to do. (3)

Spiritually it [infertility] has shaken my faith, very much so [begins to cry]. And I still have it so much and I still try to pray and think about it and say God I know there is a reason for it, but show me the way, show me what is the answer [cries harder]. That comes close to socioeconomic [impacted me too]...Doctor told me one time, you know I told him do you believe in God, cause [sic] I do. And he said very much so I said well maybe God decided that not what I'm suppose to do and he [doctor] said have you ever thought that God put me here to help people like you? and so that [socioeconomic and spirituality] went hand in hand. But if I had more of the financial means, then it could put me in contact with somebody else [additional medical treatment]. Those two [spirituality and socioeconomic status] are so close as far as the impact in my life." (3)

When a couple does not share the same religious belief, it can come between their ability to make decisions about their infertility that they both can accept as seen in the following quote:

I mean there's women, my husband told me that there was someone in the Koran who was married to his wife for like 12-13 years and he took another wife and he found out a month later that she [new wife] was pregnant and he divorced the first wife...That it is up to God, I mean, if God want you to be pregnant or if this is to happen or that is to happen, then it will...I can't accept that. Because of the way that society has taught me as an American, that hey, you got a problem, then go to the hospital. You got this, then go to the doctor's. You need help, go to the hospital. So, you know, we have things that can help us. I mean my husband, sometimes he tells me, I didn't know why you are doing all this, you know, all you have do to is just pray. (8)

In one participant's case, her choice in a husband alienated her from her family because their religious beliefs shunned her from their church. In addition to being ostracized from her parents and her church, she has also not received any answers from the scientific community either:

I am not a Christian Scientist although my parents were. Christianity and Science don't mix. My parents are Jehovah's Witnesses now and they do not believe in marrying outside your religion. When you marry outside your religion, they pretty much shun you and that's what happened to me. But I believe that belief in God is very important and this is an issue. I believe that he is the Creator and He designed me and He created me. And I have been praying to him to find out what the Master Plan is for me. Why am I not allowed to have children at this point and time in my life. Is there a point in time in my life when God wants me to be able to bear children. You know, what is going on spiritually here. Is there a spiritual reason hidden behind all of this. And then you try to think of the physical and scientific aspects and sometimes prayer works. It makes you feel better when you pray and you pour your heart out in secret to God. But then the next day when you wake up and there's no answers, you feel well maybe I need to go the scientific route because I can get an answer and when they don't have an answer, you don't know where to go. So you go back to culture and spiritualism and they don't have an answer. So you are playing volleyball with your life. Back and forth over a net. And no one, neither side has given an answer in the amount of time you feel is sufficient. Everyone is taking their time. (5)

This participant feels caught in the middle and doesn't know what to think or what direction to turn in:

When it comes to my spiritual beliefs, I think that sometimes I get caught in the middle of well God didn't give you any kids, so there is a reason for it, so quit pushing it. What if you have a child with a lot of disabilities because you keep on this track of pushing it, trying to force the issue instead of letting it happen naturally. So that's one, one side, but then there's the other side that if you can help yourself you know, I mean God can help you, but you need to put a little bit of your part. And then your part is to do all this wonderful stuff. There's two very different sides.(6)

Participants stretch to make sense of something that under different circumstances they would not have made the same meaning as this participant demonstrated:

So I just started thinking well maybe He [God] just wanted to have his baby back [miscarried at seven months], so [laughs] I guess to give it a job, to be an angel or whatever. So anyway, I came here [moved] and I met this lady that was from New York cause [sic] I was doing this home health aide, you know, and in this lady's house taking care of her Grandparents. And she asked me if I had any kids you know. And I said, well I had two. You know, I said I had the one that I lost at three months and I said that I had one that I was just pregnant with in 1983 and I lost that one you know it was stillborn at seven months and it died, and she said does it bother you or anything like that. And I said yeah it bothers me you know what I mean, but because I was crying all the way up until then over that last baby, all the way up until then, I would still cry over that baby and think about it you know, because I had little diapers and everything [laughs] just waiting for it, you know, my older cousin made clothes for it and still, you know, but it just didn't make it. And so, but anyway, she said let me read you this part in the Macabee Bible and then

she did And when she did that I stopped crying and stuff and I just didn't cry anymore then the time came around because it made sense to me and then, it made it better. But what she said was that those babies are born and die, only have one mission and that is to be born and that after they're born, I mean, all they had to do was be born and that's it, and then she said they are too good for this earth or something and that's what it said in the bible. That those babies have one mission and that's to be born because they are too good for this earth and that's why God takes them back. So that's why I have been able to accept it more, it helps a really lot [laughs]....because my ex-husband use to tell me a lot that the Bible in Jamaica they use to use it a lot, it's a certain part of the bible or whatever, but her I never heard anybody talk about it. But this lady showed me a part and she said it's the Macabee bible, and my ex use to tell me something about that too." (4)

"So I didn't fit in since I only had two children. And I grew up Catholic and the only thing they teach is the rhythm method. And for a while everything was okay, we had sex all the time and didn't have to worry about you know, I wanted to get pregnant and I couldn't, but a lot of people have the other fear. Like oh, they'd get pregnant right away." (7)

"Now I am choosing what religion I want to be, you know, I am a Catholic, but I was kind of wanting to move away from that. I have no anger toward God, but the Catholic church did kind of mess up me up a little bit, well my Mother anyway....everybody lived by the rules of that church, the Catholic ways and everything." (4)

## ***Expectations***

Expectations played a big part in how participants experienced their infertility, either positively or negatively. Personal expectations of themselves as well as expectations held by their partner and other family members, and society had the greatest influence on how these women experienced their infertility.

### **Personal**

Personal expectations of parenthood seem to correlate with how participants have dealt with their infertility. That is if one's expectation was to be a mother above all else, those women seem to have struggled more with being infertile. For many of the participants, the expectation that as woman they would automatically have children was ingrained in them and became a part of how they perceived themselves. Since they were small girls they believed they would have children.

I always thought that I would have kids and I think, hum, well, that part of well, that is part of the way I was brought up, is that is what women do, they get married, they have children, they have a husband, you know, etc., etc. (2)

"You know I think I approached it in a totally different way than I think I would have approached it now, probably because it's ten, ten years later practically. I thought it was my *duty*

[italics added] because my Mother had eight of us. but yet, I knew and my ex-husband knew and I had discussed that I only wanted, and he was behind it, two children.” (10)

I feel like it’s like, I don’t know, maybe I am wrong, my old fashioned way of thinking, but I just don’t feel, I feel like every woman is suppose to have a baby, you know what I mean. I just feel like it’s what I am suppose to do, that’s part of your job, [laughs] you know. I have to have another one. (4)

“I just kind of expected that I would grow up, get married and have kids and I kind of already did that and I was happy to finish school and I just thought I would have more children. I just like having more children, all my friends had large families. So I didn’t really fit in since I only had two children.” (7)

“Well you know, I came from a family that was very, very large, my own family and my extended families were all very large. I mean my Dad’s family alone, on his side, was one of the smallest and his twin had sixteen live births, it [having children] was a given.” (10)

“As a little girl, that is how you are taught, you are taught that you grow up and your vocation is to become a wife and a mother and that is what you are suppose to do in your life. “ (3)

“And I always thought that I too would eventually have some [kids]. But you know, I guess, after I started with my education, you know college, I just thought well, you know, who the heck needs kids. I don’t need that and so then again maybe I did rationalize and I said oh well, I’d rather do this than have kids. I’d rather have a career and be educated that have to deal with diapers and crying babies and adolescence [laughs].” (2)

“There is no one else around, there is no one here. There is no one to call me Mommy, there is no one here to say I love you. There is no one to give love to, to care about, you know, a little person that depends on you. And I’ve been around my friends and I had a friend who moved here from London and I took care of her baby. She had been through a divorce and I would say he was here for seven days a week, every day. So I got really attached to him and so when he left, I got really depressed for a couple of months.” (8)

For this participant who started with medical intervention, her expectations of a positive outcome shifted to the medical community to become pregnant:

“And for a long time, I think, the emotional aspect of it, the emotional roller coaster was even worse when there was some hope that it might happen. You have some expectations, and you think yeah, you go through insemination, and in my mind I mean before I really knew what it was all about, I was like thinking this was the answer. And you pay all this money to have the procedure done and nothing. And so it’s, you just have to draw a line, I mean you have to make a decision, and say how much more do I put myself through financially, how much more can I put myself through.” (3)

Although the intensity of their desire for parenthood varied, all the participants assumed they were fertile and eventually expected they would be mothers. Having had two children as a teenager, dealing with secondary infertility has been harder on one participant than she ever imagined:

I never thought about infertility before. I never thought it would happen to me. But the problem is I just never thought I would have that in my life. I got pregnant when I was fifteen and had my second daughter when I was sixteen. So I had two kids right away. I was really a young Mom and got married pretty young and that was a mistake. And my marriage ended and I got remarried and then when I was in my late twenties I thought well now I have a good job, I finished school, this is the time to have a baby because we wanted to have one together and my husband didn't have any children at all and he really wanted one of his own. And so I didn't understand why things weren't coming together because I was older now, a mature women, I had a good job, my husband had a good job, we had bought a house, I don't know, I just felt like now is the perfect time and nothing is happening. What's wrong here? (7)

One participant expected her body to do what is naturally and felt that she didn't get pregnant according to a biological schedule:

“And that's when I started feeling pressure with the biological time clock.” (3)

“Because there are some times when I really yearned for a child and I don't know what I was going through, probably I was thinking that was what I was suppose to do. But now, for the most part I am okay not having kids because I am pretty happy the way my life is right now.” (10)

Even for those participants who said the initial adjustment to infertility was easier then adjusting as they age, the aging process has brought them to question their decisions not to more aggressively pursue all avenues to having children.

I find it kind of scary seeing myself get to an older age and not having anybody around. You know, kids, that can check on me once in a while as I get old. So I have been thinking about that a lot, what it would be like to get to an age, like in your seventies, if I live to be that old. And then like my husband dies first, you know, what is there? And I don't think that I am the kind that, I figure if I have kids, yes, I would want to live until God knows when. but I find myself saying oh God, I don't want to live to be eighty, you know, that's why, you know, “what for” kind of attitude. (6)

As we get older, you look back over the years that are behind our shoulders and you start to think what if things could have been different, what if, what if? Why not, what would have happened if I had children. what would my children have been like, you know, you have all these question marks that you will take to your grave with you. Because I have heard older women talking who have never had kids , in fact there is a Jehovah's Witness lady who never had kids, and her and her husband have never had kids and she is 65 years old and just the point of someone mentioning that asking her, why didn't you guys have kids, it was so painful for her that her husband became angered at people asking those

type of questions all the time. So it was still something that this older couple was still having to deal with. They had no children and they had no grandchildren. So you feel like that everything that you have done in your life, you have no one else to pass it down to. You know, you can give it to a stranger, but you would more probably want to give it to your children. and your children are your life. Once you are gone, they live on and your name is carried on, they are a part of you. You live on through your children. (5)

I always think about later on in life and who will take care of me as far as kids go because we were always that type that , both of my parents are dead now, but we were always there for them, if they wanted to come visit or needed someone to take care of them we were always there. And even though I have two step children, I don't foresee them taking care of us as we are not that close to them and they are not my children. So, more of a [pause] I think sometimes when I bring it up to my husband, who's going to take care of us, that's especially when I really feel that sense of loss with no children [voice quivers] because you expect when you are elderly that you expect that most peoples' kids will take care of them. We always say stuff like we hope that my nieces and nephews will be kind enough to take us in and that is how I look at it. (10)

“We are already planning for retirement. My husband is going to be fifty next month and God willing, you know, we'll retire in seven years ant that's our plan, that's our goal. And I know that if I wanted to I could still have a baby, *maybe*, if we went through all those tests and all kinds of thing and if that was really want we wanted, but right now it's not.” (9)

Thought to be “resolved” at prior times in their lives, these participants are confronting growing old without children to care for him in their golden years or are longing for that sense of connectedness their mothers have told them about or they see in friends with children or with other family members and their children.

When participants viewed their own childhood as marginal, they were able to rationalize that they too perhaps would have been inadequate parents and so infertility was seen as a blessing in disguise at the time and now is seen as a sad and painful reality. If participants saw themselves as too immature or with too many problems during the time they learned of their infertility, they took their infertility as evidence to support their interpretations that they were inadequate

It could be an enriching experience to have kids. Well, I think that it's really bizarre even when I think about what I am saying, but I have to say that wanting children, it's still kind of selfish. I don't want to have children to be selfish, but what I guess I'm going to say is that I think it would be enriching in that it would help me in that it would help me understand my own childhood, my own needs and wants as a child that I've never ever even really looked at or really understood and having a child would, would bet me there, you know. but that's selfish and I don't think that's the right reason to have a child either. So it would be enriching in that way and I think that it would be enriching in that I could, I feel I have more to offer a child than I did before and I am more stable, more self-assured, able to succeed a little more in my life, a little more confident and I think I could give that to a child, so I am unlearning some of the values I learned when I was younger, that children are definitely of value. (2)

For those women who had poor role models for motherhood, they questioned their intentions in wanting children and tried to rationalize them:

“I don’t know my real reason for wanting children other than the only thing that I can think of for me is just to have that bond, that feeling of a deep deep connection. That deep love that I see parents feel for their children.” (2)

“All of these years, ever since then, I’ve always thought you know, no big deal. I’m not pregnant you know, whatever, God whatever, the universe didn’t want me to and so, no big deal. At least I didn’t have to lose my figure or go through the labor pains or your know. But I realized, I think it was several years ago since then, I’ve always been thinking that well, if I had a little girls I’d name her this or if I had a little boy, I’d name him that. And I’ve always just kind of done that and not ever really paid any attention to the fact that I was actually doing that.” (2)

Another is determined to overcome the negative aspects of her experience and see that infertility has given her a lessons, to focus on the positive, but underneath you can still hear her sadness:

“I use to see the glass as half empty, that’s why this has been such a huge shift. I walk around telling people just be positive, just be positive. I often tell people it often takes a negative [infertility] to make a positive.” (10)

“No matter, whatever, focus on what you have and appreciate and work on that, and if you want to try and continue to have a child, then go for it and if it doesn’t happen, they you need to make the most of it and go on.” (9)

“I still really want kids, but maybe I am dealing with it differently now [laughs]. Now that I am older and maybe these kids [works in a foster home] have helped me out a lot you know.” (4)

### **Partner and Other Family Members**

Overall the women in my study assumed the expectations of their partner’s. If the partners were ambivalent about children, they too assumed some of that. If their partners were devastated that children would not be in their future, the women assumed much of the responsibility in disappointing their partners and blamed themselves. The women who are still with their partners are protective of their partner’s feelings and tried hard to ease any discomfort around the infertility. The ability to communicate openly and honestly around their infertility has been challenging.

“My husband is one of thirteen, so you can see what the expectations are from him and his family, expectations that he would have kids, you know [voice trails off]. He wants kids, he wants them very much probably as much if not more than I do.” (8)

“It may have been different if the person I was with really wanted to have another child, that would have changed my whole life since we couldn’t have kids.” (9)

When family members’ expectations matched those of these women, that is to say, children, grandchildren, nieces, nephews are wanted and expected, the women felt as if they had let their families down and often blamed themselves for letting the blood line and family heritage dissolve.

When family members attempted to understand the position of the infertile individual, they often tried to protect that person from difficult situations such as attending baby showers or christenings. These acts were sometimes perceived by the women as further proof that they were inad

Some realized that several of their relatives also may have been infertile, but it was never openly discussed in their families.

“ I can see the pressure that my two elderly Aunts had because they were infertile and were under because everybody else had all kinds of kids.” (10)

“I think I said a lot of ‘why me’s?’ And then soon, you know like shortly after I had the hysterectomy, maybe it was a year or a couple of years afterwards, my sister who is younger than me got pregnant and nobody wanted to tell me because they were afraid I would be upset, she didn’t even want to tell me. And I was like, you know, I am happy. I was happy for her and I was really close to her, but I was still sad [voice quivers] for me and I cried. And my Mom said this is why we didn’t want to tell you.” (10)

equate since they couldn’t be stronger or needed to be protected.

## **Society**

Participants felt continually judged by society where reproduction was taken for granted and surrounded them at every corner, even while on a simple shopping trip to the grocery store.

Another consistent response from these women was confusion why other women who were marginal parents could have children. Why should women who were really incapable of taking care of children have no fertility problems? This theme became a philosophical rhetoric question :why me and not them?

Unanimously these women demonstrated through comments made to them the lack of education and ignorance the public has about infertility as well as the inability for people to openly address the reality of what those struggling with infertility experience.

The other critical aspect of how society viewed infertility to these women was that there is no public interest or policy related to the rights of the infertile population.

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Some realized that several of their relatives also may have been infertile, but it was never openly discussed in their families.

“We have gone through infertility for about ten years [pause] I think it has been a very *painful* [italics added] process [voice quivers]. I don't think that you know, that it's ever going to go away. Hmm, I think that it's very isolating because you don't find, I mean I have people that I have made friends with who have gone through infertility who've been easy to talk to, but I don't, you know, when it comes to my family, they have no clue. I don't think they will ever have a clue of what, of what it's like. And when I did make friends with women who had infertility, once they went on to having babies, they just completely didn't call again even though they were wanting the support you know while they were pregnant. That was kind of hard. But we've done IVF, we've done frozen embryos, we've done 6 cycles of Clomid, 2 cycles of pergonal, some insemination with just progesterone. So it's been a lot of medical problems. That's pretty much it. And you know, and now being at a place where I don't know what I am going to do. You know, where I don't think emotionally I can handle more medical treatment and you know my husband not wanting to adopt. So it's a very hard place to be in. God knows what I am going to do.” (6)

“Well, if you live your life according to other peoples' views and judgments, then you never live at all because true life is living in happiness and reaching your goals and never giving up.” (5)

Participants feel judged about being childless, they are given advice, seen as selfish, or make up stories to hide their infertility.

“People say silly things, like, oh, you need to take pre-natal vitamins. So you're like okay, you're taking all these pre-natal vitamins. And then you go to the doctor and they say that's an old wife's tale, they won't make you more fertile. You need to take this and then that doesn't do any good either. Then people say oh you need to eat figs, or more plums or raisins and on and on. They tell you all sorts of thins to eat and teas to drink, it just makes you feel worse because it means you are lacking here, you need to be fixed, so take this. And so you're like, that makes you feel bad and its other things or other women who have the gift of fertility who look down upon you in some ways or another in society, because they'll look at you and they'll be oh, you're married and you don't have any kids? What's wrong? They'll say things like that or they'll make comments like oh well something must be wrong with you, just straight out. Or your husband isn't upset about that, how does your husband feel about that? And it's like, you already know, and it's a big slap in your face, or people will bring their kids over and say, oh well you can borrow my kids and your husband is sitting there just like, you know, thanks, but no thanks. And he's looking at you with, he's hurt and you're hurt, it hurts.” (3)

I think at first when people didn't know why I didn't have children, some people were thinking that I was selfish, you know, good job, good husband, a nice house, and I didn't have these kids to fill it with. So people thought I was being very selfish. Now that people know about the infertility, they are okay, some of them are supportive when hearing that I may want to go through another medical procedure. They think that's the right thing to do. But they have been supportive. But I don't think, it would be harder for them to understand if I decided that this is it and I'm not doing anything else medical and I'm not going to push the adoption issue and just look at other options like foster parenting, something like that because we have considered that too." (6)

"I think I am pretty open about it now. I think I got tired of making up stories and lying about why we didn't have kids, like oh we are trying, or maybe next year, and now it's like, in some way it makes them feel worse when you say I am infertile, they kind of look at you like oh my God, I shouldn't have asked. You know, so actually that makes me feel like the pressure is off me. And sometimes it's hard because some of them will say oh you just need to have faith. And I feel like okay, we have been friends for a long time, I have talked about this for a long time, don't tell me what I need to have is faith. You know, it's like, because in their minds I think there is still some hope that by some miracle I am going to appear pregnant. And you know, I don't feel that. So I pretty much feel like it is not going to happen." (6)

"People should not take life, procreation for granted, because it is not there for everybody and for whatever reason they need to count their blessing and thank God that they can have that part. that's what this world is all about, procreation. I mean that's the only way we go on. You know and so I want them to know that is very valuable, very priceless and they need not to just take it for granted and it's a gift and it's a miracle and I think that they, people, overall, society in general, should think about things they say, not knowing who is and who is not fertile, and try to be more sensitive about it and less judgmental and think that is just a given that anybody can have kids. and automatically when we meet people and they see that we don't have children, they automatically assume that we chose that. That we don't have children because that is what we wanted. And I think that people need to understand that sometimes you do have choices and other times you don't. And in having a child, most of the time, I would have to say that 90% of the time or better when people don't have children it's not their choice and people need to understand that." (3)

"It's [infertility] still kind of so taboo and it's not something that you discuss, kind of in the old days when women were men's property and whatever happened in the home it was personal and you just didn't talk about it. I probably only have, of all the people I work with, probably only two of them know what's going on as far as my infertility. I feel, I just feel like I have, I have so much to lose emotionally to share with too many people that I have to have a more stronger relationship and a bond before I even share that with anyone." (3)

"And you know with people that you don't know being insensitive too. I mean people just assume, they see us and they say where are your kids, or some people don't you have kids, they never stop to think. And sometimes I say you know ell, sometimes I don't elaborate, and sometimes I just say well we were never able to and then they kind of, there's silence, then, nobody has ever asked why or wanted to discuss it further. It's kind of like one of those secrets that you keep hidden." (3)

“And when people come in everyday [to work] and talk about their kids they don’t even realize and I know it’s not intentional, but they talk about new little things. The woman that I work with has a baby that just turned one and every week she brings in new pictures of her baby and without understanding what I may be going through, it’s just real hard. and you try to look at pictures and say oh how cute the baby is and all that kind of stuff, but it’s so hard to do. And when the baby showers come, it’s just so hard, because you feel like you should be there, it should be you....I try to be supportive as much as I can, but sometimes it’s really so hard” (3)

Participants with other would be more sensitive and listen to their stories without giving advice or judging.

“Just listen, just listen to whatever that person is saying and don’t , don’t give any advice [laughs] on what to do or what to take. Pretty much be there and listen to someone who has infertility and respect where they are at. If they don’t want to keep treatment then just respect it and if they don’t want to adopt then well that’s their choice, so just respect it. Do not make any kind of judgments. Of feel [long pause] sorry for them [voice quivers], like and really, just kind of not sorry, pity, that something that I have a hard time with, poor thing, she can’t cope, she’s an emotional handicap. You know because she doesn’t have kids because you know I feel that is what I have gotten from some people, they make me feel as though I am emotionally handicapped and that I can’t handle something. You know, that really bothers me.” (6)

“I think my experience [with infertility] is as though you were put down because you can’t reproduce.” (6)

“I think that I made choices, early in my life, to have a career and education, and that I waited too long and I put myself into that situation and that they [society] blames me as it being my fault.” (3)

“Society in general sees a woman that is infertile from the American standpoint as no big deal, it’s not a big issue, you can get a career, you can adopt, or you are lucky you don’t have to worry about a family and family struggles and that’s still hurtful. That’s how society in general views it, they don’t think it’s a real big crisis. But it is a crisis and it is important. It’s not spoken or mentioned enough, that’s why you have this study going on I am assuming is because people are very unaware and they are insensitive and they think it’s unnatural. And you have co-workers when you turn in a doctor’s release, what’s wrong with you, why were you at the doctor’s. You don’t want to say nothing [sic] and you can’t say something because then everyone starts making comments, or gossip, and you are so through hearing what everyone has to say, you just feel like

you are alone. And I started separating myself from my friends and family and from the cruel comments they were making. They didn't know they were being cruel and that they were tearing me apart inside and that I would just start crying," (5)

" Here is an example. they [work] switched our dental insurance here and they said this was the best. So I was great, this is real good dental. But it was only great if you have kids because it covers braces, so it really covers less than what you had before. So the focus is on the family, but it discriminates against those of us who don't have kids. I wasn't asked, it was switched because most people have kids." (6)

"Ant it's starting to affect your work as well and people are saying why is this person missing. And when you do a sperm count, they give you, you have to have it in the lab an house after the specimen was taken. And so there is so much pressure that it has to happen right now because you have x number of miles that you have to drive and if you hit traffic or road construction, the specimen won't be any good. And you have to go through this all over again, And it's hard to explain to people and they don't even realize that ." (3)

"It's really hard [when friends have a baby] because they wail tell you I felt it kick or they'll say I'm six months or they'll say it's going to be a boy or I'm going for my ultrasound or whatnot. Do you want to be there at the birth, you can hold the baby? And you know, they make comments like that and you just get, you just get furious. I would be like why is God blessing them with children, because I look at their marriage and I say, we have so much love, so much trust and everything and her husband is abusive. And they have kids already, that isn't fair. And you just start think about all these thing, or her husband is in jail, why is she pregnant, she is six months pregnant. You beat yourself up about it. You're like now this isn't right, you don't have the right to think like that. God has very right to bless them with children, but you say, why them and not me. It constantly comes back to me." (5)

"It's [infertility] an inconvenience for society itself because infertility is not covered on any medical insurance." (8)

"...the backlash for being infertile, the ostracism, the criticism, and the insensitivity that other people display." (5)

"I think this [infertility] is something that happens to a lot of people. And I don't think the support of the community is out there. I mean, they have information about it once in a while, but I don't think people understand and realize that it is there. I mean we still have people that are asking us well when are you going to have children, you have been married ten years. And it's like if you see someone married for ten years and they talk about how much they love kids, there's something wrong with this picture. It doesn't click, they think you are just waiting around or we are selfish. You know I have heard people talking about infertility on the radio and stuff and they make comments not to wait until their thirties to have a child and that is something that makes the public feel that all people waited and that is why they are infertile and that is why they don't have

them because they got too old. that's a guilt trip. that's bullshit. You know I started in my twenties and my friend [also infertile] started in her twenties. I think that they can make a comment that the older you get the harder it is [to have children], but they should also make sure to let people know that doesn't guarantee having a baby by starting early. That is not the only cause of infertility, starting or not when you are in your thirties or postponing because of your career....it's a lot like AIDS. I think people need to understand a lot more." (6)

"I don't know why, but there are so many, so many Muslim women that have the same problem that I do. There was one lady who was telling me everything that could possibly work. She was trying to have a baby for 9 years, finally, she went overseas to her husband's country with him, she got pregnant." (8)

"I would just like to tell them [begins crying] that this is the most difficult thing I have ever been through in my life. And that is the only thing [having a child] that I feel is lacking in my life and that each day even through I go on, I go to work and I survive, they don't know how much pain, and how much anger, and how much frustration that I live with everyday. And, hum, not to make judgments, they have never been in my shoes and they don't know where I am coming from.." (3)

"Everyone tells me you know, you are young, you're still young. But when you are ready and you know, you see all your friends having kids, I mean, one of my friends has four kids, and her I am, it's a lot of resentment, a lot of pain. And then you worry gee, what if my husband doesn't want to be with me because I can't give him a baby." (8)

"I run into a lot of conflict I think because I don't have kids they [friends] think I don't know a thing about kids. But you know what, when you want a baby, you learn everything there is, you read everything there is, you look at everything there is to know everything about a baby. Because you want one so bad. so there's things like, just things like, my girlfriends don't talk to me about because I don't have kids, they think I don't know and that puts a halt at one certain point in your friendship and relationship with women who have kids. They come over here with their kids and there's none here for them to play with and be content. And so that kind of puts a limit on her certain people want to be your friends, and actually that is how you become friends with a lot of people, your kids and their kids get together and you sit down and you talk and there's a friendship....So that part I finally just like, over this past year, I really realized that I don't have a friendship with them anymore and I had to let go of them, a lot of them." (8)

"I think that society in general, probably thins, well, that's odd, a Hispanic woman not having children, that's very odd. But at the same time, I think that society sees women overall anymore, well recently women just don't have children if they don't want them, so it's become somewhat more acceptable. And you know it's more okay. I don't feel like I am particularly looked at as being strange, but to be Hispanic and now have children, there's still that little piece that's odd, but in terms of just being a woman and not having children, not a problem. But I do think that because of what I've experienced, there are many women who don't have children, but it's not been by choice." (2)

"I think I share that with some folks. And to some degree it's almost like ah, they might be more accepting of me knowing that it wasn't my first choice because I think some people think oh you are just selfish, you just want to do what you want to do, have all your fund and toys and not have children. So sometimes it [telling them the truth] lies me off the hook." (9)

“I don’t think it’s affect them [people I know]. I don’t think they see me any differently. But I think that I don’t want to say it’s been weird, but that when you don’t have children, and you are around people that do, it’s like you just misconnect at some level and you can only carry the relationship to a certain degree and then it kind of ends because they’re dealing with kids and you can’t relate and they can’t related to not having kids. So you can only take the relationship with people who have kids to a certain level I think. At least that has been my experience anyway and than you have to find people who don’t have kids to hang out with.” (2)

“Some [people who know me] know why I don’t have children, many of them have been there with me through all of this. the people that don’t know me well I don’t say, guess what, I can’t have babies. but I have told people O work because people often say you don’t know what it’s like because you don’t have any children. And sometimes, there was a time when a woman did it intentionally to hurt me. I said you don’t know my pain. People make assumptions about why I don’t have children. And they assume that because my husband has children [from a prior marriage] he must have had a vasectomy.” (10)

“We did not pursue medical advice, but we did hear lots of myths, like I was told to do it doggy style”. (9)

“I use to think, you know, what’s the big deal, it just didn’t really bother me so much. In fact sometimes I would get annoyed because I would think what even makes them think I really want children, they just assumed that that’s something that I want in my life and so I would feel annoyed that they would more or less stereotype me in the female role that all women, especially Hispanic women, want children and that all Hispanic women have children. So it would make me kind of angry that I would be stereotyped and just the assumption that you are suppose to have kids. So I hated that the pity, I hated that they would just look at me, oh you poor thing, you know that would bug me.”

“Some women that I know who know me, know I can’t have kids. I feel like they kind of have an attitude toward me, like they hold it against me because they tell my boyfriend that I can’t have kids.” (1)

“People would tell me that they knew people who have gone through ten years without having any children and then all of a sudden, they’re pregnant and I kept wishing I’d be like that too, but no way, so it hurt even more.” (1)

“In a way I didn’t want people, I guess, to judge me in any way. “ (7)

This participant was really worried that women from where she worked were involved in the study and wanted to be certain nobody else would find out she was in the study and therefore she also did not want to participate in any group setting since her wanted her anonymity protected. By the end of the interview, she was fighting back tears and trying not to break down completely.

“I really didn’t tell anyone. It was the big secret. That was just like too private. When I got engaged recently, people, people at work I am close to who would understand, ask me if I plan on having any kids, and I could tell them, but instead I say, well I haven’t really thought about that. And they say why, you are so young, you can still have kids, and you can have kids together. and I say well maybe, but I have never told anyone that we [ex-husband] couldn’t have kids when I was married, or after we divorced....But for some reason I don’t want anyone to know. I would

function at work like nothing is wrong, you know, I have a good life, I have kids, I am happy and I just didn't want to tell anyone." (7)

"I think there's a lot of hidden messages. I don't know, because I think it was this last month in some magazine, what they were saying about females looking at males and males looking at females, the males are thinking if they [females] can bear children and that is in their subconscious. But you don't realize that. The general population I think would say, well they already have two children and we are overpopulated anyway, so they should be happy with what they have. And in the Hispanic population, I really feel, it blames the woman, even though it wasn't my fault and all that stuff is left up to the women. In my family I don't think it mattered as much since I had children. I kind of had done that. You know because I have some other goals, like school. But in his family I know they probably talked about it all the time because we hadn't, whatever, like his sisters were sneaky and tried to act nice to my face and would ask me if I was trying or are you really stressed at school, like maybe I didn't know what I was doing. And I'd say, no, I wouldn't even give them the satisfaction. I would say, no, we aren't really worried about that right now, I mean, we are just getting to know each other. But they wanted to hear, well we have been to the doctor and we are doing, A, B, C, and D. But I would never say that and it was really hard when they asked me if I had my tubes tied. You don't know how bad I wanted to come out and say, hey listen, it's not me, but I didn't. Not until after the divorce, everything came out." (7)

"...people think if a couple is not pregnant, they assume it is the women's fault:

"And to look at him, you would never think [he's infertile] because he is really a macho guy, he worked in the oil fields and he's big, he's a lot bigger than me, had muscles, and rides a motorcycle, kind of wild, free spirit type of person, and so to look at him, you wouldn't think that he is infertile." (7)

"You don't have any idea what they [others] are thinking if they don't say it. Sometimes I look at people and they think that maybe I had abortions and stuff like that and that's why I'm not having any kids. but I've never had one of them, I don't believe in them. I don't believe in abortions or birth control." (4)

"Everyone always has the answers. Just like if you even have a new baby people say you should be doing this or you shouldn't be doing that, you know. So I kind of felt like it was the same thing, like oh well you are not trying hard enough or who knows I didn't want to get any crazy answers, like you should only make love on the fourth Monday when the moon is out or you know something like that and people come up with really weird ideas and it makes you feel so inadequate." (7)

"Inside I was really hurting, but I didn't give anybody that image to where I have to be strong. And, I guess I was grateful I could have kids and most people I talked to would say you have a child and I think because some people out here couldn't have any kids and they thought I should do the best job I can with my kids." (1)

"They [friends] don't say nothin [sic], except for my one friend, she always says [sic] you'll have one someday, don't worry about it, you know." (4)

"People tell me thing all the time, like just relax and it will happen when you are not even thinking about it, and when it did happen, the second time, I wasn't even, I didn't even have it in my mind, I wasn't even thinking about getting pregnant and it did happen; One girl I know she

would say just take you know Geritol, because that makes you fertile for some reason, because she didn't get pregnant for a long time and when she started taking it, she got pregnant right away, but it was just the right time, it really wasn't the Geritol. But I have had other people from the West Indies, because that is where my family is from, they believe that I need a what do you call it, one of those mothers, they came a long time ago in the islands when you are going to have a baby." (4)

## ***Feelings and Emotions***

These women experienced a diversity of feelings and emotions associated with their infertility. Infertility does not generate neutral reactions. Thus, narrating one's infertility is closely tied with how one feels about herself. Overall, infertility forced these participants to perceive themselves in negative images. Since their natural and assumed ability to conceive was impaired, overwhelmingly these participants felt inadequate as women. Negative Feelings of Self: Negative comments about self stemmed primarily from feelings inadequacy as women, specifically their inability to conceive in a world where it appears others conceive effortlessly. Their sense of being less than a women impacted their sense of fulfilling their obligation to their partner, family, culture, or the dominant societal norm.

Feelings about their infertility:

"My experience [of infertility] has been really hard' (1)

"The only thing that I can say to anyone woman who is going through what I am going through, I would say that it's just the hardest struggle and it's a race worth winning. And I will *never* give up." (5)

"Then inside I kind of felt less of a woman, I don't know how to put that even though because I know I'm not [voice quivers]. So every time anyone would ask me I would say I don't know, you know, I don't know what's wrong. I didn't even know they had a name for it, secondary infertility or whatever. That's the whole thing too, I think that's why we might have told them we used artificial insemination because they told us there was other stuff they could do to the sperm, spin it or something like that, but there wasn't enough even to do that." (7)

"But at first [husband kidnapped by family] I was broken in spirit, disheartened, and I felt like just looking at the wedding band, I felt that I was [pause] you just feel betrayed at one point in time or another, you feel betrayed, let down, and abandoned because you have a curse, you can't bear children. So I felt like it was a cowardly act to take him away." (5)

"I think I have a mixture of anger and I get really teary, crying a lot. Sometimes I get really angry when I see someone in the street yanking their kid and I say why her. Why can she have one and I can't have one. You know the anger of why me, why did I have to go through this. I say why me." (6)

“It [infertility] colors everything. I just really feel like killing myself sometimes. I get really sad and I get really down over it. and my husband doesn’t understand it, you know. I mean, he works hard all day and he goes to school. And when he comes home he doesn’t need, every single day, this depressed person in front of him. And so I try you know, to be optimistic, you know, he has expectations that he expects from me regardless of whether I have a good day or a bad day or a depressed day. whatever, I still have to cook him food and be his wife. So that part is hard because I don’t have anybody that I can talk to that has the problems that I have.” (8)

[feel] “powerless, powerless” (3)

“ When I said painful, I mean emotionally painful. I mean the physical stuff I feel like it was nothing compared to the emotional pain of how hard it’s been.” (6)

“[I feel] lonely [almost cries, long pause]. And it’s painful, when I see other women, especially overweight women, you know way bigger than me that you know are pregnant, and you know they have one kid here and another one here [points to stomach]. I just think that why did God have to do this to me. But, you know, I told my husband, then he gets kind of mad. You know God gave you life and he lets you live, but there are certain thing that you need in life to be happy, you know, and I think I have a lot of depression because I’m still not getting pregnant and I’m not having a child.” (8)

[feel] “...lonely and sad...Frustrated, really frustrated. Cheated, you know, I just need to work on what might help me be more successful [fertile], you know, by losing weight, eating healthy, walking, exercising. and it’s hard to do all that when you have done what you want [before]. So I am trying to mentally do that [focus]. (8)

“I don’t know what I’ll do if she [sister] ends up taking her baby back, for the time being I feel really good about myself.” (1)

“It’s just unfair and it’s frustrating you know, because I fell like I am running out of time and I am, I’m at the end right now. If they take my uterus out this time I mean when they do these tumors, It’s just going to kill me. And I’m scared and I think about it and I told them if I’m an inch away from death, you keep working on them if you can so that you can keep my uterus in me so you don’t have to take it. I said and if it looks like I am going to die and you can’t do anything else then take it, but if you can’t do anything else, you know, just do that, use it as a last resort you know what I mean, because I got to do this [have a kid] before it’s too late.” (4)

“It [infertility] was really hard at first. At first, like, at first I just denied it.” (1)

“So that’s really it, nothing happened, but I guess it didn’t really hit me until about ten years later and still nothing had happened.” (1)

“You sort of feel like you have this deep emptiness and you don’t know how to fill it, you know, what to put in it. And I think the other side is it has shown me something else in life and I think I have gained strength from it, am able to handle more, more psychological things, mores

crises, because I have gotten use to dealing with that [emptiness]. So in some way it has strengthened me, you know what I can handle and what I can't handle." (6)

"I feel like a loser because I can't have any more kids....So I kind of went through a hard time really hurting at first, then denying it. I thought I'd accepted it, but no way." (1)

"Being tough about it is how I deal with it." (1)

"Maybe I have some more time left. I certainly am going to keep trying. I am not going to give up until I can't. I am not going to give up, I'm not...And then I don't want to be old and not have anybody to come to dinner and holidays and stuff like that, you know. I don't want to be sitting somewhere and be getting old by myself. I haven't given up, not yet." (4)

"And I felt kind of worthless. I kind of dealt with it myself." (1)

Their infertility has isolated them to go into themselves:

"There's something about infertility, like I said, you can't really share it. You can talk about it and you can bond and you can understand each other and you can do loving and caring and nurturing things, but when all is said and done, that person is still alone and off in their little corner to deal with it alone, isolated. And you are alone and you go back to what is going on inside of me." (5)

"I just feel like when situations get really bad, and sometimes when other people fall apart and cry and scream and just have a fit, I just block it out, turn it off, like my body is a generator and my body just switches over to something else you know. Sometimes I can do that. A lot of times now I can. I wasn't able to do that so well then my baby died, but I learned and now I do that since that woman told me the part of the Macabee Bible and everything." (4)

"Like I said, it's the hardest issue that any woman, any man should have to deal with. It's something that the person goes through alone. Infertility is not something that you can share, no matter how close you are to someone. It's a battle within the *self*. No one can join this little war. It's just you." (5)

"I was really angry at first. I thought you know maybe they [doctors] are not doing something, it can't be like this. I mean, I just kept saying I had have two kids., how did that happen? Why did it have to happen to me. You know, then, and I use to tell myself, I said there are a lot of people out there, you know who have kids, you know, who abuse them and stuff, why do they have kids and I can't [have any more]. " (1)

"Because for a while I think that it took [dealing with infertility] over my life. that was what the goal was [having a baby] and that was what we were going to try to do. And so when I look back, I kind of think that was a lot of waster years, but at the moment, I couldn't get out of it. And it wouldn't have been [wasted] if I had gotten pregnant. But I worried a lot about it, cried a

lot about it, and for what. So to have other things going on in your life and to be able to do that. It sets you up somehow because it's all consuming. You have to be up every morning before you move around, before you go to the bathroom or anything else like that and take your temperature and chart that and everything is, it felt like my whole life was in that chart. Char this, and the sex, I had a really good sex life, I had an excellent sex life and all that kind of went downhill, even though we were happy with intercourse, but it seemed like mechanical, you know, you know, we had to, and even though when we were [pause] and I still loved him very much, but it just wasn't the same [voice breaks up], it just wasn't the same. (7)

When their negative feelings about themselves were reinforced by others' reactions to them, it further confirmed their sense of failure which led to low self esteem.

By blaming themselves for their infertility, despite the actual cause, participants attempted to protect their partners from the shame and embarrassment of their condition.

"Deep down I blame myself sometimes, that in the back of my mind, you know, that I should have just laid down, don't move. and I couldn't eat, I couldn't keep anything in my stomach. And I didn't really try to force myself, I would try to eat baby cereal, like cream of wheat and stuff like that I could eat, I would do, I would eat cheese." (4)

"It [infertility] lets me off the hook. They [others] don't see me as so selfish because it seems so important. For example, a lady at work who is about to adopt two children, her maternal instinct is so strong, she probably can't understand that is has had to become okay for us that we can't have children and so we need to pursue it differently." (9)

"We [husband and me] discussed it when I first started to go through infertility and everything. and I told the doctor that I want to make sure right now if I can or cannot have children. If I can't ever, then I don't even want to stay with my husband...when if ten years from now he really wants a baby and takes another wife, I don't think that mentally or emotionally I could deal with it.: (8)

"I know that I cried a lot and I don't know if that was crying over knowing I'd never have kids or it if was post partum depression because I cried and cried, a lot. [pause, voice softens], it was frustrating, it was like why is this happening. What am I doing wrong. I felt like it was me and I blamed myself and at one point I said it probably was me and then I felt like it was confirmed when my ex-husband went in [to the doctor's] and he was fine. I felt so alone." (10)

That was my chance [miscarried] and it looks like now I don't have no [sic] more chances, any more chances, and you know if I just had one more chance, I would be really careful. I didn't drink, I didn't smoke cigarettes, or nothing [sic], I just cleaned all the time, you know. and maybe I was putting too much strain and stress on me, and maybe I shouldn't have been moving around as much as I was, I mean I would take my time [voice drifts off]. (4)

“And sometimes I feel so, so bad for him. And I felt like, I don’t know where he is coming from either, because even though I know as much about him as I do, I don’t know how he feels about it, really.” (3)

“He [husband] never wanted to [adopt]. I think he has a lot of myths about adoption. He’s afraid that what if we adopt some kid that may have some problems.” (6)

“Well, since he’s [husband] not okay with adoption, it’s sort of my way, my way of trying to compromise, trying, okay, I’ll give in one more [IVF]. I’ll put my body through all of this, again [emphasizes] to see. It’s sort of like, I feel, part of me felt like if I did that I have a chance of having a baby and if I don’t do it, I have no chance, unless we separate [voice quivers, long pause] (6)

“I think we [husband and me] are at different stages because I think that he still has some optimism. He still would very much like to have a child. And so would I...We went to a point where we say down and talked and I asked him if he wanted to leave the relationship because I couldn’t give him a child.” (3)

“And you know [my husband] was okay with it also it wasn’t like oh we have got to have a baby, we have got to have a baby, so that made it less traumatic too... He [husband already had a son] and he said that it was so negative [because of his ex], it was just so traumatic, he said it was so difficult, it wasn’t like that child met his needs, so I guess it wasn’t a big need for him [to have another child].” (9)

“So in my mind I am always thinking, was it the birth control was it the infections, was it unprotected sex, I mean, you know in the end I just don’t know....I’m just very regretful that I didn’t pursue my sexuality differently. I just feel stupid and irresponsible for doing things that I shouldn’t have done that may have hurt having a baby later on.” (8)

“When I would think about it I would just cry. So it was hard to talk about. Sometimes just driving home I would cry a lot. Just thinking about it, I would cry a lot. Sometimes with my husband, but I would try not to cry with him, but I felt like I was putting a lot of pressure on him, so I would try not to cry with him too much..” (7)

“...so then it came down to there was no scientific explanation of why, and I wanted to know why [inflection]. Why was everyone else bearing children and I was not bearing any kids.” (5)

“And I felt like I was robbing him from something he can still do because I couldn’t give him a child and I felt like I was robbing him from something and that is *my* [italics added] fault. And I told him I wouldn’t blame you if that is what you need to do and you want to have a child. I mean as much as I love you and how much we waited for each other to come into one another’s lives. I can’t fault you for wanting a child. And I can’t give you a child, and if you need to go elsewhere to have a child, as much as it would hurt me, I would understand. And he, I think it took him a

long time to deal with it. And I mean his response, he never really did respond to the question, but he never left. And the only thing that I could figure in my mind is that's what his response is indirectly because he is still here." (3)

"I think that at some point I felt inadequate as a wife because of everything that was happening." (10)

"...but I just feel so selfish and I feel like I am taking that away from him because I want him so much and love him so much and he loves me, and I just feel so selfish and I don't know how I could ask him to give that up [continues to cry]." (3)

"And I started to blame myself more and more and my friends would be like why are you so down on yourself and they would call me and announce that they were pregnant and I would get upset with them for calling me and they'd be like what if it's him." (5)

"I realized that being infertile and going through that process was very very stressful and you have to make sure that you *both* [italics added] can handle it. It depends on the individuals. I couldn't say go for it, because it is so very stressful, but also be aware that it's not just stressful for the woman, but on the man too [voice quivers]." (10)

Feelings about their infertility were also were dependent on the stage of infertility, that is still within child bearing years, post childbearing etc.

These women felt a tremendous sense of loss:

"I've gotten more use to the idea [of being infertile] now, but it did bother me a lot before like when I was younger I was always thinking that it was going to happen this time, you know what I mean. You keep on thinking that every time you do something, maybe it's going to happen. But it didn't and I was always disappointed, you know. But I have gotten over it a little, but I desperately want some. You know and there are times that it will still bothers me, kind of destroy me a little bit sometimes. But it's not as bad as it use to be." (4)

"I haven't gotten depressed in a long time, but I am not saying I never get depressed anymore, because sometimes I do, but three years ago I had to get medication, and I went into group therapy to deal with all the loss [infertility and subsequent hysterectomy] (10)

"I think the big things for me are never knowing what it's like to give birth, and never knowing that love for a child that my Mom says is the most beautiful thing there is and [pauses, voice quivers] and not seeing my husband in that role, in a father role, because I think he would be wonderful, so that's what [pause], if you can miss something that you never had, that's what I regret if I think about it. I'll never know that now, you know, but I guess it just wasn't in the stars. (9)

“It still bothers me and I will be lonely, unless you know [I have a child], but I always have people around me and other kids, but it’s just like they’re not my own, you know, I want my own. I’m anxious to see what mine would look like what it would act like, you know what I mean, all of that. But I know if I don’t have any it will be lonely and stuff.” (4)

“You know I was just so frustrated with being in so much pain that it kind of overrode any of the other feelings. Towards the end I was like I don’t want to go through this anymore, I am okay having a hysterectomy and even now I say that because that was probably one of the greatest days of my life, quite honestly. I mean there are other important things, but as far as my physical well being, I was finally fine with it [knowing I’d never have kids] because I don’t have those kinds of pains anymore. But I miss the fact that I will never [voice shakes] have a child of my own.” (10)

“I think it speaks to acceptance. Life is not a fairy tale, it is a compromise. You work with what you have and you make it the best that you can. And I think that has been our lesson to really look at all our blessings and I don’t know if it would have made our relationship stronger. Probably. Our relationship is pretty solid, pretty tight, and pretty wonderful, and maybe it’s because we only have each other. But I think it would have even enhanced it more if we were able to have a child, I would hope, because I can’t imagine you would want to have a child unless it had that effect. But I think that, again, Just acceptance, putting our energy into our relationships now that we know we can never have a child.” (9)

“I think that one of the reasons we are planning so carefully for our retirement, because we don’t have kids we can go live with or fall back on if we need them, it’s like we have to have a certain amount [of money] to be able to function completely independently.” (9)

“I think a very large piece of me is gone, because of that tremendous loss, you know. All my female that which identifies you as a woman was gone. I was depressed a lot.” (10)

“Actually, talking about it now [being infertile] I have a little twinge. But for the most part I am okay [hesitates], I think I mean, I think there are certainly times that I tell my husband now, why couldn’t we have met each other before when I might have been able to have kids, why didn’t I save some of my eggs and see if it would have happened later. And certainly when I rethink things, all these things cross my mind at times, I don’t know, I can’t say that it will ever be totally resolved, I mean it is just something that happened, it’s just part of my life now. But I think it’s how I feel with it, because it use to be that I would cry a lot, especially after the finality with the hysterectomy, it was so final, partly because that eventually led to a divorce shortly thereafter. And there were a lot of loses. And then I am thankful that I didn’t have any children because our divorce was so crazy.” (10)

“To me it was very traumatic. It was like I told my sister not that long ago. To me having a hysterectomy made me well physically and emotionally. I had not more pain and I had to accept I would never have children. Before I had a hysterectomy I was very stressed about being infertile. Ironically the hysterectomy was a blessing. I have experienced very few problems since the operation. At first I couldn’t be on any hormones because of the cancer cells, but now I am taking hormones and everything is find and I feel great. And I prayed and prayed for the first three months because they sent everything to George Washington in DC and they said the cancer was encapsulated and it had not spread and so I felt so luck to be alive, the loss of not having a children seemed less important at first.

“How do I describe the loss. It’s well, I think the loss would have to be just that strong connection that I see parents and children have. And I just don’t have that bond, it isn’t there with anybody. That’s just not there. I don’t have that with anybody. You know, I’ve got my dogs and I feel attached to them. And certainly there’s a bond, but it’s different. It’s really different than obviously if I had that with a child and if I had had children. And I think that’s the loss that I’m feeling,. I feel an emptiness, a real emptiness.” (2)

The day after this interview, this participant called me to thank me for taking the time to care and listen to her about her story. She said she had not understood how her infertility permeated almost all aspects of her life and how she continue to ignore it’s impact. She said the interview was not upsetting, rather it allowed her to honestly face her sense of loneliness and seeing how she never allowed herself to see how never having children robbed her of fulfilling a need that her childhood robbed her of. She said she is ready now to see a therapist and discuss things about her that have been hidden and she feels hopeful that talking about her infertility has unlocked her from the sense of stuckness she has felt in her life and has kept her from moving forward. (2)

Depending on how much support participants had received either personally or professionally also impacted their feelings about themselves.

“I don’t know whether it is that they all live in Honduras, I don’t think, they never experienced this, so they can’t even imagine what it’s like. And they don’t, ah, well like you know, right now my niece is pregnant and that’s probably the hardest because she is the first one in the family of that next generation to reproduce. You know, and my feeling was sort of like I was suppose to be next, not her. It was my turn, not her turn. (6)

“Sometimes I can’t even go to them [baby showers]. For a long time I couldn’t even to into a baby section [in the store]. I couldn’t to go showers definitely, but I would avoid the baby section because I that that will never be me buying stuff for my child. It was just too sad.” (10)

These women are in internal conflict with themselves:

“Sometimes it would get me depressed and other times I got mad, just mad at myself, like why, why can’t, why me. And then I would see my friends and one of them was the best friend I ever had, and she would just take off and leave her kids with her Aunt or whatever. mean leave them, she would be gone for three four days and then her Aunt got really sick one day and was in the hospital and died. I just happened to go on down the block in NYC just to see if everything was okay. I went down just to see them and I thought she was there, but she wasn’t there. Who was there, let’s see, her baby was there, her baby was about 7 months old, or maybe 6, and the one year old was there and I think the other one was at her sister’s house and her two younger sisters were there and they had kids of their own. the baby was in her crib crying. I said how long as [my friend been] gone and I said how long has it been since she’s been out of her crib to feed her or change her or anything. And they said she’s not my baby and this and that. They just left her in there and I took her up and I changed her and I fed her and she had, you know, been wet where it ate through her skin and everything and these are the women who have babies, you know and this is why I get angry. And as bad as I want them and I know I’d take care of them and I know my baby would come first before anything and anybody. And I don’t have any, and it’s just

not fair. It's just all these little kids we have here [foster care] from neglect, abuse and everything, you know. And I still can't have any. and I just don't think it's fair you know, so that's how I fell about it, you know." (4).

"I think I would have gone as far as I could go because when I was wrapped up into that I would pretty much just do anything This is not going to beat me, I am going, you know, this should not be this hard. why is it this hard. Why is this so hard for me? And I was pretty much willing and ready to do anything. I would never even before even thought about getting donor sperm. Ever [italics added]. I thought in my head and I know this sounds awful, but I always just thought Lesbians got donor sperm. I never ever thought that I would have to be looking through pates and profiles on men and seeing their pictures and I mean thinking, I don't know, I just never thought I would have to go through something as humiliating as that, but I would have done it." (7)

"I mean some days I feel like I have done enough, leave it alone and I am okay with it. And then when I get like PMSy and closer to my periods, that's when I start picking up the phone, you know calling [doctor], trying to figure out if there is anything new in the technology. I mean I have even gotten to the point of calling the surrogate place down in Denver. And when I saw it was \$30,000, I knew we couldn't afford it. (6)

"Well on some days I fell so desperate that I would do anything that I would to any kind of extreme, you know to get a baby. I mean I have thought of getting a divorce so I can adopt as a single parent, going through surrogacy [husband doesn't want to do these things]. When I see that my options are getting to be fewer, I am willing to do things that five years ago I wouldn't have done, not even considered.." (6)

"And he [doctor] said there was nothing wrong with it [stillborn] so I'm thinking that God must have just anted his baby back, you know what I mean. it might sound crazy, but you know, this is the way I see it. You know and it helps me too because it use to get me so upset, but now that I think about it like that it doesn't, you know, hurt so much." (4)

"So all of this [dealing with infertility] was bottled up inside of me." (5)

"But yeah, he's admiring the beauty of their kids, and you're like wow. I'd love to be able to give him son, or a daughter, and like you have given all you can, all of yourself, and you just toss and turn in turmoil. It's mostly a war inside of you and it does put a lot of stress on your marriage." (5)

"And when I go back to thinking about all of this, hum, I just don't think I can handle it anymore. You know, the other day I got so desperate I called him [IVF doctor] again [IVF has failed], mainly because I know my husband would be willing to do another IVF, but he's not

willing to adopt. So I was just grasping for straws here. so there are some tests that he wants me to have done. but my logic was that I was going to get somebody else's eggs so that way I didn't feel like my body failed me again. You know sort of like they weren't mine anyway. You know that kind of attitude." (6)

"There's just a feeling of emptiness [voice softens and quivers]. Like you know how you go up high in elevation, you to in the mountains, and you say help and you get this echo. And that you are alone in this valley, just empty inside and alone. It's strange. Because I felt the problem was with me. I was having this battle inside of myself and the people who were very loving and supporting my career goals like my husband, were the people that I saw like in heaven sitting with the Heavenly Father and in hell were the tormentor, like in the Bible, it would say the people that would come to agitate and add insult to injury was the other part of life, so you just feel like there are two different lives you are living and there's no peace in either." (5)

"So then I feel bottled up like I am locked inside of a bottle. Because I felt like there was no one on either side [of our families] that I can go to and they would understand. So finally I decided to talk to a stranger, someone who knew absolutely nothing about me, who couldn't judge the situation, who wouldn't have any bias or prejudice or any knowledge of what is going on and could sit and listen. So I called the psychic hotline and she started talking with me and I started talking with her and it felt like there was a great burden lifted, that is just left. Because I had finally gotten to speak my piece and gotten to say what I was feeling inside and have someone listen and try to, they weren't trying to consult religion or culture, they were just looking at the universe for the answer, mother nature for the answer and speaking to me one to one. So it made me feel a lot better. It's like today, I am smiling because I can talk about it." (5)

"...you wait for your period to come and you don't get it, especially when doing this infertility stuff [treatment]. You think oh my God, maybe this time I am pregnant and you just pray and you hope, and then you cry and you wish, then you go to the doctor's and you get a pregnancy test and it's negative. And you just feel like somebody has just stepped all over you, *just crushed you, just kicked you in the gut* [italics added], that type of feeling like, you know. And you go through it *over and over again, every month* [italics added]. And after a while *it just gets you* [italics added]. And your emotions are up and down from all the fertility drugs, you're gaining weight, you are having hot flashes. You are having to have sex very unromantically, so I mean." (8)

"So it became a mental struggle, a battle between myself, I like to call it the heaven and hell issue. Because you feel like one part of you is just so uplifted and the other part of you is empty, absent, a dark pit. It's this lower part of your life, like what's going on inside of me, what's wrong, why can't I do the normal things that other women do, reproduction is a normal part of life, all of these other women are capable of doing this, what's wrong with me. And I started to blame myself more and more, I even started to hold resentment toward myself, hate myself.." (5)

Depending on the what stage they are at with becoming pregnant, their infertility takes up their full focus:

“Everything is on I need a baby, I need a baby, I need to be pregnant. Its’ not on work, school, live, life in general, all you can think about is a baby, you become so possessed with the issue that you become overwhelmed with it. That’s all you can think about. There’s even been months where I thought about it so much that I probably caused my period to be ;ate and to even have pregnancy symptoms. And I would go [to doctors]and they would be negative and then I would be upset. Sometimes I went through this stage where I would take the pregnancy test and it would be negative and I would break it apart and say this can’t be right, what’s wrong with this test. And I was like it can’t be, this must be wrong.” (5)

“I am going to be forty-five in a couple of weeks. I was thinking about this as I was washing the car earlier today as a matter of act [laughs]. A part of me is going yeah, buy you know I’m going to be 45 and then there’s another part going, yeah, but you know there are women that do have children when they are older, I guess I am feeling like I’m more mature, more capable of raising a child than I would have say ten years ago, but it’s just you know the biological timeclock, and maybe it will never happen now, and maybe I’ll never again have the opportunity to see, but I’ve got more patient. It think I have more understanding of children and I like them now.” (2)

“For me, number one, being a woman, you know, you get to an age, I am at the age where I have that motherly instinct, I *want* a baby, I’m ready. And then being a Moslem, being married to a foreign man, from a different country where the culture basically is the women stays home, she has kids , and she keeps the blood line going, for like you know, for the husband to have children.” (8)

“Well I think I just hadn’t really thought about it before you know, it was just like I said no big deal until now and I’ve gotten older and *it is a big deal* [italics added]. I’m getting to the point where it is more serious and I’m beginning to look at it [my infertility] more deeply. I’ve always been so flippant about it and now it’s a more serious thing for me....I would have to say it’s probably been at least during the last three years that it started to kind of affect me more and I’d have to think about it in some way and then I would put it way and it would come back and it keeps coming up.” (2)

“And hum, so I think now that I’ve gotten older, it’s started, it has started to really affect me a little bit more, I’ve been more [long pause, voice quivers] I guess sad about it. And I try to figure out why that is and I remember one time I was thinking, well gee, if I had children, then gee, they would take care of me when I get older. Then I say, well that’s a stupid reason to have children. And then I thought, well, you know, I’d thought I wouldn’t be so lonely and I thought well that’s not a good reason either. And I really couldn’t think of a real good reason as to why I really wanted to have children. But that sill has been more of a recent feeling. And it’s been feeling like more of a loss and there again, maybe it’s because I am older. I don’t know. I don’t know. I think probably [pause] I don’t know, just thinking about you know like this thing with [a man] this weekend and the idea, just the thought that someone may not be interested in me because I may not be able to have children. that was a big thing for me and it really brought it [my infertility] up again for me in a different way. I thought I will never have children, so that really hit me because for the first time I ran into a many who also really wanted just to have children as much as me. I mean, [my husband] did, but I don’t think his souls was really into it. And [my

other husband] never did [wanted them as much as me] so he wasn't a driving force until now. Now there is just no possibility I can have kids, I can't produce you know, so that's kind of what's gone through my mind or whatever and it's hard." (2)

"It's such a sensitive topic for a lot of people and it was not as sensitive a topic for me until more recently, but more recently it sure is a sensitive topic....It was not until I was a bit older that I realized the impact infertility had on me and that I wish I had paid more attention to it earlier, but I don't even know until now." (2)

By justifying their infertility was out of their control, these participants rationalized they were not personally responsible for their infertility. By not assuming control for their infertility, these women somewhat felt vindicated and did not indulge in self-blame. However, these women were often surprised when they reacted strongly to a situation and realized it was actually related to their infertility.

"People know what their bodies are going through. I haven't been sick, I have a cold and all, but nothing serious since I had the hysterectomy. To me that's why I say a negative turns out positive. I had a marriage break from not having kids, but they were growth things. But probably as far as the marriage, I was, I hate to use the word, I was probably too co-dependent., but I probably was. My spirituality has strengthened, my belief in God has probably never been stronger. So that is good." (10)

Although very open and forthcoming about her infertility while being taped, one participant waited, perhaps unconsciously, until the tapes were turned off before reported her what she called "desperation" about her situation. Since her husband is adamant against adoption, this participant is actually considering divorce so she can adopt a child herself. She was shocked by her own realization of that is what her struggle with infertility has come to and feels confused even having these intense and desperate thoughts as a way to resolve her infertility.

What stood out about these women's openness and honesty in relating their true feelings and emotions about their infertility was their relief that they had finally someone to tell their story to who would listen and understand without judging or giving advice. These participants were starved for someone to hear them and connect with their deepest feelings and emotions. Interestingly, for the women who chose not to be in the study, but who initially talked with this researcher in great detail about their stories, their need to talk and be listened to was the same.

"I think that is one of the reasons why I really wanted to talk with you because it's kind of an opportunity to talk about it and not have to hide or make excuses or be embarrassed or ashamed and to explain to somebody without really explaining it to somebody." (3)

"Thank you for coming [to talk with me]. It's really good to share it with somebody who *does* [italics added] understand. (3)

Being infertile is like being on a roller coaster, with up and down times, that come and go.

“There are good days and there are bad days. I find friends where I have support, to have a place to go where you can vent and feel supported, whatever you are feeling.” (6)

“To let it go, just to forget about it [getting pregnant]. Like no more of this. This is it. I am a good person, I have a good life, I have a good job, you know, I have children, I am a good Mom, I have a family that I love very much. You know that overall, I have a good life. Just let it go....just to quite. In fact the whole experience was back and forth. There were always ups and downs and trying not to lose hope and then nope, like clockwork, there [period] it is. No, not this month and you’d gotten your hopes up. And even my husband would get his hopes up, he’s say oh I know this time, I felt it, I know and I’d say okay.” (7)

“We were always trying and we were always excited and every month we looked forward to very month, we put don’t on the calendar, we did all these little symbols of things and very month we’d wait for the outcome to see what was going to happen. We were very encouraging [to one another]. He would constantly ask question, like did you get your period yet? Oh, I hope you’re late. It would be encouraging, you had all this love and this bond, but it never happened.” (5)

“I thought what if I find out and what if I find out that it’s really me and I can’t [have children]. But what if I find out after all these years that I really have been okay and maybe it was my ex-husbands, you know in this case that couldn’t [have kids]. And I really can. What if, what if, what if? And then I think that I might be pissed off now. You know to think that shit I could have had them and now I really want to, but I can’t at this age. I don’t know, it’s just so scary to know. I guess I still am ambivalent. I don’t know if I want to find out now, but there’s this curiosity still. I think I might do that [go to a doctor] and I might ask the doctor the next time I go in, but I don’t know what’s involved, this test, that test and for what end?:” (2)

“It’s been hard [voice inflection], I mean because you see your friends having kids and you see them growing up year by year and you are like wow. and really wanting a baby and then seeing other women with their babies and pregnant and stuff, it’s really hard.” (8)

“I felt bad because of some of the insensitive things that people had said to me, I said to her [hated her for being pregnant]. And I felt, but at that moment, the news that I had been given was not very good and I was very emotional, and at that moment, the disappointment, the anger, the frustration, the rage, every gamut of emotions that you could think of going through it was there and boom, before I knew it the words were out of my mouth. But later we talked and she said she understood and I apologized to her vehemently and every time I saw her I apologized.” (3)

## **Systems**

Infertility does not just impact the infertile individual, but it also effects those systems that surround the infertile individual. Since it is usually a couple that desires parenthood the partner within the couple is most impacted by the infertility. In addition to the infertile couple, other systems most determining their narrative of infertility are the extended families and the health care systems, including both medical and mental health care.

## **Coupled Partner**

Regardless of who is the medically infertile partner, if not both, or even if the infertility is a result of unknown etiology, the couple is ultimately most impacted by their infertility. However, from what is currently understood about gender differences, men and women typically react differently to their infertility.

Although infertility is traditionally seen as a woman's problem since women eventually conceive, the shame associated with infertility for men is frequently related to an assumption of impotency. As one participant whose husband was medically diagnosed as being infertile commented: "When you ask my husband he'll tell you there is nothing wrong with him [laughs], it's not a problem." (6)

In couples where communication broke down, the couples tended to separate or the infertility remains as a conflictual problem for them. Only two women in this study are still with their partners with whom they originally experienced their infertility. With two exceptions (the one with the hysterectomy and one other whose husband is older), all the women who are currently in relationships still desire to have children, but all still struggle accepting the finality of their infertile state.

"He's [husband] supportive, but not like a girlfriend or a Mother or someone who can really support me emotionally as much as I need, but, I mean like, as far as giving me sperm [had to masturbate for sample] or trying to help in that way, he did [provide sperm for testing], he didn't want to, it was against his morals, his beliefs, but he did it anyway, because he knew how much I wanted to have a baby." (8)

"I feel like it [infertility] has had quite an impact on our relationship, you know, on our marriage. I feel like I've always been alone when it comes to the infertility, you know, he's okay if we don't have kids. At this point he feels like he is too old to have kids. He's forty-four so he thinks it's too late [long pause]. And I think that it's so painful that he puts it away and just doesn't want to talk about it. So it's, it's real rare that we talk about it. For a while I would really keep my feeling away from him and not let him know whether I was in pain, whether, you I had been crying because we don't have kids. Because I don't think he understood what it was like." (6)

"It's [infertility] been a strain on our marriage for sure." (6)

"I am real careful whenever I bring it up, you know, I have to make sure that he's in a good mood, not stressed. And then I am petrified of what, of how the conversation is going to go. Because he would rather, he's rather not talk about it. And the time I told him that I wanted to call the doctor and see and wanted to negotiate with him and try to see, you don't want to adopt, so can we do this them, kind of thing. [Pause] Even that he didn't seem too excited about it. He

was like why don't you get these tests and see what the tests show and then we'll talk about it.” (6)

“The key factor [regarding resolution], I think there are so many, but probably having a husband who doesn't, you know who is okay with him. If I had a husband who was like I got to have a baby, I got to have, you know, an heir [laughs], that would be extremely difficult, it would be devastating, or if I had parents that were like oh, I want a grandbaby, I want a grandbaby, that would be really hard, so I don't have any of that pressure, so that's wonderful. And then I have a very full life, that we have a very full, blessed life. That we don't feel like we are missing anything in our life, because we don't [have children].” (9)

“ Because he had a son [never thought he might now be infertile]...it was never a consideration, not at all.” (9)

“You know he never, we never talked that much or about that [the infertility problem] and that was probably part of the problem, but it was just too hard. He never told me how he felt until way after the divorce, but I think he was probably relieve that it [the problem] wasn't him.” (10)

“ My ex-husband would get mad or else I don't know if he got mad because I didn't have a kid for him, he would always say, well I want you to have a baby, sometimes he would say that, but a lot of times I think he would when he was acting angry or ugly, I think he would say that just to hurt my feeling, you know .” (4)

“Turn to your partner and become stronger for it and that they not turn away and start blaming and you know venting their anger toward one another, that would be inappropriate and that they need to face it together and accept it together.” (9)

“I think the yearning was stronger for me and also because my ex-husband also wanted a child. Because you know I was on the pill for ten years and I didn't want to get pregnant and I never ever went off the pill until he said, you know, maybe we should have a baby and I could have been on the pill forever, ten or twenty years, but when he was ready so was I.” (10)

“He [husband] went through the whole process, he would go in with me for visits [to the doctor] or he would to in by himself, or I'd go in, but never did we go into how stressful this was or that as it was such a difficult thing and such a final thing. He undressed the medical and the reason for the hysterectomy, but it freaked him out. I can remember to this day when I woke up [from the operation] and my sisters where with me and I said to them where's my husband, and they said he just had to run out of the room. He had a hard time handling it, anything medical, he was just freaked out. When it came to the finality of the hysterectomy, he was out the door so to speak. Literally he did walk out two or three weeks after I got out of the hospital, he was gone.” (10)

“I think I still process a lot of things. I try to talk a lot with my husband [voice quivers] which that is the difference in this relationship, I am married to a man that is ten years older than me and has a lot more life experiences and so we talk a lot.” (10)

“My first marriage ended right after I had the hysterectomy because of al the problem with trying to have a baby, but it probably didn't end *just* [italics added] because of that, that that is

basically why I did get divorced. I truly believe I had problems [infertility] from my very first period.” (10)

“Even though my ex-husband accepted it [that I’m infertile], but there [pause] I think he was still hopeful that maybe something could happen and [pause]and he was very bitter after I lost that pregnancy, he kind of blamed me.” (1)

“He got mad and cussed me out a lot of times cause I didn’t have one [baby]. And I’d say it was not my fault because we didn’t have one. “ (4)

“And it really hurt and that’s one of the reasons why at night when nobody was around I’d cry about it. that’s when I was under a lot of stress and I said you [husband] got out your true feelings and I heard it because I don’t want to stay with you anymore. You [husband} could have said that when we met that you didn’t like [the fact] that I couldn’t have kids. (1)

“One of the reasons that he [husband] blamed me was because I put so much pressure on him because all I wanted was a baby. that’s the story he told his family, his sister told me that.” (7)

“Yeah, I was protecting him [husband]. I could have come out and say [to his family], excuse me, I have children, I have no problem having children. It’s him, but I didn’t say that, I didn’t want to hurt him. (7)

“ And I was ovulating and he would be u[set, but he wouldn’t ‘t say it that way. He would be watching football or eating something or whatever. And I would get really annoyed...It would be time [for intercourse] and he would be ah [sighs] and he would be really mad about that and that would get me mad. And I wouldn’t say nothing [sic], I just would bite my tongue. But now I would say, you don’t want to, well find, good, you know what, blah, blah, blah, but I never did that. (7)

“What if one of these days he wants a kid and I can’t give it to him.” (1)

“ But he was always the strong one, I was the one who was always falling apart, crying and upset. But he was too [upset], he just never showed it. he never really said oh you know, you know and then even when the deal came back and he had no sperm, he’s like well, well, he was real enthused but he said we could do that and we could to that donor sperm, whatever you want. But when the divorce came, there were all these hurt feelings...” (7)

“There was a lot of fighting over the infertility. It took a big toll. We were just going to separate for a while and work on our relationship and just forget about the infertility or whatever. But I just felt like he didn’t where I felt he wasn’t enough of a man in my mind, not because he couldn’t have a child, but because he didn’t stick up for r me with his family, because he didn’t say, hey, it’s really me.” (7)

“When we talked we would get into arguments and he’s say you of did [sic] something to it, you didn’t eat right, you didn’t want the marriage to work or something like that, didn’t do the right things or did everything to where you, like he was saying something like you didn’t want this. then he’s ah, you are a nurse’s aid and you probably knew what to do and stuff and I said I’m

just like you, I want a child too. And I said you didn't know how long I've thought about getting pregnant, so he kind of accepted it, but there was still that, I could still see something in him that he said it was all my fault." (1)

"Even though he didn't believe it, my ex, it was kind of hard on me too and I think that's one of the reasons I had to say, I had to give him a chance to have kids, so one of the reasons why I left him was because of that, even though it hurt, I said because you love kids so much." (1)

My boyfriend, my ex now, he's really in the culture because he's into the Crow fair and he's becoming more interested in the culture, so it was hard that we couldn't have kids." (1)

"We'll just have to wait for our grandkids, so he didn't mine it too much, but I can't accept it." (1)

"Most of the time, I hide it by crying because I didn't want him [husband] to see me crying and stuff. and him, even though he said it was okay with him, we can deal with that stuff, but at the same time his way of accepting it was to work in different states like Wyoming, Colorado and South Dakota." (1)

## **Family**

Without exception, all participants talked extensively about how family members other than their partners have either positively or negatively helped them deal with their infertility. However, even with relatives who were sympathetic, there was no real intense discussion about the impact of the infertility, rather an unspoken connection. In some cases family celebrations, such as the birth of a child, triggered the most uncomfortable interactions. Participants often put a positive intention to seemingly insensitive comments by relatives. In most cases, when insensitive comments were made, participants did not confront the offender, but rather suffered in silence or isolated themselves from situations that may be uncomfortable for them as much as possible. When family members were confronted about their behaviors or comments, their responses were usually defensive and shocked indicating they were uneducated about the complexity of infertility and of their loved one's feelings about their infertility.

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" they [family] don't even think about their comments mean anything, but if I were to sit back and dissect it then I could probably put myself in all different kinds of emotional states with that, but you have to learn to go on because you know that you can't, it will destroy you, it will eat you from the inside out if you allow it to." (3)

"And when you don't do that [become a wife and a mother] and you deviated from the norm, you are ostracized by your own family and that probably has been my worst enemy, my own family. There just has been so much pressure . They're probably the ones who are most insensitive out of anybody because they make hurtful remarks. I'm not sure if it's because they don't understand or it's because of the way we were raised, I think it's more of a cultural thing. I think that now they understand it a lot more and than they really did before, but at the same time,

they thought that I was very selfish and that I put myself first and that I made choices not to have children and that I was making those choices and they didn't feel they were the right choices." (3)

"Primarily things like if God would have wanted you to have a baby then you would have had one, you probably wouldn't have been a very good parent because that is why God chose not to give you a child and things like that. and then a lot of pressure about why aren't you having a baby, why haven't you had a baby, when are you going to have a baby, little kids, nieces and nephews, eight and seven, six, and five years old, Auntie, when are you going to have a baby." (3)

"So that it the other issue [besides marrying outside religion and culture], we were like we'll have kids and everything and then. In the Muslim religion they have a strict law that if a man has a wife and they have children, he cannot leave his wife, he cannot abandon her. so none of them [family kidnapping husband], [his family] would not have succeeded in what they have done, because they would never have been able to ask him to leave the country without him bringing his wife and children over. So if they didn't have the finances so send everyone, they he would have remain here. So I felt they got their little victory then. Everything that I had done, I felt like it was gone, it's out of my hands now. All that I have been through, all these nights of crying, the struggle to get pregnant, the battles with his family, the culture, the religion, and trying to understand myself and trying to learn their language, trying to at least come to a meeting point with them [husband's family]. some type of agreement, all on my own. I felt like I was putting in 100% and that the family was doing absolutely nothing to squash the issues that they had with me. And it's just so sad, it hurt me." (5)

"I wish I had the letter here, but I don't. He [husband] went to the point of actually trying to lie to them and saying that I was pregnant and that is why he couldn't leave [his family could not accept their first born male did not have a child]. But they [his family] had been pressuring him for a long time about the baby. And he was saying I can't [visit family out of the country] because we are going to have a kid and she's expecting, but he never mailed it off because I didn't think that he should. I did not want to live a lie so that they would constantly be calling, when's the baby going to be born. So I said no. I didn't allow him to mail it, but it got to that point [with his family]." (5)

"...I mean I haven't lived in Honduras in a long time. But the other day I was watching some show with my Mom and a lady in the show was infertile, and wasn't able to give her husband a child, and she [my Mom] called her by some bizarre name, but I don't even remember because I had never heard this word in Spanish. And I got real upset. I thought it was very insulting and she couldn't understand why I was angry. And I said that's me. That lady on TV is me [voice inflects and quivers]. You know, I haven't been able to have children. And it was a real put down of a word and I was really surprised that she was using it. And I know that she didn't mean to hurt me, but it's kind of insulting." (6)

"It's more of like a little battleground [her Mother came to help]. I know she's there because she cares, but she'll make comments like I told you those people [husband's family] were no

good, or he's worthless to do something like that to you, I'd just get a divorce. And the comments weren't making me feel better. They [comments] weren't helping." (5)

"...I mean at some point, about three years ago, my niece was pregnant and came to visit, the sister of the niece that is pregnant now. And her thing was that she was going to give us this baby. And when my sister found out that she was pregnant, she about had a cow. Hum [pause] she spend about four weeks trying to make up her mind about what she was going to do with this pregnancy. And I ended up [pause] I was the one who ended up taking her to have an abortion, translating for her and everything. And that baby my husband was willing to adopt because he knew where it had come from and it's genetic background.

And it was a family baby, so it wasn't really like not knowing what you are going to have. But she had her abortion, so, hum, [pause]and that was really painful that we could have adopted that baby. And her lack of understanding in terms of what it is like to live the way I have to live, without a baby. You know, because prior to her getting pregnant, she use to say, oh, I can be your surrogate or if I ever get pregnant I'll give you my baby, you know that kind of kid's stuff. And when it actually happened, at some point she decided she was actually going to have the baby, and then later she decided she was going to have the abortion. And she didn't realize what it was like for her to be [pause] I felt like I was being teased, like there is something that you want. And I know she didn't mean to tease me, but it was sort of like, she didn't have a clue. And she still tell my Mom, my parent never found out about it [her pregnancy], you know that if I ever want a surrogate, she would be my surrogate and there's a part of me that's saying, you didn't learn. You know, why [pause] and I told my Mom, whenever she ways that just tell her, you know, that's not something she should be saying....it sure was painful." (6)

"With his Mom [husband's Mother], they were here to visit and I got to talk with her to see if she could talk with him about adoption. she thought it would be nice and she couldn't believe that her son wouldn't want to adopt a child [laughs]. Hum, she just couldn't believe that he was being that way. And I don't know whether she did talk to him or not. But there was a part of her, one of her comments to me was "yeah, but honey, you are not using birth control." [meaning I could still get pregnant]...Because she said you are not using birth control, right? and I said no, I'm not. It could happen. And then I said well you know after ten years, it's hard and I'm almost forty, so if it didn't happen when I was 27, it's really hard for it to happen when you are a lot older. "[clarified that husband's Mother still would like a biological grandchild] (6)

"...it's their way of wanting to share this big event in the family. And they have no clue how hurtful it is and how it hurts me to hear these details [niece's pregnancy]. So my niece wants me to be the baby's Godmother and they were assuming that I would be there for the delivery at Christmas. It's like I don't think so, so I said no [laughs]...I'll be there in April, but I am not going to go there when it is already loaded for me and it's a holiday and it's going to, you know, I don't think so....well, my Dad passed away not too long ago, so you know, I haven't been home since he died, so it's going to be like going back after he died which is going to be hard, to see this

brand new baby. And then going during the holiday at Christmas when my Dad is no longer a part of it, you know (6)

“At times, I felt like, I don’t even know why I even got married. I’m ruining his life, I’m wasting his time. And I started listening to all the things my in-laws were saying about me, well she’s worthless, she’s useless, what kind of a woman is she. She can’t have any kids.” (5)

“And it’s sort of , when they call, they don’t ask hi, how are you, how are you doing, it’s sort of like, this is how pregnant she is now, this is, they have done all these ultra sounds on the baby now, it’s a baby girl, this is what she looks like and they send me the ultrasound pictures, and sending me pictures of her so I can see how she looks pregnant. And it’s like I can skip all that. And when they call I don’t stay on the phone long with them, you know, I change the topic. Hum [because it’s hard to be hearing all of this.” (6)

“Because, I think, there was a part of me that felt, I was in so much emotional pain. I had just done this IVF that hadn’t worked and here I was going home [parent’s]. And that I was going to get all this support and that was how I had it in my mind. And none of it was there. It was a very painful trip. When I look back, I wish I hadn’t done it [gone]. When I look back I realize I didn’t get anything from it. ...they had no clue. They just didn’t. I just cried and cried actually, because I felt that I was in so much need, emotionally, for somebody to be there. just there [pause] there was nobody there [voice shakes]. And all they wanted to discuss was my niece’s wedding and when she was going to have her first baby. You know and I thought what am I doing here. and I went by myself, I didn’t go with my husband so that made it harder too. So I don’t know what I really expected. (6)

“His relative call and ask when I am going to have a baby. Actually, he got a call two or three days ago which someone had told someone who went over, back home, that said he had had a little boy. So he told me that and it made me feel so bad inside.” (8)

“All my siblings had children very young and they were all in unstable relationships and it was really never thought of at that time, but now in hindsight, I have a niece in Denver that will be 12 on Friday and we have a very close relationship since she was a child which has created a lot of animosity between my sister and myself because my sister is very jealous of the relationship that we have. I have been that very special Aunt and I have been in a financial position where I am able to do things for them monetarily that their parents have not been able to do. And not just monetarily, but you know I am the only one in my family, the first to ever graduate from high school, well my younger brother ended up graduating, but I was the first one. I’m the only one who ever went to college and I have some cousins and extended family in a different generation that went, but not in my generation, I was the only one. My parents were migrant workers and so it was just a different life and my siblings felt that I was different not having kids and it created a lot of problems.” (3)

“They [husband’s family] even told me he is going to take another wife [because I’m infertile]. So I had that to toss and turn with over in my head.” (5)

“ There are no grandbabies yet in our family or great grandbabies, so there is a little pressure and desire to have the first child. My Mom is 56 and there are no grandkids yet and I would like to be the first.” (8)

“ I had no one to talk to about it, my parents didn’t understand [after husband left]. Well, they’d say, well you know, the only thing they would say is get a divorce, no one treats you like that. And so they really weren’t sensitive at looking at how I felt.” (5)

“That’s what it feels like [stigma]. I mean my sisters never ask me are you going to do any more treatment? How’s that going for you? Nothing related to that.” (6)

with tape turned off she told me about her Mother telling her it was good that God had not granted her children as she would be unbearable after seeing how she was with her dogs [who she treats like babies]. (6)

“ I think it has been harder [being Hispanic], yeah at least here [USA as opposed to Honduras] there is more knowledge of what medicine is doing. I remember after I did my IVF I went home for my niece’s wedding and one of my sisters just heard about this new thing and she said it’s blah, blah, blah, and I looked at her and I said, what do you think I just did? So I think the whole time that I was doing the IVF and what I was up to, it was like nobody got it.” (6)

Hereditary“ Nobody has ever really been aware of it {generations of infertility} before, you know until my generation, where we were all trying different things to get pregnant.” (10)

“I have talked with my sister[ also infertile]. And she pretty much has the same feeling that it might have been nice if things had been different, if she was younger than she is now when she got married, but now at her age [50], seeing that it’s such a big struggle, it’s somewhat of a relief, all the pressure is off.” (9)

“I think you know, my Dad was real, real backward about infertility. Like I remember when I went through my divorce, he said I was probably getting a divorce because men don’t handle your kind of surgery, and I am quoting him. that’s how he approached it that marriages were strictly for procreating. And I had a friend that has since moved and that was also her view about women and men and that you were to be together for procreating and although many might feel that way, with my close, close friends and relationships, I don’t think I felt judged or felt like I was an outcast in any way.” (10)

“She [her Mother] had my sister, very soon after getting married. And then they had, she gave birth to a premature little boy, Joe, who died because they didn’t have the facilities in that small town to keep him alive. And after that she was told she could never have any more children. So I guess she always prayed to have another child because she didn’t want my sister to be an only child and she did ask for medical advice to try and get pregnant even though a doctor told her she would never be able to get pregnant again. And you know, she’s always said that doctors are not God>“ (9)

“My parents never pressured either myself or my sister into having a child so they could be Grandparents and I know that happens quite often especially in Hispanic families. My husband’s parents were more wanting him to have a child or having us have a child. And it’s like *why* [italics added, voice inflection] you know, you are not even close to the grandchildren you have now. I

didn't see any nurturing, loving grandparents, and it was like why, I grew up in a small family, just two girls." (9)

"But I also believe that it [infertility] ran in my family because I have a couple of Aunt on my Dad's side that *never* [italics added] were able to have children and then I have several females cousins, the males are fine [nervous laugh], it's the female cousins who never ever have children." (10)

"Oh you know, I think I discussed it with my immediate family and close friends, and, I can't, my Dad was never one who could, he was not comfortable discussing female stuff, yet there was seven girls that he raised and one boy and he was still uncomfortable with it, but yet I think that's part of his culture [Hispanic] too. My Mom was not happy that I couldn't have kids and she felt really bad for me, but she said it's better that you don't have any more pain [use to become critically ill due to menstrual problems] and that is how she looked at it. And my sister, they were very supportive, probably more [teary eyed] than my Mom because they were here, two of them." (10)

"If I were to bring it [my infertility] up now, even then I think it would make them [family] very uncomfortable. I don't think they could talk about it because we would be talking about feelings, and they just can't go there, there's just no way they can go there, can't do it." (2)

"My sister has never said anything to me, I mean she's never even asked me have you wanted children or how do you feel about it or gee I'm sorry that you didn't have them, she's never. The only thing she did say to me and I think it was last year, she said I think you would have made a good Mom and that's it. and she never said how do you feel about it, no, she's never done that, she's not there." (2)

"In discussing it together [with husband], I think our faith probably played some part in accepting and thinking there is a different plan for us. It was meant to be, it would have happened, and it didn't happen, and [pause] we're fine with that [voice gets soft]/ So it was just some talking about it." (9)

"...My Mother never pushed or asked or said you know, why aren't you pregnant. She's never asked me, *never* [italics added] never asked me anything. My Mother has never been the kind of person who's liked children, from my experience, she's never liked children. When I grew up I think I grew up with the idea that kids are a pain in the butt, so why would you want one." (2)

"She'd never said, gee I feel sad that you don't have children or gee I wish that I'd have more Grandkids, I mean neither one of them, my Mother nor my Dad have ever said anything, not even my sister. My family has never talked about feelings, I think that's just typical. You just don't talk about it period. And maybe it has affected them, maybe they do feel sad, maybe they feel a loss, maybe they feel sorry for me, I don't know." (2)

"My parents knew we were trying [to get pregnant], but you know, it must now have been a big deal, back then, a big priority. It was like, we'll try and if it happens great, but maybe we weren't even that serious about the decision which really makes me think back about how

immature we really were about it considering how I think about it now [wished she'd had a child]." (9)

"...like raising my daughter, just the fact that after I found out, I wanted to spoil her to death. I wanted to do everything for her. I just wanted everything for her." (1)

"I have to worry because she [daughter] is really worried that she can't have kids too. And I kind of think she is much too young to be worried, but my infertility has impacted her too and she is worried." (1)

"And my sister wants a niece or a nephew because my brother's wife just lost one at five months and she still doesn't have a niece or a nephew. she's got great grandchildren, but she still don't [sic] have a niece of a nephew." (4)

"My Dad thinks it's [infertility] because I'm too heavy." (4)

"But I felt a lot of pressure from his [husband] family because he was the only male in his whole family. He has seven sisters and he was the only boy and their Dad died when he was like four in an accident and so he was the only one left, his sisters had kids but they weren't and he needed to have kids to keep the family name. And all his family right after we got married wanted us to have a baby. And they thought it was me not wanting to have a baby, since I already had two children and I was going back to school and they thought that I was the one saying no I don't want any more kids. And once at the dinner table they even accused me of are you sure you didn't have your tubes tied after you had your daughters? I said "no", my tubes are *not* [italics added] tied. (7)

"It's all because of my infertility. I think my older daughter is really affected by that because right away she got into a relationship when she was fifteen years old, she was sexually active since she was fifteen and she has not gotten pregnant at all. that's why she's worried about her fertility. I think I know I kind of rubbed it off on both my kids. My younger one is not as worried." (1)

"In the Crow culture, [if] there's a baby out there and nobody, a woman doesn't want it, then it goes to someone in the family that can't have kids." (1)

"My Father says he thinks it's my weight [why I can't get pregnant]. He says you're too heavy, you need to lose a little bit more weight, but I have lost weight. I just put it all back on and I didn't get pregnant after I lost that weight. My Mom says you don't need to have any kids, there's already kids out here that need families, which is true. And I can take them and have my own too. And [my friend] she says...you don't need any kids because men are just terrible and disgusting and you don't need to be bothered with them, you know." (4)

"That was why I was real angry after the divorce because I had protected him all that time and he never came forward to say hey stop telling us about it [trying to get pregnant]., when we want to have a kid we will have a kid or maybe it's my fault or whatever. He never once told his family that it was him, he just let them think it was me ...even after the divorce." (7)

"So we had to go with a donor and that's when we decided we wouldn't tell anyone. and I think that if we had told our families, they would have said, why even bother. Because first I wanted to have another family and to my family it was blood line. and that was what was

important. but I think to his family and to my family it was blood line. Your blood line is who you are. So if you can't get pregnant with your husband, why would you even bother to do it." (7)

"Naturally it is very hard not to tell your family because I am especially close to my Mom and my Day and I think I started to tell them gradually, because with my Mom, it would be really hard not to tell her, I got this, it's frozen, not frozen, but it's spun and you take it home and do, whatever, it would be really hard not to tell her that." (7)

"Whenever I want to, she [sister] lets me borrow her kids." (1)

Infertility tends not to be a neutral topic. Either families rally behind their infertile members and provide an understanding that surpasses outsiders' ability to support them or families alienate them as they cannot understand the biopsychosocial implications or assume fallacies as truth.

### **Friends**

Depending on the trust and the intimacy of the friendship, some of these women turned to friends as even more valuable than partners or family members as it was just too difficult to communicate with their loved ones. Regardless of the closeness of their friendship, without exception, all the participants felt that when friends conceive, seemingly without effort and subsequently have baby showers and enter the world of parenthood, their relationship with them inevitably changes radically from that point as their world with and without children becomes totally different.

Many of these women haven't even told some of their closest friends this most intimate and confusing secret, but rather suffer in silence rather than risk a lack of understanding or support.

### **Colleagues**

Confiding in colleagues was also a personal decision. However, once working women engaged in serious medical interventions, it was difficult to hide their intense and demanding medical commitment. Unless colleagues were told what was happening, participants felt their behaviors would be perceived as negative and it may jeopardize their job and that in turn could jeopardize insurance benefits. Therefore, most participants only told closer personal colleagues and disclosed to other co-workers only when it became too difficult to hide.

### **Health Care**

*Medical:* Interestingly, all the women who received some type of medical intervention for diagnosis or treatment were critical of the medical community, although they usually held their personal health care providers in high esteem, often acknowledging them as sympathetic, competent or caring. However, counseling was seldom recommended and when it was it was basically through RESOLVE. One participant who was referred to RESOLVE felt it was very inappropriate as the members were mainly white, well-educated, and upper middle class without any understanding for the cultural differences or ability to address the language barriers (her husband is Spanish speaking only).

Not one of the women in this study conceived with medical interventions. Granted, many could not continue to pursue the prescribed course of ART due to either financial, emotional, or moral considerations. Lack of appropriate medical insurance was cited as a major barrier to better medical care as well as a sense of discrimination since some of the participants did not have the personal resources to pay for treatment.

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“You know I mean it really pisses me off. I mean because your health insurance won’t pay for your treatments, you know for the infertility. when it comes to your taxes, Uncle Sam really gets to you when you don’t have any dependents to claim. But it’s not really your fault because it’s not like you don’t want to have kids, it’s because you haven’t been able. So in some ways my taxes are paying for other women to be having their babies through Medicaid. I am contributing that way. But I think people who are having a hard time having kids, I think health insurance should cover some of it, I am not saying 100%, but they should cover some of it.” (6)

“Maybe I should have let the doctor tell him [husband about problem with his sperm] or, I mean, even though he did talk to him [husband] about it. But there is always that thing, I think, that it’s the female’s fault [infertility]. That’s the first thing that they [medical community] assume is that there is something wrong with the female.” (6)

“All along we thought it [husband’s sperm count] was fine, until dr. did a test to see whether he had antibodies against his own sperm. Nobody had ever done that. And when they [doctors] did it [tested husband], he had a pretty high rejection, about 95% of his own sperm. And God knows since when that had been there because his count had looked good all along, but nobody had checked him for that.” (6)

“Muslims don’t believe in masturbation. So here was this doctor telling him he [husband] needed to go into a room and ejaculate into this cup. And he’s looking at him like there is no way, this is a sin, this is unclean, this is not holy. And so finally three days later, I got him in there by pleading and begging because he understood that he was very important and he got the point and he was just willing to try anything. And if we could have afforded the in-vitro where they surgically remove the egg, we would have done that, even though he felt like it’s not the way that it is suppose to happen.” (5)

“People who have infertility problems have to spend thousands and thousands of dollars and millions of dollars to try and become pregnant. I saw something on TV that said they should pay for it [themselves]. They will pay for a man [emphatically] who has impotence, but they won’t pay for a woman [emphatically] who has infertility. So that is kind of frustrating, it just really pisses me off. Even if I had insurance, which I don’t, it still would not pay for any of the things that I am needing to take care of We have had to pay for everything, so you know, all this adds up....that is how much we want to have a baby, we spend our money on that first and do without other things.” (8)

“Our first experience was that they really didn’t care [infertility clinic] in the initial interview when we went. They looked at us and they were like you guys are very young. what would make you think that you were infertile. and we are looking at these past years and the pressure from both sides of the family, and we both wanted children because we love each other dearly and we thought we had something to offer so society through our children, our offspring also. And as time went on, people would make more and more insensitive comments. While at the clinic people would say well there are my ultrasounds etc., and they never had a separate space for us women who were infertile to meet, so we had to sit in this waiting room with all these women, brand new mother, women with ultrasounds coming out saying their pregnancy tests were positive and here we were sitting there infertile. And then having the person on the side us of us say things like oh, you don’t have any kids, you are so bless, you’re lucky, I’ll let you borrow mine. And you are looking at them like, I’m here because I want kids, I’m not here because I want to baby-sit or open a daycare. And so it became a very uncomfortable environment, my husband got tired of going, he was like, he didn’t want to go anymore because he was watching all the other fathers, smiling, it was really hard. So he felt like there was nobody there to give special attention to your needs. So you would feel when you talked to the doctor whatever, you aren’t as important because this other lady needed to make sure they measured now many inches her fetus had grown, so they tried to rush you out of the room. I was like okay, well here we are going to try these pills again, at the time they put me on some different types of medication, Clomid, because they said I wasn’t ovulating and they tried another think out. And that wasn’t helping, I was on that for like seven months and I felt well her I am, I’m very young, seven months, I’ve tried this medication and nothing is happening. They told us to do the basal, I don’t know if I am pronouncing it, the basal, the thermometer testing, we did that, it didn’t work. We went out and spent lots of money on those home ovulation kits. We weren’t getting any results, nothing was happening, yet every time we went, they were like, there’s time, be patient, and all I was getting was the same pill, just pills, pills, pills.” (5)

“...and so they started sending me to all these specialist and they did all these tests....and then I had a uterine biopsy and they had a lot of problems they couldn’t even get the little instrument into my uterus and then I had another examination in the clinic which is the absolute more painful thing that I have ever gone through in my life. And the physician who did it was a European doctor and I had told [pause]and he was the only one capable of doing this, the rest of them were residents and interns because it was county medical. And I had told my doctor, I told her I said that when they did the biopsy it was very painful, they couldn’t get the instrument in, so they gave me some topical spray, but we was trying to get this instrument into my uterus and it was so painful and he sat there and he stood there and he said it doesn’t[’t hurt that bad and he was making very insensitive remark and it was just so physically painful. He didn’t understand [the pain].” (3)

“But we did that [insemination by husband] and my partner, my partner is from Mexico and the culture is extremely different there and having a man agree to have a sperm count done is totally emasculated [sic] and he was totally humiliated, but he was willing to do that to try and have a baby. And so it was so hard, and people don’t realize that part, how the part affects a man, especially somebody coming from a whole different culture, with the machismo, I mean for them so say, yeah, I went and I gave a sperm sample, you know the only way you can give a sperm

sample is through masturbation and so it was the most humiliating and degrading thing that he had ever been through in his life, but he was willing to do that we could try and conceive. But there again, he knew deep down, gut feeling that there was nothing wrong with him and I know too, but they had to determine that. and we that [sperm as a reason].” (3)

“...I stayed on the Clomid for fourteen months and when they took me off of it, they said that long term side effects is ovarian cancer and they wouldn't allow me to be on it any longer. And so I said well, there's nothing more we can do because financially we are not in a financial position that we can afford \$800.00 a month for the actual prescription and then the actual procedure which would run somewhere, I don't know around \$10,000 more for everything. And I don't know for the chance that 20-25% and for going through so many other things. We had no other choice by to say there is nothing else we can do because financially that is where we are at.” (3)

“Then I went to the doctor and they said, no you're not [pregnant].And just recently I went to the emergency room, I was having some pains, I was having some severe pain, my breasts were extremely sensitive, I was nauseated, I was having pain in my stomach and around my navel. So the first doctor said oh it sounds like you are pregnant and I just knew it wasn't that because my husband had already gone. They just kept making it an issue, like oh you are going to have a baby, you know, they were just casually joking about it. And then the test came back and the way he [doctor] just walked into the room and said well, good news, you're not pregnant. And I was like, even though I knew that, why does that have to be good news that you are not pregnant. Everyone was make it look like that was good news. They just thought I was one of those ladies who was in denial and going into the emergency room saying I am having these pains to find out what was wrong with me.” (5)

“And so I mean I was going in so often and I think that one thing that most people forget is how emotionally draining that is and how many times you have to go, what you have to do, the number of medical procedures, the time off you have to take from work and just all the variables related to the medical intervention if it is even there for you since we have only a two tier system of not only justice, but medical care. But if you can't afford proper treatment, it is not available to you, no insurance companies cover infertility drugs. I mean I was very, very fortunate that my doctor was able to write a letter to the insurance company and explain that the Clomid for me, the number one reason that I needed it was because I was not ovulating and that was helping me ovulated and without that I would hemorrhage and would end up in the hospital with more bleeding episodes.” (3)

“And there were people who told stories and how they put their lives on hold and sold everything and took our loans and still were unsuccessful and how it even destroyed their lives more. And that's why I thought about it and I said how much more can I let it destroy my live. How much more can I allow it to destroy my life. And I said well, the only thing that I can get is a dog, she's my baby and she's spoiled and people can make mean and nasty remarks about how spoiled my dog is and why do I let her in the house and why do I let her go on the furniture, but

she's my dog and this is her house, and she's my baby. And I clean her messes and I mop the floor and I shampoo the carpets and that's what I do and she's my responsibility and I don't care what anybody else says." (3)

"And to make a long story short, I ended up in the emergency room or at my doctor's thirteen times in three weeks before they finally decided that the embryo was not growing, basically that it was dead. So I went for three weeks basically with this dead embryo in my body and it was one of the most absolutely devastating things that I have ever been through in my life. And the last time I went into the emergency room I told them, I told the doctor, you have to do something for me, I laid there and I cried [voice quivers] and I said I can't go on anymore, I know that it's not alive anymore and , but they said, they had to be cautiously optimistic because they could not go in and abort a heartbeat embryo. but you know who knows our bodies better than we do. And that's one thing that I found was really frustrating. It was kind of like they just missed my own feelings and my knowledge of my own body. And so at that point they send me to a specialty clinic and they started doing some tests on me and that was in San Antonio. And by the way, this was the only time in my life that I have ever experienced indigent medical care. I was a full-time student, I went back to school as a returning adult, so I didn't go you know right out of high school, so I was older already." (3)

"And I said to her [female doctor] when I found out she was pregnant, which was right after I had my surgery, and we had been going through all these kinds of things and I went in for an exam and I told her I hate you for being pregnant. And she told me probably a year later, she told me she remembered that I had told her I hated her for being pregnant. And this was the first time she shared with me that her baby was an IVF baby, and I didn't know that before. And I had no idea. And that's how insensitive I was when I made that remark...And I thought later, here she is an ob/gyn doctor...but she knows what it is about [infertility] and has a lot of patients that are infertile and you know I thought she would have shared that with me when she first found out she was pregnant, but it's still so secretive and there is such a stigma. Then she told me I really need to and we talked about it and she agreed she should have told me." (3)

"I use to have, I use to have horrendous periods. And probably at the beginning they were, you know regular, and my Mom use to, said that is the way hers were when she first started and I was like 13. But in my teens, in my later teens, like probably when I was 14 or 15, I can remember having these like heavy, heavy, heavy periods. I might not have been that serious, but to be as a teenager, but to me, it felt like I was bleeding to death half the time. And I had cramps throughout all my cycles, to the, I mean I started my period the night before I had the hysterectomy. It would not let me go, I guess is the way I looked at it." (10)

"I guess other than the doctor suspecting it, the only way that I learned [about my infertility] is that when I was with [my first husband], and then in my second marriage, we never ever used any protection, and we were together for over twelve years or so. I just never did get pregnant....But you know, all these years, all these years, I never have used any protection" (2)

"We did not look into other measures or check out [medically] why we weren't getting pregnant. We tried, it didn't happen, after we tried for a while, we thought, you know, we really

like our lifestyle and we are really okay with not having children at this time. Maybe that will change, but it hasn't. It's been over six years now." (9)

"Just because of the length of time and not having used protection while having regular intercourse." [but never having it confirmed medically] (2)

"My ob-gyn, I basically took control by telling him I cannot go through another one of these [hospitalizations]. And I had told him that he had to do something or I will do something. They never offered me anything [counseling] to make sure that [hysterectomy] is what we really wanted to do. I remember the doctor telling me, never do [pause] never say yes to something you can't change your mind on. That was the extent of the therapy [laughs, but almost cries]." (10)

"I think, if I remember correctly, I realized that I couldn't get pregnant when I was around 30. And that was in my second marriage and we were really wanting to have a baby. And I remember going to the doctor and basically just talking about just talking the temperature and having to do that on a daily basis. And also my husband at that time had a low sperm count. And we tried to get pregnant." (2)

"I have been thinking more and more about that [not knowing medically what is wrong] and even the thought occurred to me that maybe I should go and get checked out again [by a doctor] and see what the problem really is. If there really is a problem, but then again, maybe it's just been the luck of the draw. I mean, I don't know. It could very well be that. But I guess when I was younger, it was never, maybe it was never that important or maybe I thought I was really too busy and I was interested in other things and not about raising a child. But this has been on my mind for a while now and then you came along." (2)

"The only thing that they could ever tell me was that I might have developed a really high fever and I remember being sick, probably about when I was fifteen or sixteen and being really delirious, like fever like, and them just telling me it was the flu." (10)

"The pain for me was key. Because I think that if I hadn't had a hysterectomy at that time I would still have yearned and tried to have a child for a lot longer. But the only way I can describe it is that I had lower back pain, part of the endometriosis is that, lower back pain. I had that pain, not knowing where it was coming from and now I don't have that constant pain anymore." (10)

"I know that when I was in the hospital, I was in the Catholic hospital when I had the stillborn and they treated me like garbage, and someone said that because you are losing that baby, they don't care, they don't have respect for you. And none of that and they are going to treat you like shit and they actually did. I had that baby by myself, in a room, they wouldn't give me anything for the pain, they wouldn't, they were just really cold and nasty. I'm thinking that they were probably thinking that I'm less than a woman or you know because I didn't have this baby that I should be punished or whatever, you never know. Because they treated me like garbage, they wouldn't give me a clean gown to put on, and my Mother and my husband hadn't brought my stuff up yet/ they wouldn't even give me a blanket, you know, they just snatched my baby out of the bed right in front of me and threw it in a bucket and just prayed over it and took it away; They didn't offer to let me see it, they wouldn't tell me what it was, whether it was a boy or a girl, and I still don't know and don't think that's fair. I think I got my rights, I think that I should know. You know I am the one that threw up for seven months you who couldn't sleep and who went to the doctor's every month to get a shot to get my blood drawn and I feel that I should

know because it was mine. I felt like I should know; I don't know to this day what they did with my baby's body. You know and I don't think that was fair at all." (4)

"And they [doctors] didn't know, they couldn't give us an answer of why it was happening. They didn't have any idea at all. They thought that when he was drilled in the oil fields something could have happened, it was frustrating." (7)

"At one point I went to the doctor's and he looked at me and after he's looked at all my lab work, he said you know you realize you can't have any kids and you already know that and I don't know what you want me to do? What do you want us to do? and he said I really don't know, I can't really help you, and I said I know. I know that, but is there anything you know, is there anything else that you can do to help me." (1)

"The [doctor] said you should be grateful that you have two [children] and at that point I just started crying, I didn't realize that I was depressed. That is what he said. I want you to go and talk with somebody because I know you are depressed about it and I said just the way you said everything to me just really hit me because I don't think I need to see anybody for depression because I know I can handle it myself. I really don't need anybody to help me and I know what if I need help I'd be the first one, I'd be the first one in here asking for it. I said just the way you said it really hurt me and all. In some way I got the feeling that nobody cares about me because I can't have any more kids." (1)

"They [doctors] said everything is okay, this and that. You know, I said I don't think so, I can't keep anything in my stomach. I said something is wrong and they are telling me it's nothing. And even when the baby dies, they are telling me there was nothing wrong with the baby or with me." (4)

"I'm Spanish and I didn't want to take the chance of getting one [sperm donor] with blond hair and blue eyes when nobody in our families has blond hair and blue eyes. At first I kind of wanted to do it, I was really excited to get the donor. And I thought, who would know, nobody would even know that it wasn't my husband. And we wouldn't tell anyone in our family. And they already knew we were working on our infertility and I was going to say it worked, I finally got pregnant, we weren't going to say that we went to get donor sperm. But then after we got the list, they, I was willing to try a guy who was Italian and that was close enough to Spanish, but he was much shorter than my husband. And he said he could go through with it at first, but in the end, I think he just couldn't do it." (7)

"Well it's [insurance] only paid for some of the drugs. So when we did it [IVF], it was like over \$10,000." (4)

"It's [medical intervention] too much emotionally. And now every job that I am on you have to wait a year or two before you can get insurance and then or they don't have insurance and it's just ridiculous." (4)

"I think it would have made a difference because if I'd gotten the proper care[medical], you know [laughs] I'm sure they could have done something by now, you know. But just going to doctors here and there." (4)

“Well, I don’t know what happened, because the doctor I told you about and that I went and started working with before I left and came here, he sent away for my records and stuff because I asked him to because I wanted to know what was wrong with that baby [stillborn]. And he said nothing, there was nothing wrong with you and there was nothing wrong with that baby, nothing.” (4)

“But I lifted up, I would put pillows under, that was one thing the doctors told us, after we had intercourse to live up and put your feet in the air. Even though in the back of my head, I kind of always knew it was him, because I remember the first time I slept with him and after we made love or whatever, I got up and went to the bathroom and when I wiped, usually, you know, some will come out or whatever and it looked really thick and it felt like water. And I thought well my first husband was not like that, but I just attributed it to him since they were different men, that sperm is probably not the same consistency or whatever. And I just blew it off, then after all this stuff started coming up about infertility, that was always in the back of my head, that is was him, but they never tested him for a long time until after I had all that stuff done to me.” (7)

“And I felt like they can do everything, they can put men on the moon, they can make clones, they can do this and they can do that. How come they [medical community] cannot fix me? You know what I mean. Any maybe I don’t have a whole lot of money. You know, we’d love our kids just as much...it’s just not fair....It’s just torture, I mean it’s really bad.” (4)

“By that time I was getting mad and I just refused [to undergo another medical procedure]. My Mom was saying well why haven’t they tested my husband because maybe there is something wrong with him.” (7)

“So the first year they [doctors] wouldn’t do anything. We were still living in Cheyenne and I went to a doctor that I’ve always [sic] to and he said well has anything happened since you had your last child, have you ever had STD or anything like that. And I said no, not that I know of and so he checked me for all that stuff and I didn’t have anything and my husband didn’t have anything. Well he said maybe we weren’t trying all the right times and they weren’t really going to do anything for the first year because we have had to have an infertility problem with that one partner for over a year and then if something didn’t happen, then to come back. Which I felt like was a year wasted. So nothing happened the whole year, we tried. Nothing happened. And so I went back to the doctor’s and I got and at that point we’ll run some tests on you. but they really didn’t look at my husband, but they really didn’t look at him for a whole other year. they basically ran more tests on me....And so everything was looking really good with me [voice inflection]. So the next tests they gave me was the beginning of the third year of us trying. They tested me to see if you actually ovulated or whatever, I had that done. And I was ovulating so they said maybe my tubes were clogged, but they didn’t know and suggested that run fluid through your tubes.” (7)

“So at the clinic they have donors, they have donors there or whatever, and so we were checking out the profiles, but it wasn’t going to work out for us. With all the stress on our marriage through this and there wasn’t any donors that matched my husband, that had features where they described the person that was donating the sperm. most of them are angle males, and there was one Afro-American that I’d seen that was in there, but my husband is Spanish.” (7)

“I said ‘I don’t think so’ and I didn’t know what was happening. Then finally I said somebody has to listen to me, it took three years and finally I went to that planned thing. I kept missing my periods and they’d say that’s all in your head because you’re under stress because you are going to school.” (1)

“If I had some money, I guess I would have done everything. I’d go all the way, whatever was out there so I could carry a baby inside of me. My friend [also infertile] and I talked about it, how we can’t have kids. We talk about all the ideas of how we could have a baby. that’s a way we relieve our stress about not being able to have a baby.” (1)

”And then most of the doctors, all of the doctors I went to were male and they would all say, you’re young, you have plenty of time and just because I look really young, I am over thirty.

and they would always say you don’t want to have any more children after you are 35 because it smarts to get more and more risky, but you, but it seems to me they were wasting my precious years because I always seemed and looked younger. Oh you are young, don’t worry about it. If nothing happens in another year, come back then. They didn’t really take anything that serious and I look younger than I am. And I thought they judge me on how old I looked and that I already had two children so maybe if I didn’t have any children, they would have been more, I don’t know, on top if it and started and tried harder that first year, I don’t know.” (1)

“They [doctors] always focused on me at first, definitely, And then the expense. My husband, I would say together we made about \$35,000...And it was mostly his income and how much we were getting charged and not it seems that was another frustration because our insurance did not pay for infertility treatments like I have heard they use to. So you know, with all this stuff, we were paying it ourselves and that put an additional strain on our relationship. And I thought why don’t they just test him. And I never wanted to have an affair, but a couple to times I thought maybe I should just pick someone out who looked kind of like my husband and find out when I ovulate and then get pregnant and I mean we were paying so much and that would have been free [emphasizes]. But because of the medical bills I was thinking crazy like that, but I would never have done that.” (7)

“I asked my friend if she would donate me some eggs and she said of course she could, but it would cost \$10,000 and I don’t have that kind of money to spend.” (4)

“When I was in New York they gave me fertility pills to take, I took them, but they didn’t work because I just feel like you know they didn’t do everything, you know step by step, like clean out the uterus and those tissues that had grown, and then work me up with those pills, they just didn’t do everything step by step. I was like let me do this, well I’ll try to give you those pills and I’[ try to do this and I’ll try to do that. I don’t think that’s fair because they are playing with somebody’s life and to do something before it’s too late. I get frustrated, I really do. I want somebody to just help me.” (4)

*Mental:* Although all but one participant (who had not received mental health counseling) wished they had received counseling to deal with their infertility. However, few realized the potentially devastating impact of their experience until it precipitated some other often seemingly

unrelated crisis, such as depression or marital discord. Additionally, one participant said they had limited resources and so went for medical intervention as they thought that was a more guaranteed and better use of their limited resources. Yet, now she realizes counseling could have saved her marriage. Other participants felt that mental health counselors were not attuned to their cultural background and the challenges infertility imposes on the couple unless that counselor has also experienced infertility.

When some of these women entered counseling seemingly for reasons other than their infertility, it became evident that their infertility was a major life crisis that contributed to them subsequently seeking counseling.

Probably the biggest barrier to counseling was expense and second was access to an appropriate resource.

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“I think it [group counseling] got me more stirred up. Part of RESOLVE. Seeing how some people are going through three, four, and five IVF’s/ And then you get into that thing of oh, well I guess I can do another one.” (6)

“The medical community is not good about telling you when to stop since the technology is there. If you’ve got the money, then it’s on the treadmill. But I felt that maybe I was constantly hitting myself with it, you know [by going to groups]. (6)

“Just me [went to counseling]. He doesn’t feel like there is a problem or anything. And he doesn’t think we should to and tell our problems to anybody. So he plainly refuses [to go to counseling]. (6)

“I think it would have been helpful, it [counseling] would have happened when he was still here [husband gone]. Then both of us would have gotten more strength and encouragement together and plus they would have worked on some of these family issues and pressures and he may have been able, after having one to counselors, to deal with it psychologically and emotionally than he did. Sometimes we are caught between a rock and a hard place, because we didn’t know what our options were or what we could be doing or how to use psychology to help us.” (5)

“ If I had to do it all over again, turn back the hands of time, I would have went [sic] for counseling. but at the time, we were dealing more with the immediate and didn’t understand how the long-term issues [of infertility] were affecting us.” (5)

“He [husband] just didn’t see anyone understanding. Because if our family couldn’t understand, the love that we had, how were we going to go to a stranger who had no experience with this culture and who knew nothing about it except the Hollywood version or the stereotype [of husband’s culture] really understand.” (5)

“We thought about it [counseling], looking at it pricewise and then wanting to do the IVF. Then we decided that since we wanted the baby more and we thought that would resolve a lot of the issues, that saving for that [IVF] would be more profitable and more beneficial to the marriage

than going to some counselor. and he also felt that when it got down to the bottom line, being that, we probably wouldn't find anyone who had the type of experiences that we were going through. It is very rare that and Afro-American is married to someone from his culture.' (5)

"I think I would have found them more appropriate for our circumstances [culturally sensitive therapists] because a person with a more Westernized attitude about it, like I said, would probably bring in the lack of concern for his family, not understanding why he can't just forget about then such as the American man. They are more away from their family. Once they take a wife, okay, it's me and my wife. Okay, Mom, Dad, whoever, this is who I love. Hey they would tell them [family], you don't matter. So they would be looking at him in a different light. Like how old are you again, why do you care [what your family thinks]? And they [counselors] wouldn't understand that this was something that was really eating away at him inside, because to have no family, to be disowned, dishonored by your family is the greatest humiliation than any man, Muslim man, could ever endure. To be shunned by your family is in their eyes they consider the person dead. So he would be alive, but he would be dead inside.' (5)

"But the actual counseling I didn't think, I felt like she told her story too much. There were stories that she told me several times. I felt like I didn't need, so you told me once, that's okay, but that was my time [laughs]. That kin of, there was some sessions that I did by myself that I didn't feel that I had gotten, that she really wasn't listening to where I was at. Because I was seeing her when my niece was having the abortion and she wanted to talk about what kind of treatment are you doing next. And I wasn't there, I was getting ready to go and pick her [niece] up and take her to have the abortion...that is critical [being listened to and not judged." (6)

"Probably counseling is something I would advise [for us]. but then again, it is something that is available, unless you go to a private person, who can afford it. And where my husband works, they don't give you insurance." (8)

"I'm certain that it [counseling] probably would [have been helpful]. When we were going to see [the doctor], he gave us the names of people, like a group of people and they had support groups [RESOLVE] and stuff....And I called them one time and they sent me some information, but I felt that it was so geared to while, middle class people and my significant other has a language barrier and speaks very little English and , I just felt it wasn't the right professionals or the right mechanism for ms. And I felt that he and I knew more than anybody of what we were going through together and we kind of leaned on each other for that emotional support. But I think that if there were somebody out there that was a bi-lingual, bi-cultural problem that could deal with us as a couple, I think that is something we probably would have wanted to do. ...I feel that probably has been one of the most difficult things for us is the lack of professionals to help with our unique situation, our bi-lingual, bi-cultural situation." (3)

“initially it [counseling] was just about my infertility and I thought it was very helpful because I had pretty much said to [my therapist] that you know I was find with it because I was tired of the pain. As far as after the surgery we dealt a lot with my depression, as I think it was then that I was pretty much depressed about it [the finality].” (10)

“Actually, you know, in the end, for me it wasn’t because I always felt, because we went through the church, to when we went through the divorce, and I felt like the minister had sided with my husband, ex-husband. I remember saying I am not going back to this guy or this church because all my ex would tell me is he is fine with the [our] divorce, but he [minister] left his ex-wife for a parishioner. And that is when I said I need to go by own therapist.” (10)

“I think that even people who are not infertile would get counseling before they have children around the responsibility of having children. Because life throws a lot of curves at you and you need to be prepared.” (10)

“I think that at the time probably my education was what also pushed me into doing therapy and getting help for it [infertility]. I don’t think my Aunts [also infertile], they were not highly educated, they would have never, and their culture [Hispanic] also would tell you that you don’t go out and get help. So my education had a lot to do with me getting help and that really helped me.” (10)

“I think it [counseling] would be beneficial if my ex-husband had gone in too instead of all by myself thinking it’s my thing....And maybe if I had included him or insisted that he go, we could have dealt with it better. And not to say that we wouldn’t have gotten a divorce, because there was probably more [than just infertility], but it could have helped and it [infertility] certainly was stressful. (10)

“We have used therapists, individually and marriage and sex therapists as a couple, but we didn’t for our infertility I guess because we feel like the two key people [us] talked about it and we were okay with that decision then. That’s a good question why we didn’t use a therapist for the infertility.” (9)

“I think it would have been a big help if I had someone who would have helped me think it through some more, allowed myself to think about it more. I would have said I really should talk with someone about it, it would have helped, but I never allowed myself. I think I was running away from it more and never really wanted to look at it until now [stage of my life]. I think probably I could have, maybe [voice softens] come to understand, obviously my true feelings around having children that I really did want them and I could have resolved it way back then and looked more thoroughly how I was influenced and really even come to know and accept, no you really can’t biologically have children.” (2)

“I actually was in therapy right before I had the hysterectomy to deal with the fact that, I had talked it over with my ex-husband and my gynecologist and that we had concluded that the last year that I had tried to get pregnant I was in the hospital probably 7 to 8 different times because I had cysts that would rupture. And I had finally said to the doctor, you can’t see me in the emergency room anymore, I *can’t* [italics added] take it anymore. Every months when I started my period, a cyst burst [voice crackles and eyes fill up]. And so there was really no choice [but to have the hysterectomy].” (10)

“I think of it [my infertility] as a medical problem first, because you know I had gone through all the testing and he [husband] had gone through the testing and it wasn’t him. I also use to develop a lot of ovarian cysts and then I ended up with endometriosis which kept recurring and which is something that both of my cousins had>“ (10)

At the very end you know I asked him to [go to counseling] because we would get six or eight free sessions through work or whatever and I had called and he was just so close to it, he just didn’t want to do it and I was the only one who shoed up to the appointment, he didn’t even show up. He just was not willing to talk with anyone about it. It would have been good to get my feeling out too because I felt like I was always walking on eggs or pinshells or needles because I would be really made because sometimes he would sulk and I would tell him okay, today’s the forth or whatever [for conception].” 97)

“I think that after I found out I couldn’t have more kids, I think counseling would have helped me even then from doing anything drastic. It kept building and building and sometimes I guess that’s how I relieved it by crying. I don’t think I could have been able to talk about it at first because when I did, I would just be in tears.” (1)

“Now I realize I should have had a counselor and that may have helped me get it all out...I was too embarrassed to go after that, it was suppose to be a couples’ thing and he didn’t show up. We talked about going again and if he would show up, but then it got so bad and we got divorced.” (7)

“I don’t know [if talking with a counselor would have been helpful]. Well like five or six years ago I’d say yes, because I was actually crying all the time, I’d cry and get all depressed especially in the month of may because that is when it happened...every May around that time I get really depressed. I t gets really bad, I mean really bad. I just didn’t want to talk to anybody., but ever since that woman told me about the Bible part, it don’t [*sic*] happen so much no [*sic*] more. It just shut if off the pain and I think of them as little angels, both of them, so I don’t feel as bad about it now because God he wanted them both back and who am I to deny him [laughs] you know. And I just use to deal with it by myself and then what made it so bad.... So everything I wanted, you know, I had for a little while and then it was all dead. So it really messed me up [laughs], you know. Who knows, it [counseling] might have helped, but I might still be messed up from it.” (4)

“I am really sorry it had to end [divorce] the way it did. I wish something had happened or someone had intervned earlier so maybe you could have gotten some support. (7)

### **Insurance Coverage**

Not all the participants chose to seek medical intervention upon suspecting their infertility. Two participants actually have never had medical confirmation of an infertility problem. Although

neither have ever been pregnant and they both meet the accepted criteria for infertility (one's husband had a child in a previous relationship) both perceive and consider themselves infertile based on their own assessment. Since infertility treatment has not been an issue, they have not experienced problems with medical coverage.

However, every other participant has felt betrayed by their medical coverage for treatment of their infertility. Ironically, some insurance companies would pay for surgeries, bypassing the question of infertility, but which were much more expensive than paying for non-invasive potentially effective medications. In general, their diagnostic workups have been covered in part, but little else. As a result of the inability to personally pay for treatment as well as poor insurance coverage, seven of the other women in the study had to involuntarily suspend medical treatment.

## Chapter Six: Interpretation of Data

*Continuing with Wolcott's Schema, Chapter Six focuses on the interpretation of the data to understand these women's experiences of infertility on a deeper level. Based on the analysis discussed in the previous chapter, all participants fell within one of three separate and distinct categories describing their experience of infertility: defeated, resigned, or denying. The negative connotations of these categories as failures to achieve resolution is interpreted as an inability to construct a positive autobiographical narrative. The data suggests that infertile minority women face virtually insurmountable barriers to constructing a healthy identity because their cultural and social context provide no supportive community in which they can learn to narrate a positively valued story about what it means to be an infertile minority women in our society.*

Interpretation answers the question what does it mean? Although interpretation is a creative process which is intended to discover the deeper meaning of a phenomenon, it does not give the researcher free reign to speculate about the meaning. Rather, it allows the researcher to make connections with the data gather to get to the heart of the matter, although it may not necessarily be explicit from the raw data.

### **Infertility Categories**

The three categories which emerged from the data are: defeated, resigned, and denying. By identifying with one category, the characteristics which set one group apart from the others are more easily illustrated. These three categories represent individual participants unified into one voice within each category for a total of three collective voices. It is these collective voices that illustrate the commonality and differences between categories based on an individual's personal experience of infertility and their understanding and interpretation of that experience. As a collective voice their individual experiences are more vibrant and demonstrative, but are supported by their individual quotations. The collective voice within each of these three categories demonstrates how women with mutual histories and backgrounds have come to understand and interpret or socially construct their own experience of infertility. That is, women experience infertility through their own eyes and awareness. When women have similar experiences, they interpret a particular phenomenon as more similar than different. A synopsis of each category follows.

#### **Defeated**

Within the defeated category, these four women continue to focus on their infertility as the major event in their lives. Despite the length of time they have been dealing with their infertility, these women see almost all aspects of their life in relationship to children they have not been able to have. All of these women suffer from primary infertility and all have sought as much medical intervention as available to them based on their ability to access treatment and their ability to pay. All of these women are in married relationships with the partners with whom they have tried to

conceive. These women display apparent low self-esteem. They have essentially admitted defeat and despair of ever achieving a positive identity without motherhood.

### **Resigned**

Within the resigned category, these three women sought no medical intervention, even for diagnosis, of their primary infertility. Although all three women wanted and tried to have children, their commitment to becoming parents was somewhat ambivalent at the time they realized they were infertile. Only later in life have they really begun to understand their true feelings about their infertility and realize its true impact on their lives. All three women came from migrant or blue class families and rejected to some degree their culture's social norm of women as mothers. All three are the first in their families to receive college degrees and all have succeeded in their careers. This group is resigned to their fate and long ago turned to other outlets for defining a positive sense of self. However, they are resigned to the belief that these alternatives will never be as valued as motherhood.

### **Denying**

Within the denying group, all three participants struggle with secondary infertility, yet all three perceive themselves as infertile. Currently all three women are single and left their last significant relationships primarily because of the conflicts regarding their infertility. Although all three participants have had some contact with the medical community about their infertility, it was been relatively minimal, mainly due to finances or logistics. All three participants report fairly negative results from their interactions with the medical community including either gender discrimination, poor care based on ability to pay, or insensitivity and emotionally unable to respond to their situation. In denying their fate, these women turn against others to blame them for their infertility. Unable to accept the fact of their infertility – possible because they were formerly able to have children – they direct their anger toward spouse, doctor, family, culture.

### **Narratives**

All the women in the study face a common problem: they have no supportive community in which they can learn to construct a positively valued autobiographical narrative about themselves as infertile minority women. Faced with a culture riddled with taboos and myths about infertility (and sexual matters generally), they can find no one to tell their story to. This is a widespread problem throughout society and most infertile women are overjoyed when they somehow come across someone with whom they can discuss their burning secret. However, higher income women have resources to hire therapists and medical specialists or to seek out support groups and sympathetic ears. Within the more traditional cultures of most minority women, in which old-time religions still wield considerable influence, the barriers to this are much harder to overcome.

Lave and Wenger (1991) argue that the primary function of Alcoholics Anonymous is to provide a supportive community in which members can learn how to tell a story about their experience and construct a narrative about themselves as non-drinking alcoholics whose identity is valued within the community. For someone who is condemned by the society's dominant values to construct a positive autobiographical narrative is a difficult task that requires discipline, contact

with role models, and community support. These are simply not available to infertile minority women. They are on their own in an impossible position.

## Chapter Seven: Discussion

*Chapter Seven discusses the limitations of this study and the implications for social work practice, education, and future research.*

### **INTRODUCTION**

The social work profession has not been centrally involved with the infertility crisis. The medical profession has been primary. Social work, when involved, has typically been on the periphery, either as an adjunct support to the medical model or by providing supplementary counseling to infertile individuals.

As our understanding of infertility grows, it is becoming more and more evident that the psychosocial components of infertility are as important as the biological components. Infertility impacts more than the identified infertile individual. The affects of infertility over an individual's lifetime have not yet been adequately addressed. Therefore, professions other than just the medical profession must become more knowledgeable about the needs of the infertile population and more actively involved in meeting the varying needs of those directly and indirectly impacted by infertility. The psychosocial concerns are not the only needs which social work is in a position to address. In addition to direct practice needs, social work is ideally suited to address indirect practice needs, especially as related to policy and research.

It is often assumed that infertility impacts only certain groups, specifically women, and particularly women from more well-educated and higher socioeconomic categories since these women have been most visible in seeking medical intervention. In reality, as seen from the previous chapters, infertility impacts all social groups, including those groups that social work has typically served, such as minorities and lower socioeconomic groups.

Statistically, we now know that the causes of infertility are almost equally distributed between men and women. Because women appear to have more explicit emotional reactions to infertility than men, women have been the focus of more research. Even if the infertile person is the male, the women is usually the center of the medical interventions. Research into gender differences related to infertility are still at the neophyte stage. Men may actually be at higher risk for psychosocial repercussions from infertility because of the social stigma that impotency is equated to infertility.

Social work is the most likely profession to provide needed services to men and women faced with infertility. The values and basic premises of social work theory support understanding and meeting the needs of the infertile population from a biopsychosocial perspective. The most fundamental principle of social work is to understand individuals, their environment, the society, and the interactions between individuals and their environment (Hepworth & Larsen, 1990). Accepting social work's concept of person-in-environment, social work addresses the whole phenomenon of infertility—not only as it impacts the infertile individuals, but also as it impacts their surrounding systems. The social work and social welfare needs of those dealing with

infertility can most adequately be accommodated once social work becomes more involved with all aspects of infertility including understanding specific medical interventions and their broader psychosocial impacts on the infertile couple.

This chapter is intended to bring together the concepts and themes presented and already referenced in the preceding chapters on history, theory, policy, and research, as they are applicable to the implementation of social work and social welfare. The need for social work's participation with infertility will be examined from direct and indirect practice perspectives by looking at the micro, mezzo, and macro levels of practice common to social work already referred to in the theory chapter (Zastrow, 1992). Then, the goals of social work—enhancing social functioning, remedying personal dysfunction, and promoting social justice—(Hepworth & Larsen, 1990) will be explored and applied to the problem of infertility.

## **SOCIAL WORK PRACTICE**

### **Micro Level**

When examining the current relationship of social work and infertility, the interaction tends to happen primarily at the micro or direct practice level. Micro level practice of social work has tended to be with individuals, couples, or groups who are currently experiencing infertility. Through face-to-face contact, often one-to-one, sometimes in groups, social work has addressed the individual's psychosocial reactions commonly associated with infertility. This takes place especially during the initial diagnostic and treatment stages. Generally it has been with women or couples. In this way, to some degree, social work has been addressing the psychosocial needs of a limited number of individuals who are infertile.

From the biopsychosocial perspective, many people impacted by infertility might benefit from social work intervention. Infertility interrupts the normal developmental life cycle and stimulates a series of complex emotional responses. Infertility has been identified as a psychosocial crisis. Individuals who have not previously needed mental health support often seek out counseling to aid in their adjustment to the crisis of infertility. Since infertility impacts systems, support systems indirectly affected by the infertility could also benefit from social work's expertise and intervention. As seen in the research chapter, well-meaning friends and even family members may be uncomfortable dealing with issues of infertility and thus unknowingly add to the stress already felt by the infertile couple. Family members not directly impacted by infertility may also have psychosocial reactions to the infertility. They could benefit from interventions which address their concerns while becoming aware of more beneficial and appropriate ways to support the infertile individuals in their family.

Social workers who are already running groups for other targeted problems may be in an excellent position to introduce or incorporate concerns related to infertility into those groups. Social workers have knowledge and training in developing and running groups and can be an asset in increasing the coping strategies of infertile individuals.

Social work has generally been accessible only to a small percentage of the individuals who could benefit from the services. Social work has not been traditionally credited with addressing

infertility needs. Since those with higher levels of education and economic security also enjoy better health and have increased access to health related services, it would behoove social work to address the needs of disadvantaged populations who have a higher incidence of infertility but generally less access to appropriate services. Social work has a responsibility to meet the needs, direct and indirect, of all those affected by infertility.

As infertility treatment has become more medically technical and ART has advanced, infertile individuals must deal with difficult choices that may challenge their personal moral and ethical values and beliefs. Seldom are these dilemmas explored within the traditional medical model context of doctor and patient. Frequently these decisions must be made rapidly, during specific treatment phases, with little forethought about the long term effects and possible consequences of these decisions. This is another critical area where social workers have training and expertise in helping individuals sort out complex and difficult personal choices, as well as access to additional resources.

One of social work's main functions is to be a resource and source of information to the population it serves. Yet much of the material related to infertility (as seen in the research chapter) has evolved independently and separate from social work. Social work could expand this information by addressing other related issues such as policy concerns, insurance information, financial alternatives, legal, moral and ethical issues, and research.

In order to more effectively work with infertility, and especially to serve as advocates for the infertile population, social work must expand its present knowledge base since there is currently little literature and research from the social work perspective. Social workers wanting to work in the area of infertility must seriously examine their own values and beliefs about reproduction. Since infertility is so embedded in the medical community, social workers will need to develop new strategies for interacting within the medical context if patients/clients are to be served from the perspective of a broader biopsychosocial theory. Improving the knowledge and skill base of practitioners is essential to ensure successful intervention at each level of social work practice.

### **Mezzo Level**

Mezzo level social work practice minimizes direct practice with clients. Rather it focuses on indirect practice, usually administrative. There has been little mezzo practice related to infertility within social work since few agencies other than medical facilities specialize in working with the infertile population. However, it is critical that social work not just emphasize micro level practice, but also consider the implementation of social work values and beliefs at the mezzo level of practice.

Historically, mental health workers, including social workers, and medical personnel have had different interests and have had difficulty working together as colleagues (McDaniel, Hepworth, Doherty, 1992). Generally, the mental health needs of the infertile population have not been dealt with directly within the medical settings, but are more frequently referred to other professions, often with poor follow-up. There has been limited integrated collaboration between social work and infertility medicine; one of social work's goals must be to bridge that gap in order to provide more effective and appropriate services for the infertile. In particular, the integration of mental health and medicine is a critical aspect of almost any medical condition.

Since infertility is still essentially treated from a medical model, social work must become more actively involved within the medical community. Social work must also establish itself as a credible and separate entity in dealing with infertility. The medical sub-specialties which have developed to deal with the various problems of the medical aspects of infertility tend to be housed within one department or clinic with specialized personnel and facilities which cater solely to medical needs of the infertile individuals. These facilities are currently administered by either medical or business personnel, generally without any social work background or representation. The merging of medical and social work concerns is especially important with infertility for two main reasons. First, the longitudinal, psychosocial ramifications of infertility are only now beginning to be understood. Individuals dealing with infertility may continue to need psychosocial services long after medical intervention has been terminated. Second, the treatments for infertility continue to advance rapidly into previously uncharted water, raising new moral and ethical dilemmas not inherent in other medical conditions. Not only do those who are affected by the infertility need support with these concerns, often so do the medical personnel treating these patients. Therefore, the mezzo level of practice needs to address both patients and medical personnel.

Social work should be represented within the administrative level of medical facilities specializing in infertility, as well as within other systems which have access to those directly and indirectly dealing with infertility, whether it be insurance companies, counseling centers, or family oriented agencies. From an administrative perspective, social work can help balance services and assure that clients potentially dealing with infertility receive an integrated biopsychosocial approach, regardless of the focus of a particular agency. Additionally, such administrative positions within medical facilities can supervise the micro level staff and help ease the adjustment into a field that has been predominantly medically orientated.

### **Macro Level**

It is important that social work become more responsible for the processes of social planning and community organization that macro level practice has traditionally addressed. Even though many of the treatments for infertility have received sensational media attention and publicity, the intricate details and understanding of infertility are generally not available to those not directly impacted by infertility. What many lay people believe about infertility may not only be scientifically incorrect, but is often prejudiced and biased. Infertility and its potential treatment is usually an emotionally charged topic because of individual values and beliefs related to intimacy and sexual intercourse. Therefore, even initiating dialogue about this important topic at the macro level of practice within agencies and communities has been a challenge, but one that must be acknowledged and overcome. As was seen in the policy chapter, infertility policy and legislation related to infertility are still relatively limited. Policies that exist are inconsistent, often informal and unspoken. Infertility has been a relatively secret topic, much like abortion was in the past. It is time to bring infertility out of the closet and implement public policy and legislation at the macro level.

Since the right to reproduction is protected by the intention of the Constitution, the question of the infertile person's right to reproduce using medical technology will inevitably be challenged with future lawsuits in the near future. Therefore it would benefit the infertile population for

social work to raise the issues and concerns related to infertility as policy becomes more established. To date, social work has not been adequately represented in the policy making arena. Social work's voice as an advocate for the infertile population is critical. Social workers advocating for the rights and needs of the infertile population and impacted systems would be pioneers on the cutting edge of discussing policy which has moral and ethical implications.

## **GOALS OF SOCIAL WORK**

### **Enhancing Social Functioning**

One of the most important goals of social work is to enhance the social functioning of individuals, groups, and communities through direct and indirect practice (Hepworth & Larsen, 1990). Social work's role can be defined further by understanding how infertility relates to the prevention, restoration, and remediation functions of social work. Although similar to direct and indirect practice, these functions further elaborate the importance of social work's involvement with infertility.

#### *Prevention*

Many conditions which lead to infertility can be prevented. While one goal of most sex education classes is to prevent early or unwanted pregnancy, there is an obligation to educate individuals about the potential consequences of birth control, abortion, sexually transmitted diseases, and other potential risk factors for future fertility. School social workers are in an excellent position to address issues within already existing curriculums on sex education, living skills classes, group, or one-to-one counseling with children within educational settings.

Social workers at administrative levels are also in an excellent position to develop more comprehensive programs for populations considered at-risk for future infertility problems, such as sexually active adolescents.

Social workers have the training to understand the person-in-environment, so they can be instrumental in designing and developing programs that address potential concerns around infertility. They can introduce these programs to a wide variety of audiences in ways that are developmentally appropriate and culturally sensitive.

#### *Restoration*

At the restoration level, social work has an obligation not only to address the psychosocial factors associated with infertility, but also to raise some of the moral and ethical issues that are involved in decision making related to infertility. With the advances of ART, many infertile couples see no alternative but to pursue medical forms of resolution. Adoption and choosing to be childfree are often not explored with the infertile population. Social work can help fill this gap. Social work has a responsibility to advocate for services for at-risk groups within the infertile

population who may not have knowledge of, or access to, services for addressing the biopsychosocial aspects of infertility.

### *Remediation*

With regard to remediation, social workers must strive to eliminate many of the social conditions that lead to infertility. It is estimated that 50% of the cases of infertility could have been prevented (Evans, 1989). This would especially involve high risk groups such as adolescents engaged in sex or lower socioeconomic groups lacking access to adequate health care. Additionally, social work may be well advised to consider the future needs of children born from ART, as they may have needs different from biologically conceived or adopted children.

### **Remedying Personal Dysfunction**

For some, the experience of infertility can be so debilitating that it impairs one's ability to utilize available and appropriate resources. This seems particularly true with infertility. Frequently, while the medical needs of the infertile individuals are being met their psychosocial needs have been less adequately met. Social work's involvement within and outside the medical community can help support individuals to identify and access relevant resources and services. Infertility's secret nature has often resulted in the infertile individual pulling away from relationships and interactions with the fertile world. Social work can help bridge that gap between the fertile and infertile world by providing counseling to the infertile population. Social workers can draw on individual interpersonal skills to reduce the isolation from the fertile world. They can also provide education and information to the fertile world.

### **Promoting Social Justice**

Infertility does not discriminate, although certain groups may be more susceptible to infertility than others. Yet there have not been equal resources and opportunities available for all those impacted by infertility. Therefore, on the indirect level, social workers must assure that laws, policies, and services ensure accessibility to all those in need of such intervention, medical or psychosocial. Social work's role of advocacy and social action must be orchestrated to assure the needs of the infertile population and of those indirectly impacted by infertility are addressed.

To date, almost all the research and work on infertility has been done with traditional married couples. Research and literature related to infertility have made no mention of special populations. ART is a viable option for same sex couples to become parents, but the needs of this population have been totally ignored from a research and policy perspective. In addition to addressing the needs of an already identified population, social work also has an obligation to address the needs of other special populations.

## **SOCIAL WORK SUMMARY**

Infertility is not a new problem. However, as the number of people impacted by infertility grows and the complexity of the problem due to medical intervention continues to increase, social

work must become more actively involved in addressing the problem of infertility by addressing the policy, research, and direct and indirect practice needs outlined in this paper.

## CONCLUSION

This paper has established the historical medicalization of infertility. We have seen the need to understand the experience of infertility from a broader theoretical base than just through a medical model. The current dominance of the medicalization of infertility provides too narrow an understanding of the complex biopsychosocial nature of infertility. The broader biopsychosocial view espoused in this paper has significant implications for the profession of social work. Social work needs to take action in three main areas of infertility: policy, research, and practice as elaborated on in the respective chapters.

To a large extent, infertility can be prevented and the psychosocial impacts of infertility can be mitigated through effective social work intervention. Through increased policy advocacy and future research, social work can expand current understanding of infertility. Social work can increase its response to infertility by increasing counseling to those directly and indirectly impacted by infertility. In addition, social work can educate the public about infertility.

The need for the expertise of social work in dealing with the social problem of infertility is evident and there are numerous ways social work can become actively involved in addressing the problem of infertility.

Infertility is a social problem that is not going away. It needs the expertise and support of the social work profession. In the words of one anonymous writer:

My infertility resides in my heart as an old friend. I do not hear from it for weeks at a time, and then, a moment, a thought, a baby announcement or some such thing, and I will feel the tug—maybe even be sad or shed a few tears. And I think, “There’s my old friend.” It will always be a part of me.

### ***Implications for Social Work***

What implications does this study have for social work, specifically for social work practice, education, and research? Social work has virtually ignored the infertile population. Most likely even the profession of social work has been erroneously influenced by the media and popular culture, maybe even seduced into thinking that medical intervention resolves infertility. The myths that exist about infertility may reach into the very profession that could be of assistance to the infertile population. This research alone suggests social work would be an appropriate profession to get more involved in supporting the infertile population.

#### **Practice**

It is important for social work to look at its own values and beliefs about infertility. By virtually ignoring the population impacted by infertility, social work has erroneously supported the myth that infertility is a medical problem that needs to be resolved within the medical community. Social work has been reluctant to cross the boundary into the medical community to work in

partnership with those who seek medical solutions to a biopsychosocial problem. Social work may have fallen victim to believing the unspoken myths about infertility and must examine those beliefs.

Therefore, social work has a responsibility to screen, assess, and evaluate if infertility, primary or secondary, may be a contributing factor when working with any clients. It is imperative for social work to recognize that infertility is present regardless of gender, race, ethnicity, age, socio-economic class. Additionally, those individuals that may appear to have resources such as access to medical intervention, education, socio-economic status, are suffer from the psychosocial effects of infertility and should not be discriminated against by the social work profession simply because they are not the population typically served by social work.

### **Education**

The social work profession has a responsibility to educate themselves more fully infertility and to begin to validate it as a biopsychosocial condition. This means that not only does social work have an obligation to education those in social work training, but they do also educate those outside of social work as well.

In addition to educating themselves about infertility, social work must become more informed and proactive in the debates surrounding insurance coverage. Additionally social work has a need to address policy and regulations about infertility to make certain groups of infertile individuals are adequately represented.

### **Research**

There is a paucity of social work research related to infertility. This study is an attempt to highlight the need for additional research in the field of infertility. From a systems perspective, infertility research is still at the neophyte stage and there are many, many areas that must be explored to fully understand the scope of infertility. Although infertility is not exclusively a woman's condition, the research has focused primarily on women. Considering that the incidence of infertility affects men and women equally, it is interesting to note that in the limited studies, only women have been studied. Therefore, one clearly identifiable area of research would be with men.

As mentioned several times within this study, only a specific population of women have been studied to date. Another area of research would be to broaden infertility studied to a more diverse population. In addition to studying men as individuals and men as part of couples, considering that infertility impacts more than the infertile system, diversity should also include other systems that are impacted such as extended families, friends, and colleagues.

In light of the recent Bragdon v. Abbott Supreme Court ruling in June of 1998, which decided that reproduction is a major life activity and falls within the Americans with Disabilities Act (ADA), there needs to be a focus on policy and regulations surrounding the whole infertility treatment industry. As individual cases may soon come before the judicial system to test this ruling, more research is needed to more fully understand the dynamics and need of the infertile population.

## ***Limitations of Study***

This study was exploratory in nature and qualitative by design. Describing the experience of infertility among a previously unstudied population is descriptive of these participants only. The sample was selective and purposive and the findings cannot be generalized to a broader population of women who have experienced infertility.

In addition to generalizability, other limitations exist. First, many women who wanted to participate in this study were excluded due to the language barrier of the researcher. It was determined that due to the nature of the phenomena being studied, the researcher would have a better ability to describe, analyze and interpret the data if the participant and researcher could communicate in a common language. Unfortunately, many women who qualified for this study and who wanted to participate were not interviewed.

Second, this study only includes those women willing to participate and therefore, it is not representative. The participants in this study were willing volunteers. There was no attempt to contact women who qualified for the study, but who did not openly volunteer. Several eligible women who were excited about the study subsequently decided not to participate because they worried that their secret would be discovered or in some cases that their partners would disapprove of their sharing their stories despite being guaranteed confidentiality and anonymity. Therefore, the women who did participate shared their voices, although these women may be in different positions to do so than those who had the desire to participate, but for whatever reason felt they could not participate. Participation by the women who declined may have shed different light on this research including their reluctance to participate.

Third, the original research design of the study had to be altered and tweaked as the study progressed. The main digression from the initial plan had to do with the focus groups which was designed so participants could meet, share experiences, and clarify themes from early data analysis. For a variety of reasons, this did not happen, primarily due to the women's anxiety of coming together in a public forum, but also partly as the result of logistics and the distances between participants and accommodating their schedules. As a researcher, the absence of the focus groups could be viewed as a limitation. However, it may simply be a finding that these participants were not willing or motivated to participate in the group structure.

Fourth, although infertility crosses genders, this research again only looked at women. Although these women may not have been biologically infertile, this research focused on them and their experience of the infertility although the impacts of infertility are systemic. Future research should address the other systems affected by the infertility.

Fifth, the sample could have been more diverse, particularly with regard to the socio-economic levels of the participants as well as their cultural backgrounds. Therefore, a limitation of this study was access to a more diverse population, especially in light of the language barriers.

Sixth, this research is simply symbolic as there was not opportunity to verify the participants perceptions with anyone else, other than using their own reports. There have been many insights from this research alone and several areas for future research have been identified.

### **In Summary**

Infertile minority women striving to construct positive autobiographical narratives for themselves face barriers at every level of their culture and society. These barriers are virtually insurmountable by individuals with few resources. Social work has a special commitment to helping the low-income minority population overcome social barriers to the pursuit of happiness. It behooves the social work profession to take into account the needs of infertile minority women and to address these needs at every level possible.

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## **Appendices**

***A. Confirmation Letter for Research from Dissertation Chair***

***B. IRB Application and Letter of Approval***

***C. Information Letter to Perspective Participants***

***D. Informed Consent Forms***

***E. Recruitment Flyers***

***F. Recruitment Letters***

***G. Demographic Information Form***

***H. Interview Guide***

***I. Coding Categories***