The Crisis of Infertility: Understanding its Emotional Impact

Patricia Ferguson Clayman

University of Pennsylvania

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The Crisis of Infertility: Understanding its Emotional Impact

Abstract
Through the use of a questionnaire and selected interviews, this study addressed several major psychological issues regarding infertility. Specifically, as it relates to the infertility experience, these included: (1) the consideration that demographic variables impact significantly, (2) the psychological importance of gender differences, (3) the effect of medical diagnosis and treatment and (4) the possibility that there exists a well-ordered emotional continuum. Subjects were derived from the population of infertile couples ranging in age from 22 to 45 years old. Questionnaires were distributed locally through the offices of infertility specialists and at Resolve (a national infertility support group) monthly meetings. Based on questionnaire results, selected follow-up interviews were utilized to elucidate provocative findings. The goal of this study was to provide new information that would allow a greater understanding of the emotional aspects of infertility.

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THE CRISIS OF INFERTILITY:
UNDERSTANDING ITS EMOTIONAL IMPACT

PATRICIA FERGUSON CLAYMAN

A DISSERTATION
in
EDUCATION

Presented to the Faculties of the University of Pennsylvania
in
Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy

1990

Supervisor of Dissertation

Graduate Group Chairperson
DEDICATION

This dissertation is dedicated to my husband with love and thanks for his consistent support, encouragement and assistance.
ACKNOWLEDGMENT

I wish to thank many of the key people who were integral in the development, execution and completion of this project.

To Michelle Fine, PhD., I say a most special thank you for enabling me to work closely with her from the time before I entered the University of Pennsylvania until now. She has been a continuous role-model. Her endless amounts of energy and enthusiasm are unparalleled. Her insight, focus and clarity of thought made every interaction a positive as well as intellectual one.

To my other two committee members, Demie Kurz, PhD. and Peter Kuriloff, PhD., I am also indebted. Demie’s expertise with interviewing techniques and subsequent data collection were an invaluable resource. Peter was especially instrumental in both the development of the original idea and in understanding the process of completing a doctoral degree.

My statistical consultant, Bonnie Stewart, was also an integral participant in this project. Without her expertise and advice regarding the statistical analyses, findings from this research study would have been far less interpretable and meaningful.

I wish to acknowledge one last critical person, my husband, Mike. His flexibility and willingness to become involved at a moment’s notice, often at less than ideal times, was greatly appreciated.
ABSTRACT

THE CRISIS OF INFERTILITY:
UNDERSTANDING ITS EMOTIONAL IMPACT
PATRICIA FERGUSON CLAYMAN
SUPERVISOR: MICHELLE FINE, PH.D.

Through the use of a questionnaire and selected interviews, this study addressed several major psychological issues regarding infertility. Specifically, as it relates to the infertility experience, these included: (1) the consideration that demographic variables impact significantly, (2) the psychological importance of gender differences, (3) the effect of medical diagnosis and treatment and (4) the possibility that there exists a well-ordered emotional continuum. Subjects were derived from the population of infertile couples ranging in age from 22 to 45 years old. Questionnaires were distributed locally through the offices of infertility specialists and at Resolve (a national infertility support group) monthly meetings. Based on questionnaire results, selected follow-up interviews were utilized to elucidate provocative findings. The goal of this study was to provide new information that would allow a greater understanding of the emotional aspects of infertility.
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CHAPTER I

Introduction

The Crisis of Infertility:
Understanding Its Emotional Impact

Infertility is becoming an increasingly common problem for men and women of child-bearing age. It has been estimated that as many as one in five couples are incapable of having biological children and as such the medical, psychological and emotional impact of this problem is becoming increasingly evident. It is fair to say that, at the present time, almost everyone has had some experience with infertility either directly or indirectly. What is not appreciated, however, is the fantastic toll this process takes on those directly affected. Accordingly, this study seeks to further understand the important emotional variables that are called into play as a couple experiences the infertility process and consequently, to provide a reasoned framework for approaching this problem.

It is currently recognized that infertility is a two-fold phenomenon comprised of both physical health and psychological components (Bresnick, 1981). The latter can be further divided into presumed etiologic factors and emotional reactions. Thus, for many years it has been thought that infertility can result from stress, anxiety and a variety of other psychopathological processes arbitrarily referred to as "female inadequacies." In addition, it has recently been appreciated that infertility itself results in
a heavy emotional burden consisting of grief reactions, depression, marital discord and financial strain (Menning, 1977; Seibel and Taymor, 1982). Further, the anxiety-provoking nature of the generally obligate medical evaluation and therapy has never been examined in detail. These considerations deserve further exploration because it is the contention of this thesis that they can play a paramount role in the overall psychological aspect of the infertility process.

Health care is a two-edged sword. On the one hand, it can involve physical pain, humiliation, embarrassment and stress but, on the other, it is almost always holding out hope that the next test, procedure or treatment will result in the definitive resolution of the problem; i.e., a successful pregnancy. This is a close to addicting process because it is rare that one is either informed of or spontaneously appreciates the possibility that a natural child is biologically out of the question. In fact, the state of the medical art is such that a statement to this effect can almost never be made based on the available information. In the absence of this, couples invariably look to the next cycle as their salvation and are emotionally devastated at the end of that cycle when pregnancy is not achieved. This "emotional roller coaster" has been described before by P. F. Schreiber (personal communication, March 10, 1985) but has never been scrutinized in a formal manner.
Previous literature has explored the emotional aspects of infertility in generally one of two ways; either by analyzing the process according to different stages, akin to Kubler-Ross’ portrayal of death and dying, or by suggesting that the infertility experience is unique and cannot be understood using any conventional psychological perspective. It is this latter view that indicates that the multitude of personal and familial variables must affect the way in which the members of a couple respond to their infertility. Thus, the basic importance of achieving a family weighed against career ambitions, extended family and peer pressures, financial status and overall life goals may dictate very different responses amongst couples with different orientations. In addition, little research has directly focused on the differential experience of females and males with regard to the issue of infertility, and how this may impact on individual levels of stress and the couple’s relationship.

In sum, this study filled the informational void regarding certain important aspects of infertility. In particular it addressed the emotional nature of the experience in three distinct areas. The first was the role that medical intervention plays in contributing to the overall stress of the infertility process. Secondly, the concept of well-defined stages versus unique experiencing of the infertility process was assessed and further developed. In this context, the interaction between one’s goals, values
and relationships and the prospect of childlessness was evaluated. Finally, particular attention was also be paid to the differential experience of males and females in facing the infertility issue.
CHAPTER II

Review of the Literature

Overview of Infertility

Infertility is defined by the American Fertility Association as the absence of a successful pregnancy leading to a live birth within one year of unprotected, regular sexual relations (Mazor, 1979). Following the initiation of such relations, 63% of all couples, 22-40 years of age, will achieve a pregnancy within 6 months of exposure, and 80% will do so within one year (Thompson, 1984). Thus roughly 20% of couples fulfill the stated criteria for infertility. Nevertheless, during the second year and third years, an additional 9% will conceive, leaving only 11% infertile at the end of this period. In 1978, approximately 10 million couples in the United States were diagnosed as infertile (Menning, 1980). The chances that couples in this group will subsequently achieve a pregnancy decreases over time in the absence of specific treatment (Mazor, 1984). Through the advances of modern technology, treatment is effective in approximately 50% of infertile couples, leaving half of such couples in a persistently infertile state (United States Congress, 1988).

Contrary to common belief, infertility affects men at a rate equal to that of women. Thus, in approximately 40% of cases the cause of infertility will reside with the woman, and in 40% of cases it will be caused by a male factor. Of the remaining 20%, a problem is found in both partners in
15% of cases, whereas in 5% of cases no cause can be documented and the infertility is then referred to as idiopathic (Menning, 1977).

Although exact figures do not exist, preliminary data suggest that the percentage of couples diagnosed as infertile is steadily increasing. Maximal fertility for both males and females occurs in their mid-twenties, so that the postponement of childbearing until after this time will increase the statistical likelihood of an infertility problem. In recent years such delays have become increasingly common for a variety of personal, social and economic reasons. In particular, the average age at childbearing for both males and females has increased progressively over the past several decades and it has become increasingly clear that many couples await firmer financial footing and better established careers before pursuing the possibility of childbearing. Also contributing to infertility rates is the rising incidence of venereal disease which can cause irreversible scarring of the reproductive tract in both men and women. Other causes of infertility include the use of certain contraceptive methods. For example, the intrauterine device (IUD) may cause infection and scarring of the Fallopian tubes, and contraceptive pills may lead to problems in ovulation after their use is discontinued, especially in women who have prior histories of irregular menses.
Endometriosis occurs when portions of the tissue lining the uterus (the endometrium) migrates to other areas within the abdominal cavity. This condition is also strongly associated with infertility, although this is somewhat controversial, since approximately one quarter to one third of all women have it and many of these are perfectly capable of conceiving. Nevertheless, its effective treatment in infertile women has been temporally correlated with the subsequent ability to achieve pregnancy. Therapeutic abortion, even in the absence of infection, may cause damage to the cervix and the ability to carry a later pregnancy to term. Other factors include exposure to various drugs, chemicals and radiation, which are thought to contribute to infertility and whose effects may not be evident until many years later. For example, women were exposed to diethylstilbestrol (DES) in utero often have reproductive tract abnormalities which become evident only at the time that they are evaluated for infertility. On an anatomical basis, female infertility is ascribed to abnormalities of the Fallopian tube in 30%, of the ovaries in 20% and of the cervix in 15%. In the remaining 35% of cases there are a variety of causes including drugs, infections, etc. (Thompson, 1984).

For many years the medical conditions associated with male infertility were thought to be untreatable. This is no longer the case and to date monumental strides have been made in this area (Newton, 1984). It must be noted,
however, that at present, treatment for men with infertility problems is primarily empirical and is not based on a complete understanding of relevant pathophysiology. Current statistics reveal that approximately 25% of male infertility may be due to obstruction of the vas deferens or epididymis (pathways that semen follow). In these cases, surgery is the treatment of choice, and much success has been documented thus far. Varicocele (varicose vein in the scrotum) accounts for an additional 25% of male problems. Surgical intervention is again the treatment of choice and a success rate (defined by achieving a pregnancy) of 35-45% has been reported (Mazor, 1984). Amongst those with a diagnosable condition, the remaining 50% of male infertility problems may be attributed to various chromosomal defects (which are not treatable at the current time), infections (whose contribution to infertility per se is highly controversial and poorly understood), autoimmune responses (a highly speculative area with relatively few conclusive cases published) and endocrine defects (hormonal imbalances which may respond to pharmacologic treatment) (Newton, 1984). A substantial percentage of male infertility patients fall into the "idiopathic" category where no etiology can be determined (Rosemberg, 1976).

The perception of an increased incidence of infertility is related to both a genuine increase in such statistics and the fact that infertility has become an increasingly less taboo area for discussion. Although in the vast majority of
cases infertility is not caused by problems in sexual function, the traditional association of sex and reproduction made the subject seem shameful and embarrassing. As it has become acceptable to discuss sexual matters more freely, it has become easier to acknowledge infertility. Recent advances in diagnosis and treatment possibilities offer greater hope to the infertile couple, so there is a real impetus to pursue the problem more aggressively. The general public is now more informed, and people expect and demand treatment for medical problems.

Another significant push toward recognition of the problem comes from the fact that there are relatively few infants available for adoption. The relative ease of obtaining therapeutic abortions, coupled with the tendency of unwed mothers to keep their babies, has made adoption a difficult project, requiring an enormous investment of time, energy and money. Adoption is no longer the easy alternative it was once thought to be. Furthermore, it should be noted that adoption is not a cure for infertility, but is an alternative method of building a family. Although everyone knows about couples who adopt and immediately become pregnant, the pregnancy rate for infertile couples who adopt and those who do not is the same (Arronet, 1974).

Recent media exposure has heightened the lay public's awareness of the issue of infertility. Media coverage of all aspects has become increasingly common (witness the cover story of Time magazine, April, 15, 1985), but this has
particularly concentrated on the technical advances in treatment and tends to create a somewhat unrealistically positive impression of the likelihood of successful medical therapy. The fact that many of these treatments are experimental and expensive and that they are effective in only a minority of patients is often omitted. Consequently, new developments are frequently confused with effective therapy. While these advances have unequivocally contributed valuable information to the treatment of infertility, the tendency to emphasize technical aspects results in the relative overshadowing of psychological issues. In particular, the profound emotional impact of infertility on the affected couple has seemed to attract media attention to a much lesser degree and as such is a substantially less evident problem to the lay public. More recently, infertility is being viewed as a two-fold phenomenon composed of both medical and psychological components (Bresnick, 1981). Without a balanced presentation of infertility and what it involves, most people cannot be expected to accurately understand what infertility is, how it affects couples and what can be done to alleviate some of its sequelae. As a result, the lay public cannot be expected to be sensitive to the often overwhelming and always difficult, emotional experience of being infertile. This lack of understanding tends to isolate the infertile couple at a time when they are feeling
most vulnerable and are in greatest need of emotional support.

As with any relatively new phenomenon, the infertility literature is fairly small but rapidly growing. Currently, it is comprised of two basic categories: those works which address the medical aspects and those which focus on the emotional component. It is currently acknowledged that regardless of the medical etiology, infertility carries with it a significant psychological impact which often goes unaddressed but dramatically affects ones' existence and the ability to deal effectively with the reality of the problem (Leader, 1984).

**Medical and Nursing Literature**

Originally, the literature was composed predominantly of medical reports. First reports appeared in the 1700's and 1800's and these were primarily written by the male physicians of infertile female patients. Throughout its history, the medical community has focused on the diagnosis and treatment of specific disorders, emphasizing organic etiologies and their appropriate therapy. The theory of psychogenic infertility (discussed below) evolved, however, when no obvious physiologic basis could be discerned.

Reproductive Endocrinology, which includes the subspecialty of infertility, has only been recognized as a scientific field of study since 1974. Because this area of infertility is only 16 years old, much remains unknown. Currently, while it may be possible to identify specific
causes for many infertility problems, there also remains a significant percentage of cases where this is not currently possible. Even when a specific etiology can be determined, effective treatment may have yet to be developed. Because women were viewed as the child-bearers, it was assumed by male physicians that any difficulty associated with child-bearing must be attributed to a female factor. As a result, women have tended to be the primary focus of infertility and consequently, more research has been directed toward the female aspects of this problem. As a result, more is known about female infertility.

It should be noted that there continues to be a focus primarily on women with respect to the treatment and evaluation of infertility. They continue to undergo many more of the procedures and are usually the primary focus of medical treatment. The most recent statistics state that 40% of the time the etiology of infertility lies with the woman and 40% of the time the etiology lies with the male. Why then should so many more treatment options be available for the woman? The obvious answer is that much more of the research has focused on women. In attempting to answer this question, a leader in the field of infertility was contacted. According to Dr. John Jarrett (personal communication, February, 1990), the rationale is primarily a practical and technical one. The reproductive systems of the female and male are very different. The female system is a more simplified one and one of shorter duration. For
example, the development of the egg takes 10 days whereas the
development of the sperm takes approximately 75 days. As
such, there are many more opportunities to evaluate and
experiment with the reproductive system of the female, i.e.,
7:1 more opportunities. It is therefore understandable why
more efforts have focused on the female reproductive system.
It is inherently easier and simpler to work with. This
rationale seems, in a large part, to account for the
emphasis on female reproductive issues, which has resulted
in many more treatment options being developed for women
versus men.

The Infertility Evaluation

In order to better understand the psychological impact
medical intervention can have on the individual and/or
couple, one must first understand what the medical
evaluation and treatment is comprised of. A brief overview,
therefore, is necessary so that one may fully appreciate
this aspect of the infertility experience. It should be
noted, however, that while these evaluation procedures are
typically recommended, there remains much variability
regarding the actual sequence of these procedures.

The infertility evaluation is fairly simple and
straightforward. While it is generally agreed that the
couple should be treated as a unit throughout the
evaluation, in practice this is often not the case.
Following a complete physical examination of both partners,
the formal assessment is comprised of essentially five basic
tests. The initial tests are commonly those that are the least invasive and uncomfortable but are still highly informative. A semen analysis is typically performed as the initial test, primarily because semen is a major factor in conception and the testing involves a very simple procedure. Attention is focused especially on the sperm count, the microscopic appearance and the characterization of their movement. If an abnormality is noted at this stage, approximately 40-80% of cases can be effectively treated by surgical or medical means (J. S. Check, personal communication, February 21, 1986).

Ovulation is the second area of evaluation. This is accomplished primarily by the use of the basal body temperature (BBT) and verified by endometrial biopsy. Although an area of some controversy, it is believed that a change in temperature is an indication that ovulation does occur, thereby ruling out an anovulatory problem. Endometrial biopsy indicates the adequacy or inadequacy of hormonal changes associated with ovulation. These hormones are primarily associated with implantation of a fertilized egg as well as maintenance of an optimal chemical environment for sustaining a pregnancy. If an abnormality is noted in either of these areas, treatment via medication is available. The effectiveness of such pharmacological treatment (with Clomid or Pergonal) is variable. It has been reported however, that pharmacological induction of ovulation is successful in 70-80% of cases (Behrman, 1975).
It must be noted that even if hormonal abnormalities can be corrected, there is no guarantee, at the present time, that these improvements will result in a pregnancy. Normalization of hormonal levels is often not enough.

The post-coital test is performed next. This test allows for evaluation of the cervical environment and the ability of the sperm to thrive in it. According to Taymor (1978), there is a significant correlation between good post-coital tests and a subsequent occurrence of pregnancy and bad post-coital tests and no pregnancy being achieved. This test also provides an indication of "immunologic factors" which are relatively poorly defined at this time but are felt to be a cause of infertility. In this context, it is thought that something in the cervical environment acts to reject the sperm as if it were a foreign invader or infectious agent. Treatment of this problem is controversial and no therapeutic modality has been shown to be unequivocally effective.

The fourth component of this evaluation requires an assessment of the uterus and the verification of tubal patency. These are accomplished by intrauterine injection of radio-opaque dye (hysterosalpingography, HSG). It is believed by some that this test can have a therapeutic effect in addition to its diagnostic usefulness. Specifically, small blockages may be removed by the force of the dye injection, thus improving patency of the tubes. If tubal obstruction is found, surgery is the treatment of
choice and reportedly carries with it a 40-50% success (pregnancy) rate.

The final test in the infertility evaluation is a laparoscopy. This is a minor surgical procedure which enables direct visualization of the pelvic organs. As a result, structural abnormalities can be identified. It is frequently indicated for the diagnosis of endometriosis (the presence of endometrial tissue outside the uterine cavity), adhesions (scar tissue due to a variety of causes) in addition to other structural abnormalities, according to Newton (1984).

Psychological Components as Causative Factors

Historically, the psychological component of infertility has been acknowledged primarily in causative terms. Thus, the earliest literature alludes to psychogenic infertility primarily to explain the inability to conceive amongst women with no clearcut pathologic basis for their problem. In the absence of a medical explanation, many authors assumed that some psychological aberrancy must be involved. One of the earliest authors who addressed this issue was Buchan in 1797. He stated "Barrenness is often the consequence of grief, sudden fear, anxiety or any of the passions which tend to obstruct the menstrual flux. When barrenness is suspected to proceed from affectations of the mind, the person ought to be kept as easy and cheerful as possible. All disagreeable objects are to be avoided and every effort taken to amuse and entertain the fancy". (p.
This statement was made by a physician at a time when there was little technology available for the evaluation of infertility. What is particularly interesting regarding that statement is that the sentiment continues to be believed today by some people.

In a classic article reviewing the psychological infertility literature from 1935-1963, Noyes and Chapnick (1964) provided an insightful critical analysis of the available information up to that time. Of 235 relevant papers initially surveyed, 75 were found to specifically discuss psychology with respect to infertility. The authors attempted to analyze objectively the quality of the reports using a standardized format. Results of their analysis indicated that this literature was of extremely poor quality in a number of areas. It was found that, while most authors favored the position that psychological factors caused infertility, only one paper explicitly stated so in its null hypothesis. Materials and methodologies primarily involved retrospectively studied case reports which were entirely devoid of statistical analysis. There were essentially no efforts made at including control groups or standardized tests. Many papers implied that because major psychic disturbances were known to cause amenorrhea and impotence, psychological involvement must also cause infertility, though the mechanisms were obscure. Finally, many papers confused the issue of psychogenic infertility by contending that treatment of psychic disturbances was of great value.
whether or not the patient became pregnant. This solution addresses a very different aspect of the infertility issue, mainly whether psychological intervention can help alleviate some of the negative sequelae associated with infertility, despite the absence of a pregnancy. It has nothing to do with the question of whether or not psychological factors may cause infertility. The reviewers generated a list of psychic variables reported in the literature as causes of infertility. These included, for example: (1) masculine-aggressive personality in women, (2) feminine-immature personality, (3) rejection (meaning that the woman doesn’t really want the pregnancy) and (4) hostile dependence on the mother. Almost invariably, these conditions were extremely poorly defined, if at all. Of particular note was the fact that 73 of the 75 articles concluded positively that infertility was related to psychogenic factors, despite the lack of appropriate supporting evidence. Only two articles (Wittkower, 1940; Hanson, 1950) reported negative findings, meaning that no causal relationship between psychological factors and infertility could be documented. In sum, none of the papers reviewed provided sufficient evidence that specific psychological factors could effect fertility.

A large number of papers written from 1950-1960 (Benedek, 1952; Mandy and Mandy, 1958; Ford, Forman, Wilson, Char, Mizon, and Scholz, 1953) dealing with psychological aspects of infertility are reflected in the prototypical comment of Fischer (1953). Without providing substantive
supporting data, he states that "Psychogenic sterility can be defined as sterility in a couple in whom no pathology or dysfunction can be demonstrated by any method available today." This, then, becomes a diagnosis made purely by a process of medical exclusion. Numerous other poorly supported (and often subsequently proven almost entirely without merit) statements generated during this time have survived intact. For example, pregnancy following psychotherapeutic intervention was and is frequently taken as evidence that a cause-effect relationship exists between psychic factors and fertility (Noyes, 1964). The problem with these analyses is that there is no time control, which is important since it is well-appreciated that the likelihood of achieving a pregnancy is proportional to the duration of time spent attempting to do so. After 1960, modern technological advances have contributed so much new information to the understanding of organic causes of infertility that psychologically caused infertility has lost favor within the medical community (Check, personal communication, 1986).

Shift in Psychological Emphasis

While the earlier psychological works related to infertility focused primarily on psychogenic causes, more recently these have addressed the emotional effects of infertility. This body of work can be categorized into three separate groupings: 1) a discussion of specific psychological variables as a result of infertility, 2)
discussion of infertility as a process ie. a stage, transition or progression theory and 3) a collection of anecdotal stories portraying a variety of experiences with infertility. Some of the earliest writings dealt with specific psychological variables and came from physicians who were treating infertility patients, usually women. They reported on what they observed during clinic visits and what patients discussed about their feelings and perceptions. Common findings included reports of emotional disequilibrium, feelings of vulnerability and loss of personal control in their lives (Leader, 1984). Other articles reported feelings of hopelessness, depression, and despair (Farrer-Meschan, 1971). More general concerns such as anger, shame, inadequacy, guilt and personal failure were also found in the literature (Menning, 1977; Rosenfeld, 1979). More observable reactions included signs of anxiety, tension, frustration, and isolation (Bresnick, 1981; Menning, 1977).

Despite the fact that infertility has long been recognized as a devastating emotional experience, only recently has it been deemed a true crisis by many in the field (Leader, 1984). For example, Kraft (1980) refers to it as a developmental crisis, Bresnick (1981) coined the phrase "crisis of infertility" and Zaslove (1978) describes it as a life event crisis.

Developmentalists have defined a crisis as a turning point that offers the opportunity for regression or growth.
Because infertility is an unanticipated crisis (unlike others which are in the back of all of our minds; i.e., the death of a loved one, etc.), most people have not developed the necessary coping mechanisms to respond to the pain and suffering that accompanies the fruitless effort to conceive and bear a child. A couple may be considered to be in crisis to the extent that their usual coping mechanisms are inadequate to respond to the impact of infertility. Rapoport (1962) emphasizes that crisis situations create problems that are perceived as threats, losses or challenges.

Psychological Variables as Responses to Infertility

More recently, research endeavors have tended to focus on the identification of specific psychological variables deemed relevant in the infertility process. This body of work is largely comprised of dissertations, although there are some independent studies in the literature. Bergin (1983) looked at self-esteem and found that it was lower in an infertile population. Other areas of research have included infertility and its impact on ones locus of control (Sklar, 1984), psychopathology and sex-role identity (Perkel, 1985; Allison, 1977; Holtz, 1983) and body image and self-esteem (Cooper, 1980). Other work has focused on reactions and perceptions of infertility in relation to adulthood, marriage and coping mechanisms (Chiappone, 1986; Davis, 1985) and on the perception of adoption related to infertility (Miall, 1985).
While these are significant contributions to the infertility literature, they evaluate specific variables which are deemed important by the authors. Before investigating specific variables, a general framework is necessary in order to ground future investigations under one common rubric. What seems to be missing in the literature is a comprehensive conceptualization of what infertility means to those so diagnosed. This general overview seems to be a necessary precursor to more detailed evaluations of specific issues. As with any new phenomenon, before relevant factors can be identified, a clear understanding of the entire field needs to be obtained. Typically, when this is accomplished it is more likely that relevant variables will be identified and they are then able to be studied further. To date, the majority of studies however address very different aspects of the infertility issue. As a result, readers are left with a confusing description of the infertility experience. The identification of specific emotional responses to the experience of infertility may not accurately portray what people feel during such a time. Rather, what is needed is an understanding of how these disparate feelings interact with one another and what the result is for infertile couples.

**Progression Theory Versus a Unique Experience of Infertility**

The second body of psychological literature related to infertility attempts to develop a time line conceptualization of the process of infertility. In
describing the process, many have gravitated toward a stage or transition theory in an attempt to better portray the entire experience. If infertility can be portrayed by a series of steps that couples or individuals pass through, this may be helpful to those in the midst of the experience in terms of validating their current concerns. Seeing that there is, in fact, a norm for this unique experience may offer the infertile couple much needed comfort and alleviate some of the fears of the unknown as well as the future. It may be reassuring to hear that they are not going 'crazy', as often discussed in RESOLVE support groups. (RESOLVE is a national organization for infertile couples which provides education, counseling and medical referrals upon request.) This seems to be especially true for women but of equal concern to those husbands who are confused by and concerned about their wives' psychological well-being (P. F. Schreiber, personal communication, April 2, 1985). It is also possible that understanding where a patient is emotionally would greatly enhance the medical community's ability to meet the needs of their patients. If some individuals or couples are in more serious need of professional psychological services, this may become more obvious if those providing treatment had an idea of what to look for. Stage or transition theory could be extremely valuable if, in fact, it could be documented.

In this regard, developmental theories have addressed the issue of infertility. For example, from an Eriksonian
perspective, the failure to reproduce could have a significant effect on the generativity versus stagnation stage of development (Erikson, 1963). It is unclear on what basis, except theoretical, these claims are made. Since this phenomenon is relatively new, one questions if anyone who is infertile and who has reached the generativity stage of development has been studied or researched regarding their views and feelings. Kraft (1980), however, supports this view as he states that the entire developmental process is a preparation for parenthood. This, again, seems to be a purely theoretical perspective.

In support of a stage theory, Berk and Shapiro (1984) state that 'emotional responses to infertility tend to follow a fairly predictable pattern for most couples'(p.160). The major components include disbelief and denial, helplessness, anger, guilt and finally depression. According to their view, the initial disbelief allows couples to slowly integrate new information and to postpone treatment decisions. Helplessness reflects a loss of control and is projected as anger toward spouse and the medical profession. Finally, the last component of this is self-recrimination and guilt leading to feelings of depression. Resolution, according to Berk and Shapiro, depends on ego strength, the couple's ability and experience in handling crises and the psychological importance of having one's own biological offspring. While they describe particular factors and allude to some type of progression,
they do not clearly portray a continuum on which couples experience infertility. Rather, they acknowledge specific emotional responses to a traumatic event. It is unclear, however, that there is any research to support the theory of an ordered emotional progression through the trauma of infertility. Furthermore, there is a lack of any type of analysis of social context affecting those involved in the treatment of infertility.

One of the most enlightening discussions of stage or transition theory related to infertility was presented by Shapiro (1982). Essentially, this involved an adaptation of Kubler-Ross' theory of death and dying to the experience of infertility. She described infertility as a crisis which involves a mourning process. Initially couples respond to the news with denial, shock and disbelief. Anger follows denial. People question "Why me?" and become angry at themselves and the medical community as well as others who are fertile. During the third phase, couples grieve. This leads the to the final stage of the mourning process which eventuates in acceptance. Shapiro states that this involves the 'laying to rest of the hope for biological children and enables them to look ahead at options. Acceptance suggests that one is no longer preoccupied with the earlier stages of the mourning process and is instead, ready to move ahead with life decisions and new directions' (p. 87). This may be the least applicable stage for the infertility experience. While acceptance is clearly the goal for all infertile
couples, it is unclear how acceptance is experienced by them. From my own experience, it seems that some couples may reach total acceptance and feel completely resolved with their particular situation based on the choices that they make. Others may never be completely free from the issue. There seems to be much variability at this point. Some individuals seem to be able to explore options and make decisions, while others experience great difficulty and need much more time. Perhaps for the infertile couple, the stage of acceptance is somewhat different. It may involve just 'accepting the reality of their situation'. It seems that people need to get comfortable with their particular situation after some of their anger has dissipated. The stage of acceptance may offer them a time to return to some degree of normalcy or develop a way to lead their lives in light of their infertility. Just getting comfortable with the fact of infertility as part of one's life takes time. Being able to see yourself as part of an infertile couple---being able to talk to others about it without experiencing very negative feelings---is something that may be a hallmark of the level of acceptance one has attained.

While these stages of Kubler-Ross may be useful in regard to infertility, they are very general and can be readily applied to any emotional trauma. Additionally, while some similarities may exist between the experiences of death and dying and infertility, there also seem to be major differences which differentiate the two phenomena. For
example, both are traumatic events and emotionally devastating. The evolution of 'time', however, is one factor which seems to distinguish death from infertility. With death, 'time' tends to be a positive factor. Time allows some distance to be created between the emotional trauma associated with death and the actual event. This space enables people to develop a more objective perspective. Memories of the trauma fade and often resolution/acceptance of the situation evolves. While many of the same emotions may be involved in the experience of infertility (denial, anger, etc.), the progression of time tends to heighten the trauma. Time complicates and emphasizes the reality of the situation, forcing people to confront this difficulty on a continuous basis.

While these stages may describe some of the emotions felt by couples facing a devastating trauma, infertility presents the couple with some unique issues which may compound their emotional reactions. For example, the decision-making process may be very difficult in light of the couple's recent emotional highs and lows in response to their infertility. Obviously, any choices made during this time would have life-long ramifications on the couple's future because these decisions would be largely focused on how the couples have decided to build their family, remain childless or generally, lead their lives. Infertility, unlike other traumas, affects all aspects of one's and a couple's being -- nothing is excluded. It changes the lives
of the individuals and the couple as a unit forever because it is not a single event that they are forced to deal with but rather, it is a path that their lives have taken. Everything they perceive and contemplate will be slanted by the reality of their infertility. The fact is that infertility presents a change in how one views oneself, the marriage, his/her partner, their dreams, career choices and decisions, communication patterns and their perspective of a family. In addition, pressures from family and peers as well as significant financial strain may also add to the already overwhelming burden felt by those individuals faced with infertility. How these factors impact on the experience of infertility may not be obvious to the fertile world and as such deserves further exploration and comment.

Anecdotal Reports

The third body of psychological literature is comprised of a variety of anecdotal stories. Often these are written by women who have gone through the experience and have somehow resolved their situation. These tend to be subjective descriptions of personal journeys. They are rich in emotion, content and idiosyncratic circumstance. As an example, in one such book entitled 'With Child'(1986), Susan Viguers described her and her husband’s experience with infertility that ends with the successful completion of their family by adoption. This involved her many experiences in the medical sphere which included various tests, medications, conceptions and miscarriages, in
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addition to the entire adoption process. She details the emotional highs and the lows that both she and her husband felt. Her book is an excellent illustration of these types of contributions to the literature. They are heart warming, and do convey a true sense of what the infertility experience may be like for some couples. The major concern with this type of work, however, is that they portray one couple's experience in great detail. However accurately described, it is so heavily weighted with unique, personal content as to be of questionable applicability to the infertile population in general. Often these anecdotes end on a positive note which in no way reflects the experience of many other infertile couples. The positive outcome becomes the most appealing to the readership not dealing with infertility. The fact is that these books are valuable in and of themselves but they do not address the more global task of detailing the experience of infertility rather they tell the tale of one woman. Despite these contributions, there remains a need for a more research oriented undertaking to more objectively delineate the process of infertility. The combination of well documented research categorizing infertility and these more personal stories would provide a rich understanding for all.

Differential Gender Effects

Although writings have recently acknowledged, to some degree, that emotional effects of such an experience do affect the 'the couple,' few studies have differentiated
male and female perceptions of and reactions to infertility. The literature, therefore, implies that both people experience the same emotions and that there are a few general emotions which are associated with infertility. Less often have authors considered the possibility that infertility may differentially affect men and women or furthermore that these differences could contribute more emotional stress to an already overwhelming situation just because what is emotionally devastating for one partner may not be as relevant for the other.

More recently, some work has been done on the possible ways that infertility may affect men differently than women. Bresnick (1981) performed a two part study where one aspect focused on the degree of emotional upheaval experienced by couples and the second addressed specific spousal concerns such as communication, sexual adjustment and career attitudes. She found that women experienced more negative emotional upset specifically related to infertility as a phenomenon and the reality that effective treatment may not be available. In contrast, men reported experiencing most difficulty in the area of communication. Bresnick also developed a counseling program to deal with these issues and reported that women benefited more. It was hypothesized that women may be more psychologically minded and more open to such an intervention, therefore they may have been more responsive to this approach than males. While this study is interesting, the major limitation is that it is primarily

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descriptive. It does not address the potential impact on both the couple as a unit and on the particular individuals involved. This would seem to be an area of major concern and thus deserves further study.

Along the same lines, Karow (1982) found that when a couple is faced with infertility, women tend to discuss the problem more outside the marital unit, whereas men tend to not want to discuss the problem with anyone in or outside the marital unit. Additionally, from the start, women are more able to entertain the possibility of an infertility problem and, as such, are more prone to initiate medical evaluation. In contrast, men seem to avoid acknowledging this as a possibility for a much longer time. While these findings are notable, the ramifications of such differences deserve further study. What impact could these have on a couple's relationship and what additional burdens may arise from such differences?

Kraft (1980) also discussed some uniquely male responses to the infertility crisis. He stated that most men experienced infertility as a blow to their masculinity, to their feelings of virility and to their self-image. As a result of these feelings, men have more difficulty in discussing the infertility situation and their feelings about it. This supports Karow's work.

Owens and Read (1984) studied differences in male and female attitudes toward the infertility evaluation process in relation to where the etiology lay. They found that when
female problems were documented, rather than male problems, both partners reported a more positive experience with infertility and its evaluation. The physicians were viewed as more empathic and informative. This was in marked contrast to the situation where a male etiology was established. During those instances, men and women tended to view the entire infertility work-up as unsatisfactory, in general. His explanation for such findings was that even though a male factor could be specified, this, in general, led to no meaningful therapeutic options. Unfortunately no data are provided to support these statements and this contention is in direct contrast to other available information. (Check, 1986). Regardless, it appears at least possible that there are other explanations (e.g. that there may be an inherently greater psychological insult related to male infertility, that men may deal with the trauma of their own infertility by withdrawing and therefore limiting therapeutic discussions between themselves and their spouses, that husbands deal with this information primarily through denial and thus preclude further discussion) for such findings, none of which were acknowledged by the authors.

Regarding where the infertility etiology lies, Berk and Shapiro (1984) wrote that the infertile partner reported feeling guilty, worthless and fearful of abandonment. Divorce was sometimes even offered to the other, so he/she could find a fertile partner. Others have described the
fertile partner as blaming the infertile one for their difficulties (Notman and Nadelson, 1983).

Very recently, research has focused more on the couple as a unit, but to date the scope has been fairly narrow. There have been essentially two areas of concentration—marriage and sexuality. Berk and Shapiro (1984) reported that some couples describe an enhanced level of communication as a direct result of dealing with the infertility issue. They feel that dealing with this issue leads to a 'stronger marital bond'. More open patterns of communication tend to increase feelings of empathy, caring and supportiveness toward one another. But, by contrast, the majority of couples report an increase in strain on the relationship primarily because of the tremendous feelings of pain and disappointment. While this may be so, the authors do not report where this information was obtained nor from whom. Kraft (1980) went so far as to say that many of these marriages do not survive. He, however, does not provide any supporting statistics for such claims. As a result, it is unclear how accurate these statements really are.

In terms of sexuality, couples report many changes in response to infertility. Typically, they report an increase in stress and a decrease in interest as well as spontaneity, with therapy-dictated sex on demand being substituted (Berk and Shapiro, 1984). Sexual activity is reduced to a mechanical act without any pretense at privacy (Menning, 1979). Frustration is increased as is resentment of the
spouse, the problem and the medical community which is attempting to rectify the situation.

Summary

Despite recent recognition that the psychological aspects of infertility are important areas which need to be addressed by physicians and others involved in the treatment of such patients, patients report that their needs are not being adequately met (Snowden, 1983). One hypothesis for this is that a sufficiently detailed understanding of what issues are involved and what feelings arise has not yet been completed. Without a clear understanding of the infertility process viewed from the patients perspective, physicians and others involved in the treatment of patients cannot be expected to adequately address these important areas.

In attempting to address these issues, data collection must be extensive in order to ensure all issues have been adequately assessed. Currently available standardized research tools are not adequate for these purposes. The experience and process of infertility involves issues and perspectives not readily obvious to the fertile world. It is therefore incumbent on those involved in the study of infertility to carefully identify and clearly communicate the issues and their underlying meanings to those unaffected as well as those working with infertile couples.
Current Research

Because infertility elicits such emotional reactions, there has been some difficulty quantifying and qualifying factors and variables. In light of these concerns, it seemed that the optimal way to explore this relatively new phenomenon was to use both a closed and open-ended format.

The closed-ended approach incorporated ideas and findings from previous literature and attempted to verify their accuracy, relevance and importance in relation to the overall experience of infertility. This was accomplished primarily through the development of a questionnaire addressing the key issues as determined from the literature and patient input. The questionnaire was comprised of seven sections. The first section requested demographic information including age, income, religion, length of time in treatment, etc. Sections two through five relied on a Likert scale to respond to statements describing a number of relevant issues. These were categorized as the following: stress, emotional reactions, psychological considerations, social issues and current feelings. The final section offered respondents a chance to discuss any issues they felt were relevant and either not addressed within the questionnaire or warranted further discussion. An additional section, which was optional, was at the end of the questionnaire. It requested voluntary participation in the second aspect of this research endeavor. More specifically, respondents were asked if they, as individuals
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and couples, would be willing to be interviewed regarding their infertility. The questionnaire was administered to 100 couples currently involved in the treatment of infertility.

In contrast, the open-ended component was comprised of interviews of 10 self-selected couples. Interviews were structured in the following manner. Initially one individual, either female or male, was interviewed. The individuals determined for themselves who would be first. Following that interview, the other partner was interviewed. Each interview lasted approximately one hour and addressed the same issues; i.e., the same questions and format were used for both. During the third and last hour, both partners were interviewed together regarding their infertility experience. This approach enabled immediate follow-up of newly identified issues as they appeared. Additionally, this approach also allowed an in-depth exploration of avenues which became obvious only through lengthy discussions with infertile couples who were trying to convey their feelings and perspectives regarding infertility. As such, I undertook an exploratory research study aimed at comprehensively describing what the psychological impact of infertility encompassed. Three distinct areas were addressed. The first was the role that medical intervention played in contributing to the overall stress of infertility. Secondly, the concept of well-defined stages versus unique experiencing of the infertility
process was examined. In this context, the interaction between one’s goals, values and relationships was evaluated. Finally, particular attention was also paid to the differential experience of males and females in facing the infertility issue. Only with these pieces could a truly comprehensive conceptualization of the experience of infertility be documented.

Research Question

From a self-selected (i.e., voluntary) group of couples which had experienced infertility within the prior twelve months, the following questions were addressed.

(1) What is the psychological impact of the medical treatment of infertility? More specifically, what are the relevant psychological variables and how are they perceived and experienced by infertile couples and individuals?

(2) What is the relationship between individual circumstances (i.e., background, education, occupation, etc.) and both the individual’s and the couple’s experience of infertility?

(3) Is infertility experienced differentially by men and women?

(4) Does the absence of a definitive diagnosis distinguish couples emotionally from those who have a clear diagnosis?

(5) What is the relationship between the experience of infertility and one’s emotional reaction to infertility? More specifically, can the infertility experience be
approached as an emotional continuum or is this experience so unique as to preclude such generalizations?
CHAPTER III

Methods

Subjects

Subjects were derived from the population of infertile couples ranging in age from 22 to 45 years, located within the Philadelphia, Pennsylvania and Indianapolis, Indiana areas. Two major referral sources were used. The first was those patients involved in medical evaluation and treatment with infertility specialists. The second source was comprised of attendees at monthly RESOLVE meetings. RESOLVE is an organization which offers a variety of services to infertile individuals and/or couples, including counseling, medical referrals, and educational programs covering many topics related to infertility. Participation was on a purely volunteer basis. It was hoped these groups would provide both a representative cross-section of infertile couples. An attempt was made to obtain approximately equal numbers of subjects from medical treatment alone, concurrent medical treatment and RESOLVE involvement, and RESOLVE involvement alone. As it turned out this was not possible. My final sample consisted of primarily people involved in medical treatment without any Resolve affiliation. In fact, 69% of my sample had never been to a Resolve meeting. Twenty-nine percent of this sample were concurrently involved in both medical treatment and Resolve and two percent of the sample 2% had terminated medical treatment and were solely involved in Resolve meetings.
Additionally, an attempt was made to obtain subjects at varying points along the infertility treatment continuum, i.e. at the beginning of medical evaluation, at the conclusion of medical evaluation, during medical treatment, at or towards the end of such treatment and following termination of medical treatment. It was hoped that this cross-section of subjects would provide a broad-based perspective on the infertility experience. What became evident during this research endeavor, however, was that the length of treatment is only one of many relevant variables. Because of the extreme variability among physician’s approaches to treatment as well as widely differing patient problems, length of treatment per se becomes less meaningful. Rather it assumes the role of an interesting demographic.

This study was conducted in both the Philadelphia and the Indianapolis metropolitan areas for two reasons. First, these two cities have major concentrations of medical expertise and therefore had sufficient numbers of infertility experts to make access to their care straightforward. In addition, both Philadelphia and Indianapolis were chosen because during the time of data collection, these were this investigator’s places of residence. Regarding the investigator, it should be noted that she was personally involved with the medical treatment of infertility for four years and is currently expecting her third child. The first was adopted and the second and third
were conceived by Gamete Intra-Fallopian Transfer (GIFT), an advanced medical approach to infertility.

**Design and Procedure**

This study was exploratory, in the sense that a relatively new phenomenon was being investigated. The actual research approach, however, involved a semi-structured informational gathering vehicle. The goal was to identify relevant issues and attempt to gain an understanding of their psychological impact on couples as well as the individuals that comprise these couples. The study was divided into two parts. Part one involved the distribution of questionnaires to voluntary subjects. Part two was comprised of follow-up interviews with ten couples, five from Philadelphia and five from Indianapolis. Criteria for selecting the couples who were interviewed was based solely on both the woman and man’s willingness to participate. Geographic location was a consideration only to the extent that equal representation from both Philadelphia and Indianapolis was obtained. The interviews attempted to describe in greater depth relevant issues, areas of disparate responses, and recurrent themes or styles identified by the questionnaire. In this way, the more common emotional responses to infertility in addition to those unique ones were documented and evaluated.

**Identification and Selection of Respondents**

At two monthly RESOLVE meetings, the investigator briefly discussed the need for infertility research,
particularly as it applied to the psychological aspects of this problem. Following that, volunteers were solicited to answer a questionnaire, which required approximately 20 minutes to complete. Respondents were supplied with addressed, stamped envelopes for returning completed questionnaires, if they were unable to do so at the conclusion of the meeting.

For those subjects derived from physician's offices, questionnaire distribution was handled differently. Specifically, infertility specialists in both the Philadelphia and Indianapolis areas were approached regarding participation of their patients, on a voluntary basis, in the study. A letter of introduction requesting patient participation was included as part of the routine clinic appointment materials. See Appendix A for a copy of the letter of introduction. Patients were asked to complete the questionnaire while they waited to see their physician. In the investigator's experience, this would typically provide more than ample time for this effort. If that was not possible, they were encouraged to return the completed questionnaire by mail, using an attached, addressed, stamped envelope. At the next clinic visit, nurses reminded patients who had not returned completed questionnaires to do so at their earliest convenience.

Two hundred questionnaires were completed and returned. Initially, 800 questionnaires were distributed. This represents a 25% overall return rate from physician's
offices. Follow-up interviews were conducted with 10 couples. Interviewees were derived from a group of respondents in which both the woman and man had agreed to be interviewed. It should be noted that the questionnaire was anonymous for all except those willing to be interviewed. This latter group identified themselves by listing their first names and telephone numbers on the last page of the questionnaire. To maintain maximal anonymity, no information regarding last names was solicited.

Following the questionnaire distribution period, couples and individuals who had volunteered were approached regarding interviews. The total interview session time was approximately three hours: one hour for each individual member of the couple and one hour for the couple together. Information obtained during the individual interviews was treated confidentially. All sessions were audio-taped after permission was obtained. The location of the interviews was based on the wishes of the interviewees.

**Instruments**

The questionnaire used in this study was developed by the investigator specifically for the purposes of this study. See Appendix B for a complete copy of the questionnaire.

During October, 1986, a variation of the final questionnaire was piloted. Respondents were infertile couples who had been participants, with the investigator, in a support group sponsored by RESOLVE, during the winter
months of 1986 (January through March). A response rate of 40% was obtained (Total N=10; 4 were completed and returned over a one month time period). The following themes were noted: 1) Unanimous agreement was described regarding the presence of depression in response to finding out that an infertility problem existed. 2) All reported feelings of a loss of control over their lives initially, with gradual improvement in this area over time. 3) Holidays and family gatherings were acknowledged to be extremely stressful events. 4) A withdrawal from friends and a lack of understanding from family were also commonly identified as contributing to the overall stress inherent in dealing with infertility. 5) Some discussed regret at not exploring options for family building at an earlier time. 6) Interestingly, all who responded reported stronger marriages as a result of having to deal with the heavy emotional burden of infertility as a couple. In general, women tended to report more negative and more intense emotional reactions to the issue of infertility. Men reported some difficulty dealing with their wife’s strong emotional reactions but gradually, over time, were able to better understand their wife’s perspectives and offer more support to them.

The final questionnaire was developed from pilot questionnaire data, issues described in the literature and my own personal experience. Briefly, it addressed many issues facing infertile couples and attempted to gain an understanding of how these issues psychologically impact on
both the couples as units and on the individuals comprising these couples.

The questionnaire was comprised of four sections. The first section asked demographic information; the second assessed specific psychological variables deemed relevant to the experience of infertility; the third focused on the validity of a stage or progression theory related to infertility and the fourth and final section requested personalized descriptions of the individual's/couple's experience. A brief description of each section follows.

The demographic section contained items such as age, occupation, length of time the couple had been trying to conceive, what procedures had been completed and whether a definitive had been made.

The second section was comprised of questions related to eight factors which measured relevant psychological variables. The first factor measured levels of stressfulness, while the remaining seven factors were measured in terms of degree of agreement or disagreement, i.e., strongly agree, moderately agree, moderately disagree, strongly disagree.

The eight factors included the following: 1) Stress, which was measured in terms of degree from 'not' stressful to 'extremely' stressful. Representative statements included: "Interacting with friends who have children is ..." and "Responding to questions about why we do not have children is ..." 2) Depression: Representative statements
included: "At times I find myself crying for no apparent reason"; "I feel my life is ruined because of our infertility". 3) **Locus of Control**: Representative statements included: "I feel like my whole life is dictated by others"; "I do not hesitate to question our physician when I do not understand what is to be done or why".

4) **Self-Concept**: Representative statements included: "I feel inadequate much of the time"; "Despite infertility, I feel good about myself". 5) **Mood Swings**: Representative statements included: "One minute I am happy and the next moment I am very sad"; "My emotional fluctuations are normal". 6) **Marital Satisfaction**: Representative statements included: "Our sex life was not affected by our infertility"; "I feel closer to my spouse because we have had to deal with infertility". 7) **Support**: Representative statements included: "Our physician is meeting our needs adequately"; "Only people who have been through this can understand how I feel". 8) **Anxiety**: "As a result of our infertility, I am more critical of others"; "I am tense much more of the time since I have been dealing with infertility".

Using the same type of Likert measurement scale; i.e., strongly disagree, moderately disagree, moderately agree, strongly agree, the third section of the questionnaire assessed the presence or absence of psychological stages hypothesized in the literature and through my own experience to be relevant. These proposed stages included: shock,
denial, anger, depression, acceptance, rejuvenation and accommodation/resolution. Included in the questionnaire were four items assessing each of these areas.

The fourth section asked respondents to provide personalized descriptions of particular aspects of their infertility experience. Examples included questions such as: "Of the alternatives for building a family that you and your spouse have discussed, on which do you agree and on which do you disagree?"; "When you tell people about your infertility what do you say?".

The questionnaire was comprised of both open-ended and closed-ended questions in an attempt to derive as much information as possible. The obvious advantage of closed-ended questions was that the answers were simple to record and analyze. Additionally, this type of question provided responses which facilitated comparability. The major limitation was that they circumscribed the area under investigation and thus minimized the likelihood of unique responses. The inclusion of open-ended questions was deemed necessary for a number of reasons. Since this was an exploratory study of personal experience, respondents needed to be free to express their own ideas and opinions. The use of open-ended questions was especially useful in that they allowed the researcher to probe for particularly interesting and relevant responses, thus allowing the amplification and/or clarification of answers. This approach provided a much richer and more valuable source of information. Open-
ended questions were useful in the development of relevant hypotheses and allowed an understanding of how one's ideas and feelings evolved. Additionally, they provided a strong basis for follow-up interviews. It must be acknowledged, however, that response time was longer and the responses were more difficult to code and analyze. Another inherent limitation of the open-ended question was the possibility for the accumulation of highly divergent responses and themes. To some extent this did happen. It was, nonetheless, highly informative and added additional perspective.

Data Analysis

A variety of statistical measures were employed to assess both quantitative and qualitative aspects of the questionnaire. In order to clarify the statistical analyses appropriate for the different questionnaire responses, each question will be presented here followed by a brief discussion and justification of the analyses utilized.

Question 1

The first question is "What is the psychological impact of the medical treatment of infertility? More specifically, what are the relevant psychological variables and how are they perceived and experienced by infertile couples and individuals?" In order to determine the relevant psychological variables impacting on the infertile people, a Factor Analysis of the items comprising the questionnaire was performed. Initially the questionnaire was designed to
collect data from separate but sometimes overlapping emotional areas affecting infertile couples. Five psychological components of the infertility experience were identified. They included the following: degree of stressfulness, emotional reactions, psychological considerations, social issues, and current feelings. The specific items comprising these variables were derived from the infertility literature and interviews with infertility patients. Initially a Factor Analysis was performed using all of the items in the questionnaire. It was hoped that the resultant factors would prove to be the most relevant psychological aspects of the infertility experience. What evolved, however, was quite different. Essentially one large factor became evident which depicted a global negative entity. While it can be acknowledged that much of the infertility experience is negative, one large factor seemed to mask the complexity of the emotional aspect of infertility. It therefore seemed likely that more discrete psychological components would comprise this infertility experience. This idea was supported by the current literature as well as numerous interviews with infertile patients. Ultimately, then, each of the original five psychological categories was factor analyzed. It was anticipated that with each analysis, the identification of the most relevant items from each category would be possible and assurance that those psychological variables were
accurate in their description of the infertility experience would be attained.

It should be noted at the outset that two factor analyses were intended, one using only the responses of females and the second using only the responses of males. I had hoped to be able to describe gender differences and elaborate on a new area of importance related to the infertility experience. Only after the data collection and some preliminary analyses did it become evident that this would not be possible. This was primarily due to the fact that the sample size was inadequate to provide appropriate power. The results of any analyses would not have been reliable or reproducible in light of the ratio of questionnaire items to male and female sample sizes. In order to get accurate results one would need to have sampled ten subjects for each item on the questionnaire. My categories (ie Stress, Emotional, Psychological, Social and Current feelings ) each had approximately 20-25 items. I therefore would have needed approximately 200-250 females and an equal number of males subjects in order to obtain reliable results. My sample consisted of only 100 women and 100 men. I, therefore, was unable to statistically analyze female and male differences.

Alpha coefficients, measuring the internal consistency of items within the factors, as well as eigen values, describing the amount of variance accounted for by each factor, were performed. They are presented and discussed in
The measures section which follows a discussion of question 1. The intercorrelations among the demographic variables will be detailed more clearly at the end of question 2. Additionally, it was surmised that there may have been some overlapping relationship among the demographics and some items on the questionnaire. In order to determine any such potentially confounding relationship, a correlation analysis between the demographic variables and all of the items on the questionnaire was performed.

Question 2

The second question posed by this research asks "How do individual circumstances, including region, gender, education, religion and presence of previous children, influence an individual's/couple's experience of infertility? This was statistically evaluated by a series of Analyses of Variance. More specifically, each demographic variable was assessed with respect to each of the twelve factors derived through the Factor Analysis. It should be noted, however, that some limitations were evident. Specifically, the age range was so close for all of the respondents that it was impossible to divide them into categories. This prevented an analysis of different age groups with respect to the twelve factors comprising the psychological experience of infertility. Similarly, the fact that 99% of respondents were White limited any analysis of race and the emotional aspect of the infertility experience.
Question 3

Question 3 asks "Are there any gender differences regarding the psychological experience of infertility?" The question of gender differences was addressed both quantitatively through statistical analyses of the questionnaire data and qualitatively using content analysis of the data obtained during the interviews. The quantitative approach involved primarily two types of statistical analyses. First, an Analysis of Variance was performed examining gender and each of the psychological factors. Second, scores for each item on the questionnaire were obtained according to sex. More specifically, for each item, male and female scores were compared. This in-depth evaluation enabled a clearer picture of any gender differences which may have been muted by an evaluation of gender differences among the categories.

Gender differences were addressed in the interviews in order to flesh out the quantitative findings. During the interviews each respondent was asked about his or her personal view regarding a particular issue as well as their view of the opposite sex's perspective on that same issue.

Question 4

Question 4 asked, "Does the presence of a definitive diagnosis distinguish couples emotionally from those without a clear diagnosis?" Originally I had planned to perform T tests comparing those people with a diagnosis to those without in an attempt to identify the potential impact a
diagnosis may have on one's psychological well-being. This information was more difficult to obtain than initially anticipated. The questionnaire asked respondents, both male and female, whether they as individuals had carried a specific diagnosis or not. It was hoped that obtaining this type of information would provide a demographic description of those people, both men and women, who carried a diagnosis and those who did not. Following that, comparisons would be made of their responses on the other items on the questionnaire. Hopefully this would offer a multitude of invaluable information.

Initially results appeared promising. Fifty-three percent of respondents stated they did not have a diagnosis while 47% stated that they did have a diagnosis. Upon closer evaluation, however, it became clear that the actual percentage of males and females presented a serious confounding variable. Of all those who reported having diagnoses (N=106), only 21.5% (N=23) were males and the remaining 78.5% (N=83) were women. This means that of the 47% who reported not have diagnoses, 82% (N=77) were males and only 18% (N=17) were females. This significantly uneven distribution of men and women added the issue of gender to an already confusing issue and essentially prevented any meaningful statistical analyses from being able to be performed.

Another related issue also became apparent which further complicated the answering of this question. The
wide variability, degree of severity and availability of treatments presented the researcher with many more confounding variables than originally anticipated. What became increasingly evident was that the experience of infertility cannot be described unilaterally. There tends to be much overlapping information which makes it impossible to glean a clean, accurate picture of the experience of infertility. One of the limitations lay with the basic difference in the availability of effective treatment options for both men and women. Despite the fact that there is essentially an even distribution of female and male etiologies related to infertility, women have more and better treatment options available to them. This is due primarily to the fact that the female reproductive system is simpler and easier to evaluate and impact on. Because the development of an egg takes only 10 days and the development of sperm takes 75 days, the focus of research has been on the egg development and possible ways to impact on infertility by addressing the female reproductive system. It is just easier to evaluate something that occurs more frequently. If the man is found to have a medical problem; i.e., a diagnosis, there are often fewer options available which can effectively rectify the problem. As a result, in addition to dealing with the issue of infertility, mens' situations are compounded by the lack of options. The bleak prospects of their quest for effectively treating their infertility may pose a whole different set of
issues for them to wrestle with. Therefore, the actual psychological impact of a diagnosis may be very difficult to determine in concert with other emotionally charged variables.

One final complication warrants comment at this point. In a study such as this, the individual data are further confounded by the fact that these individuals comprise couple units. If one individual within the couple carries a diagnosis then it is the couple as a unit who must deal with the issue of infertility, despite the fact that only one person may carry a primary diagnosis. What becomes critically important then is whether the couple as a unit has a diagnosis or not. In an attempt to further evaluate the impact a diagnosis may have on couples as units, scores for both the male and female of one couple were combined together for each of the factors. It was hoped that by merging this information together a picture could be obtained depicting something about how a couple may react to carrying or not carrying an infertility diagnosis. Upon closer evaluation, however, it became evident that the initial apparent even breakdown was in fact not so. When individuals were combined with their respective mates, the statistics changed dramatically. In 83% of couples one or both of the individuals had a diagnosis. Only 17% of couples had no diagnosis. This wide disparity prevented any statistical evaluation from being performed as the sizes were too uneven to make any valid comparisons.
In summary, it would seem then that who and what the diagnosis is, in addition to how many diagnoses are present, may have an impact on how the people as individuals as well as part of a couple may feel about their infertility. As a result, they may face different issues which are raised directly as a result of their specific diagnosis, their sex and the resultant treatment options available to them. Because of the difficulty posed in answering this question, this particular area was addressed with each of the people interviewed. The particulars of this experience were discussed and documented during interviews with the couples. This information is presented in the results section also.

**Question 5**

The fifth research question was, "Can the infertility experience be approached as an emotional continuum or is this experience so unique as to preclude such generalizations?" Initially I had hoped to be able to quantify individual responses regarding where they were emotionally. Numerous attempts at quantifying the data were unsuccessful. The fact that each couple's particular situation is so unique made any attempts at quantification futile. For example, some couples who had been in treatment for five years were just beginning to contemplate more aggressive treatments such as IVF, while others who had been in treatment for a relatively short period of time; i.e., one and a half years were already pursuing aggressive treatments or alternatives such as adoption. It appeared
that some individuals/couples could or wanted to move at a much faster pace and that others needed to move much more slowly. This is only one example where individual circumstances impeded the quantification issue. Ultimately, issues regarding decision-making and progression through the infertility experience were addressed predominantly in the interview setting and to a much lesser degree in the questionnaire. Because of the complexity of such a question and the array of confounding variables, this issue was pursued during intensive interviews with ten couples.

In order to minimize the individual’s influence on their partner, questions concerning this area were posed to each partner in the absence of the other. Questions about this aspect were posed in as open-ended a way as possible. Because of the lack of cues given to respondents, however, sometimes responses were not directly related to the question, thus, necessitating more precise framing on behalf of the interviewer. This may have influenced the responses to some degree, but given the open-ended nature of the questions, it is hoped that minimal bias was imposed. Valuable information was obtained by the inclusion of such questions. Of particular note is the fact that after each person responded, regardless of their answer, questions about the opposing viewpoint were asked. Interestingly, not uncommonly the individual could cite examples and a rationale for choosing that answer, despite the fact that
they had chosen the opposing view. This may reflect the ambivalence which permeates this entire area.

**Interviews**

Questionnaire responses were amplified through the use of interviews, which provide an additional rich source of data. Using content analysis, an attempt was made to identify the presence or absence of generalizable themes to various aspects of the experience of infertility. Particular attention was focused on three specific areas. First, whether there were any themes relevant to gender differences was addressed in question 3. Secondly, whether specific and progressive stages could be identified through the experience of infertile individuals and couples was discussed in question 5. Finally, the third area assessing the presence or absence of generalizable themes was entitled "Additional Areas of Importance Identified by Respondents", which follows question 5 in the Results section. It must be acknowledged that this process primarily relied on self-report and as such is subject to the respondents' poor memory and/or their desire to withhold information.
CHAPTER IV

Results

In this section I will describe the demographics of the sample used in this research as well as addressing the five questions of my research. One additional section entitled "Additional Areas of Importance Identified by Respondents" follows the results of the fifth research question. This section evolved from data obtained during this study and is deemed important and relevant to the overall understanding of infertility and its emotional impact. The demographics will be descriptive in nature, while the first three questions will be analyzed statistically. The fourth, fifth and final sections will be qualitatively approached. The results will be presented in five discrete but integrated sections.

Demographics

The questionnaire was designed so that on the first page, responses included age, sex, occupation, income, ethnicity, religion, education, medical history and insurance coverage. Following the collection of these data, frequency analyses were performed and the results presented in frequency tables. Because the sample was derived from two distinct regions of the country, the East and the Midwest, T-tests were performed on the collected demographic data to determine if there were any statistically significant differences between regions. No significant differences were noted on any of the demographic
information. Thus the two samples were combined into one sample, with a total size of 200.

A total of 104 envelopes were returned. Of these 100 contained completed questionnaires from both partners of the couple. The remaining four envelopes contained only one completed questionnaire, three by women only and one by a man. These questionnaires were not usable because only one of the partners completed the questionnaire and both partners were requested to do so.

The age range for the sample was 24 to 45 years of age with the median age being 32 years old. Fifty percent of the subjects ranged between 30 and 36 years of age. A more detailed display of the age ranges can be seen on Table 1.

Table 1

<table>
<thead>
<tr>
<th>Age</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>24-29</td>
<td>36</td>
<td>18</td>
</tr>
<tr>
<td>30-34</td>
<td>101</td>
<td>51</td>
</tr>
<tr>
<td>35-39</td>
<td>47</td>
<td>24</td>
</tr>
<tr>
<td>40-45</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>200</td>
<td>100</td>
</tr>
</tbody>
</table>
Total household income ranged from below 9,999 to above 160,000, with the median range being 30-59,999. Seventy-two percent of respondents reported incomes between 20-69,999. Table 2 illustrates the income levels in terms of both frequency and percentage.

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-19,999</td>
<td>6.5</td>
<td>6.5</td>
</tr>
<tr>
<td>20-29,999</td>
<td>17.5</td>
<td>17.5</td>
</tr>
<tr>
<td>30-39,999</td>
<td>19.5</td>
<td>19.5</td>
</tr>
<tr>
<td>40-49,999</td>
<td>18.0</td>
<td>18.0</td>
</tr>
<tr>
<td>50-59,999</td>
<td>11.5</td>
<td>11.5</td>
</tr>
<tr>
<td>60-69,999</td>
<td>6.0</td>
<td>6.0</td>
</tr>
<tr>
<td>70-79,999</td>
<td>9.5</td>
<td>9.5</td>
</tr>
<tr>
<td>80-89,999</td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>90-99,999</td>
<td>4.0</td>
<td>4.0</td>
</tr>
<tr>
<td>100-119,999</td>
<td>2.0</td>
<td>2.0</td>
</tr>
<tr>
<td>120-139,999</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>over 140,000</td>
<td>1.5</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Cultural identity was predominantly Caucasian (98%). One percent of the respondents were Black and 0.5% described themselves as other. This is displayed in Table 3.

Table 3
Cultural Identity of Respondents

<table>
<thead>
<tr>
<th>Cultural Identity</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>197</td>
<td>98.5</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
<td>1.0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0.5</td>
</tr>
</tbody>
</table>

In terms of religion, Table 4 details the cross-section.

Table 4
Religion of Respondents

<table>
<thead>
<tr>
<th>Religion</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roman Catholic</td>
<td>70</td>
<td>35.4</td>
</tr>
<tr>
<td>Protestant</td>
<td>80</td>
<td>40.4</td>
</tr>
<tr>
<td>Jewish</td>
<td>22</td>
<td>11.1</td>
</tr>
<tr>
<td>Other</td>
<td>25</td>
<td>13.1</td>
</tr>
</tbody>
</table>

Duration of marriage ranged from 1 to 19 years. The median fifty percent of couples reported between four and
ten years of marriage. Of note is the fact that four couples reported being married for 19 years. Nineteen years is clearly a long time to be married, trying to build a family and to be in medical treatment. This clearly demonstrates that for some, the quest for building a family and being in medical treatment are essentially endless. A complete listing of the duration of marriages can be found in Appendix C.

The median length of time couples reported trying to conceive was 30-36 months (2&1/2 - 3 years). The median fifty percent of couples reported trying to conceive for 18-54 months (1&1/2-4&1/2 years). Table 5 illustrates this information.
Table 5

Duration of Conception Efforts

<table>
<thead>
<tr>
<th>Months/years</th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>12/1.0</td>
<td>37</td>
<td>18.5</td>
<td>37</td>
<td>18.5</td>
</tr>
<tr>
<td>24/2.0</td>
<td>37</td>
<td>18.5</td>
<td>74</td>
<td>37.0</td>
</tr>
<tr>
<td>30/2.5</td>
<td>15</td>
<td>7.5</td>
<td>89</td>
<td>44.5</td>
</tr>
<tr>
<td>36/3.0</td>
<td>35</td>
<td>17.5</td>
<td>124</td>
<td>62.0</td>
</tr>
<tr>
<td>48/4.0</td>
<td>26</td>
<td>13.0</td>
<td>150</td>
<td>75.0</td>
</tr>
<tr>
<td>60/5.0</td>
<td>23</td>
<td>11.5</td>
<td>173</td>
<td>86.5</td>
</tr>
<tr>
<td>72/6.0</td>
<td>9</td>
<td>4.5</td>
<td>182</td>
<td>91.0</td>
</tr>
<tr>
<td>96/8.0</td>
<td>4</td>
<td>2.0</td>
<td>186</td>
<td>93.0</td>
</tr>
<tr>
<td>120/10.0</td>
<td>3</td>
<td>1.5</td>
<td>189</td>
<td>94.5</td>
</tr>
<tr>
<td>above 10.0</td>
<td>11</td>
<td>5.5</td>
<td>200</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The majority of couples did not have any children (67.8%). Of the remaining 32.2% who did have children, 18% (N=18) had biologic children, 10.1% (N=10) had adopted children and 2.5% (N=2) had step-children. This is clearly displayed in Table 6.
Table 6

Type of Children

<table>
<thead>
<tr>
<th>Type</th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>136</td>
<td>68.0</td>
<td>136</td>
<td>68.0</td>
</tr>
<tr>
<td>Biologic</td>
<td>37</td>
<td>18.5</td>
<td>173</td>
<td>86.5</td>
</tr>
<tr>
<td>Adopted</td>
<td>20</td>
<td>10.0</td>
<td>193</td>
<td>96.5</td>
</tr>
<tr>
<td>Step-children</td>
<td>5</td>
<td>2.5</td>
<td>198</td>
<td>99.0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1.0</td>
<td>200</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The length of time couples had been in medical treatment varied. Additionally, couples reported varying amounts of time that they expected to remain in medical treatment. Tables 7 and 8 illustrate these responses.
Table 7

**Duration in Treatment**

<table>
<thead>
<tr>
<th>Years</th>
<th>n&lt;sup&gt;a&lt;/sup&gt;</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 1</td>
<td>36</td>
<td>36.0</td>
</tr>
<tr>
<td>1 - 2</td>
<td>26</td>
<td>26.0</td>
</tr>
<tr>
<td>2 - 3</td>
<td>16</td>
<td>16.0</td>
</tr>
<tr>
<td>3 - 4</td>
<td>8</td>
<td>8.0</td>
</tr>
<tr>
<td>4 - 14</td>
<td>13</td>
<td>13.0</td>
</tr>
<tr>
<td>Total</td>
<td>99&lt;sup&gt;b&lt;/sup&gt;</td>
<td>99.0&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>a</sup>Number of couples

<sup>b</sup>One missing couple
Table 8

**Duration of Anticipated Treatment**

<table>
<thead>
<tr>
<th>Years</th>
<th>n(^a)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>32.5</td>
<td>32.5</td>
</tr>
<tr>
<td>0 - 0.5</td>
<td>18.5</td>
<td>18.5</td>
</tr>
<tr>
<td>0.5 - 1.0</td>
<td>17.0</td>
<td>17.0</td>
</tr>
<tr>
<td>1.0 - 2.0</td>
<td>5.0</td>
<td>5.0</td>
</tr>
<tr>
<td>2.0 - 3.0</td>
<td>4.0</td>
<td>4.0</td>
</tr>
<tr>
<td>3.0 - 5.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Indefinitely</td>
<td>22.0</td>
<td>22.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

\(^a\)Number of couples

Initially I had planned to derive half of my sample from the Resolve organization. However, the numbers of respondents from there were too low. Nevertheless, I requested information about peoples' participation in that organization in order to assess the utilization of service available to the infertile population. From my sample of both women and men, 69.3% (N=138) had never attended a Resolve meeting, 11.6% (N=23) had attended only one meeting, 8.5% (N=17) had attended 2 to 12 month's worth of meetings,
5% (N=10) had attended 14 months to 2 years, 4% (N=8) had attended 2 1/2 years to 4 years and 2% (N=4) had attended Resolve meetings for five years. Table 9 illustrates the Resolve participation.

Table 9

<table>
<thead>
<tr>
<th>Duration of Attendance at Resolve Meetings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Months</strong></td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2 - 12</td>
</tr>
<tr>
<td>13 - 24</td>
</tr>
<tr>
<td>25 - 48</td>
</tr>
<tr>
<td>49 - 60</td>
</tr>
</tbody>
</table>

When asked whether the individuals had medical diagnoses or not, 53% of individuals reported that they did not, while 47% stated that they did. As previously discussed, when these data are viewed in terms of couples with diagnoses compared to couples without diagnoses, the breakdown became 87% with diagnoses and 13% without. Consequently trying to identify the impact of having a diagnosis on the couple was extremely difficult. Twenty-one
men (21%) reported a diagnosis of some type of male factor. This was the only male diagnosis described by the male respondents. In contrast, seventy-three women (73%) reported some type of diagnosis. Females reported diagnoses of endometriosis (N=30), history of miscarriage (N=10), tubal problems (N=17), low progesterone (N=2) and lastly, other unspecified diagnoses were reported by a total of 53 women. These are displayed in Tables 10, 11 and 12.

Table 10

Individuals with a Definite Diagnoses

<table>
<thead>
<tr>
<th>Response</th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>106</td>
<td>53.0</td>
<td>106</td>
<td>53.0</td>
</tr>
<tr>
<td>Yes</td>
<td>93</td>
<td>47.0</td>
<td>199a</td>
<td>99.5a</td>
</tr>
</tbody>
</table>

aOne individual is missing

Table 11

Couples with Definite Diagnoses

<table>
<thead>
<tr>
<th>Response</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>13</td>
<td>13.0</td>
</tr>
<tr>
<td>Yes</td>
<td>87</td>
<td>87.0</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
<th>Total female reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individua</td>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>Tubal</td>
<td>Endomet</td>
</tr>
<tr>
<td>Male</td>
<td>Low pro</td>
<td>Endomet</td>
</tr>
</tbody>
</table>

Table 12

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Table 12

**Individual Diagnoses**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male factor</td>
<td>21</td>
<td>21.0</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometriosis</td>
<td>30</td>
<td>30.0</td>
</tr>
<tr>
<td>History of miscarriage</td>
<td>10</td>
<td>10.0</td>
</tr>
<tr>
<td>Tubal problems</td>
<td>17</td>
<td>17.0</td>
</tr>
<tr>
<td>Low progesterone</td>
<td>6</td>
<td>6.0</td>
</tr>
<tr>
<td>Other</td>
<td>53</td>
<td>53.0</td>
</tr>
<tr>
<td><strong>Total female</strong></td>
<td>116</td>
<td>116.0</td>
</tr>
</tbody>
</table>

*Total female diagnoses exceed 100% because some women reported multiple diagnoses*

In terms of procedures performed, it is clear from Table 13 that the majority of the procedures were performed on the women. Very few were performed on the men.
Table 13

Procedures Performed

<table>
<thead>
<tr>
<th>Procedure</th>
<th>% Female</th>
<th>% Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sperm analysis</td>
<td>--(^a)</td>
<td>94</td>
</tr>
<tr>
<td>Laparoscopy</td>
<td>71</td>
<td>--</td>
</tr>
<tr>
<td>Hysterosalpingography</td>
<td>59</td>
<td>--</td>
</tr>
<tr>
<td>Endometrial biopsy</td>
<td>70</td>
<td>--</td>
</tr>
<tr>
<td>Inseminations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>45</td>
<td>--</td>
</tr>
<tr>
<td>Donor</td>
<td>7</td>
<td>--</td>
</tr>
<tr>
<td>Other</td>
<td>52</td>
<td>--</td>
</tr>
</tbody>
</table>

\(^a\)Dashes indicate data not applicable

With respect to the degree of insurance coverage of infertility expenses, there was much variability. The vast majority of patients (88.3%) had some type of insurance coverage for their infertility treatment. Table 14 clearly denotes such coverage.
Table 14

Insurance Coverage

<table>
<thead>
<tr>
<th>Amount of Coverage</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No insurance</td>
<td>10</td>
</tr>
<tr>
<td>10 - 70%</td>
<td>8</td>
</tr>
<tr>
<td>80%</td>
<td>45</td>
</tr>
<tr>
<td>81 - 90%</td>
<td>21</td>
</tr>
<tr>
<td>100%</td>
<td>16</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100</td>
</tr>
</tbody>
</table>

The subject sample was drawn from two different geographic regions of the United States. Forty-eight percent of the sample came from an East coast city, Philadelphia, while, fifty-two percent were drawn from a Midwestern city, Indianapolis. Subjects were obtained primarily from the offices of physicians who specialize in the treatment of infertility. In comparing the samples from the two regions, there were no statistically significant differences with respect to education, age or socio-economic status. More specifically, comparing the educational levels of Indianapolis respondents with Philadelphia respondents, 21 versus 16 had obtained a High School education, 48 vs 53, respectively, had completed college and 35 versus 27 had sought further education; i.e., graduate school.
Table 6

Type of Children

<table>
<thead>
<tr>
<th>Type</th>
<th>n</th>
<th>%</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>136</td>
<td>68.0</td>
<td>136</td>
<td>68.0</td>
</tr>
<tr>
<td>Biologic</td>
<td>37</td>
<td>18.5</td>
<td>173</td>
<td>86.5</td>
</tr>
<tr>
<td>Adopted</td>
<td>20</td>
<td>10.0</td>
<td>193</td>
<td>96.5</td>
</tr>
<tr>
<td>Step-children</td>
<td>5</td>
<td>2.5</td>
<td>198</td>
<td>99.0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1.0</td>
<td>200</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The length of time couples had been in medical treatment varied. Additionally, couples reported varying amounts of time that they expected to remain in medical treatment. Tables 7 and 8 illustrate these responses.
Question 1

FACTOR ANALYSIS

To identify the relevant empirical psychological variables facing people involved in infertility treatment, a Factor Analysis was performed using the previously described conceptually derived variables. This questionnaire was designed for the purposes of this research endeavor by the author/researcher.

Initially all the items from the questionnaire were simultaneously factor analyzed. One large factor emerged, which emphasized primarily negative and sad feelings and issues associated with infertility. This led to the interpretation of one large Depression factor. The fact that when all of the items on the questionnaire were factor analyzed together, only one factor evolved is noteworthy. Identifying only one factor from any factor analysis is very unusual and has significant meaning for the experience of infertility. The fact that there was one global factor derived which was overwhelmingly depressing is a strong indication of the overall experience of infertility. This finding was supported by all of the other data gathered during this research endeavor. Because the identification of one large general factor tends to mask other important thoughts, feelings and issues, I decided to conduct independent factor analyses using all of the items within
each of the previously described conceptually derived categories. In this way, I hoped to more comprehensively identify and describe the most important issues and concerns facing those people involved in infertility treatment.

This approach proved to be extremely useful. A total of twelve factors emerged using eigen values of greater than 1 as well as scree tests described by Cattell (1966). The following headings represent the original psychological categories designed for this research. Within each paragraph the results of the research will be described.

**Stress**

Within the Stress category, one factor emerged which included five of the original six items, all with factor loadings of greater than .40. Inspection of the pattern of significant loadings (above .40) such as "Being around people who talk about their children ..", "Holidays ..." and "Being involved in medical evaluation and treatment ...", all were reported as extremely stressful. Thus a Stress factor was named, which accounted for 48.6% of the common factor variance.

**Emotional Reactions**

Within the category entitled "Emotional Reactions", two factors emerged, labelled Depression, Factor II, and Anger, Factor III. Depression was comprised of fifteen items such as "At times I find myself crying for no apparent reason", "I have an intensely negative reaction to pregnant women"
and "I am depressed much of the time because of our infertility." Because of its high depression content, this factor was termed Depression and accounted for 32.4% of the common factor variance. The third factor was entitled Anger and included six items such as "I am angry at my spouse for burdening me with infertility" and "I feel my life is ruined because of our infertility." Seven and a half percent of the common factor variance was accounted for by this variable.

Psychological Considerations

From the category called Psychological Considerations, four factors (IV, V, VI and VII) were identified. Negative Psychological Effect, Factor IV, accounted for 18.2% of the common factor variance. It was comprised of 8 ideas and included items such as "I feel ugly" and "I view myself more negatively" and "I can't control my emotions". Shame, Factor V, accounted for 10.0% of the common factor variance. It was comprised of five items such as, "It's embarrassing to discuss our infertility" and "Initially we were very secretive". No Control, Factor VI, accounted for 9.0% of the common variance and consisted of three items, such as "I prefer to let our physician make all the decisions" and "I don't feel I can refuse a test or procedure recommended by our physician". The last factor, Control, Factor VII, accounted for 8% of the common factor variance. It was comprised of four items, including such examples as "I feel capable and qualified to be actively involved in my medical
decision-making" and "We do not hesitate to question our physician when we do not understand what is to be done or why."

Social Issues

From the Social Issues category emerged two factors, Physician, VIII, and Negative Social View, IX. The Physician factor included such items as "Our physician's optimism keeps us motivated to return to treatment each month" and "Physicians are sensitive to the psychological needs of their patients." This factor accounted for 17.2% of the common factor variance and was comprised of 7 items. Negative Social View, Factor IX, accounted for 11.7% of the common factor variance. High loadings were obtained from items such as "Infertility has negatively affected my relationships with friends" and "I believe people are basically insensitive to the issue of infertility." Six items comprised this factor.

Current Feelings

From the Current Feelings category, the last three factors were identified, Hope, Isolation and Acceptance. Factor X was titled Hope and included six items such as "I realize there are still a number of viable options to pursue" and "I don't think it's a question of 'if' so much as 'when' we will have children." The Hope factor accounted for 14.2% of the common factor variance. Isolation, Factor XI, was comprised of six items such as "I will always feel different from the fertile world" and "I will always view
myself as an infertile person." It accounted for 13.1% of the variance. Acceptance, Factor XII, included six items and accounted for 10.0% of the common factor variance. High loadings were obtained from items such as "I can once again get excited about what the future may hold for us" and "I feel good about the decisions we have made about building a family."

**Measures**

In order to insure internal consistency among items of each factor alpha coefficients were performed. These measures verify that items within a scale are in fact measuring the same single construct. Results of this analysis may be found on Table 15. Of additional importance is the determination of what amount of variance each factor accounts for within the more global scales from which they were originally derived. Only factors with eigen values greater than 1 were considered relevant. Results of this analysis are provided in Table 15.
## Table 15

**Internal Consistency of Measures**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Alpha coefficient</th>
<th>Eigen value</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Stress</td>
<td>.76</td>
<td>2.92</td>
</tr>
<tr>
<td>II. Anger</td>
<td>.67</td>
<td>7.78</td>
</tr>
<tr>
<td>III. Depression</td>
<td>.90</td>
<td>1.80</td>
</tr>
<tr>
<td>IV. Neg psych effect</td>
<td>.82</td>
<td>4.18</td>
</tr>
<tr>
<td>V. Shame</td>
<td>.64</td>
<td>2.24</td>
</tr>
<tr>
<td>VI. No control</td>
<td>.46</td>
<td>2.13</td>
</tr>
<tr>
<td>VII. Control</td>
<td>.50</td>
<td>2.12</td>
</tr>
<tr>
<td>VIII. Physician</td>
<td>.74</td>
<td>3.27</td>
</tr>
<tr>
<td>IX. Negative social view</td>
<td>.63</td>
<td>2.22</td>
</tr>
<tr>
<td>X. Hope</td>
<td>.68</td>
<td>2.99</td>
</tr>
<tr>
<td>XI. Isolation</td>
<td>.70</td>
<td>2.76</td>
</tr>
<tr>
<td>XII. Acceptance</td>
<td>.62</td>
<td>2.11</td>
</tr>
</tbody>
</table>
Question 2

IMPACT OF SPECIFIC DEMOGRAPHIC VARIABLES

Once the factors were derived, the data were analyzed for any differences with respect to geographic region or any of the other demographic variables included in the questionnaire. In order to determine this, a number of Analyses of Variance were performed on the factors taking into account: 1) region and gender (to be discussed in response to Question 3, Gender Differences), 2) education (See Tables 16 and 17), 3) religion (See Table 18) and the impact of previous children (See Table 19)

Results indicated that there were no statistically significant differences for region among any of the factors. There were however, statistically significant differences among the factors for the following demographic variables: gender, education, religion and the impact of previous children.

EDUCATION

Educational level did demonstrate two factors where differences were statistically significant. The two factors were Physician and Hope and are displayed in Tables 16 and 17.

Physician

On the Physician factor, however, it must be noted that educational level only accounted for 4% of the common factor
Duncan’s Multiple Range test revealed that differences lay between High School/College and Graduate School. More specifically, individuals with either a High School or College education evidenced more confidence in their physicians’ abilities than people who had graduate school training. See Table 16 for the statistically significant ANOVA’s and means. (Table 16: HS/College=20.87/20.42; Graduate School=18.50; F=4.19; p<.02)

Table 16

<table>
<thead>
<tr>
<th>Education X Physician ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
</tr>
<tr>
<td>Education</td>
</tr>
</tbody>
</table>

*p < .02

<table>
<thead>
<tr>
<th>Duncan Grouping</th>
<th>n</th>
<th>M</th>
<th>Education level</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>37</td>
<td>20.87</td>
<td>High school</td>
</tr>
<tr>
<td>A</td>
<td>101</td>
<td>20.42</td>
<td>College</td>
</tr>
<tr>
<td>B</td>
<td>62</td>
<td>18.50</td>
<td>Graduate school</td>
</tr>
</tbody>
</table>
Hope

There was also a significant difference among educational levels with respect to the Hope Scale. Again, however, education only accounted for 4% of the variance. This time Duncan's revealed significant differences between High School and College educated people. More specifically, College people demonstrated more hope with respect to infertility and its treatment than High School educated people. Table 17 more clearly illustrates this. (Table 17: College=17.03; High School=14.60; F=4.32; p<.01)

Table 17

Education X Hope ANOVA

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>ANOVA SS</th>
<th>Mean Square</th>
<th>F Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>2</td>
<td>163.56</td>
<td>81.78</td>
<td>4.32*</td>
</tr>
</tbody>
</table>

*p < .01

<table>
<thead>
<tr>
<th>Duncan Grouping</th>
<th>n</th>
<th>M</th>
<th>Education level</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>101</td>
<td>17.03</td>
<td>College</td>
</tr>
<tr>
<td>B</td>
<td>62</td>
<td>16.11</td>
<td>Graduate school</td>
</tr>
<tr>
<td>B</td>
<td>37</td>
<td>14.60</td>
<td>High school</td>
</tr>
</tbody>
</table>
RELIGION

Anger

The effects of religion were statistically significant only on the Anger factor. Table 18 illustrates these findings and the Duncan's Test identified the significant differences between Protestant and Jewish/Other. More specifically, Protestants were considerably more angry about their infertility than were Jews or those who categorized themselves as Other. (Table 18: Protestant= 9.88; Jewish/Other=7.85/7.82; F=3.28; p<.02).

Table 18

Religion X Anger ANOVA

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>ANOVA SS</th>
<th>Mean Square</th>
<th>F Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religion</td>
<td>3</td>
<td>125.11</td>
<td>41.70</td>
<td>3.28*</td>
</tr>
</tbody>
</table>

*p < .02

<table>
<thead>
<tr>
<th>Duncan Grouping</th>
<th>n</th>
<th>M</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>80</td>
<td>9.88</td>
<td>Protestant</td>
</tr>
<tr>
<td>B A</td>
<td>70</td>
<td>9.14</td>
<td>Roman Catholic</td>
</tr>
<tr>
<td>B</td>
<td>26</td>
<td>7.85</td>
<td>Other</td>
</tr>
<tr>
<td>B</td>
<td>22</td>
<td>7.82</td>
<td>Jewish</td>
</tr>
</tbody>
</table>
IMPACT OF PREVIOUS CHILDREN

Comparing people with children to those without, four Analyses of Variances demonstrated statistical differences. These included the following scales: Stress, Shame, Anger and Acceptance, and are illustrated on Tables 19 to 22. More specifically, statistical analyses revealed the following.

Stress

A statistical difference was evident on the Stress scale. The Duncan's Test indicated that people with children evinced less stress than people without children. (Table 19: Means: With children= 8.81, Without children= 10.10; F=5.56; p<.02).
Table 19

Previous Children X Stress ANOVA

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>ANOVA SS</th>
<th>Mean Square</th>
<th>F Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>1</td>
<td>152.29</td>
<td>152.29</td>
<td>12.13*</td>
</tr>
<tr>
<td>Children</td>
<td>1</td>
<td>70.02</td>
<td>70.02</td>
<td>5.56**</td>
</tr>
<tr>
<td>Sex X Children</td>
<td>1</td>
<td>5.81</td>
<td>5.81</td>
<td>0.46</td>
</tr>
</tbody>
</table>

*p < .0006; **p < .02

Duncan Grouping

<table>
<thead>
<tr>
<th>Duncan Grouping</th>
<th>n</th>
<th>M</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>134</td>
<td>10.10</td>
<td>0 (no children)</td>
</tr>
<tr>
<td>B</td>
<td>64</td>
<td>8.81</td>
<td>1 (had children)</td>
</tr>
</tbody>
</table>

Shame

A statistically significant difference was also noted on the Shame scale. The Duncan’s Test revealed that people
with children evidenced less shame than people without children. (Table 20: Means: With children= 10.31, Without children= 11.61; F=6.09; p<.01).

Table 20

<table>
<thead>
<tr>
<th>Previous Children X Shame ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
</tr>
<tr>
<td>------------------------------</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Children</td>
</tr>
<tr>
<td>Sex X Children</td>
</tr>
</tbody>
</table>

*p < .01

Duncan Grouping n M Children

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>134</td>
<td>11.61</td>
</tr>
<tr>
<td>B</td>
<td>64</td>
<td>10.31</td>
</tr>
</tbody>
</table>

Anger

The Anger scale also evidenced a statistically significant difference. The Duncan’s Test revealed that people with children (n=134) were less angry than those without (n=64). (Table 21: Means: With= 8.27, Without= 9.56; F=5.75; p<.02).
Table 21

Previous Children X Anger ANOVA

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>ANOVA SS</th>
<th>Mean Square</th>
<th>F Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>1</td>
<td>30.50</td>
<td>30.50</td>
<td>2.36</td>
</tr>
<tr>
<td>Children</td>
<td>1</td>
<td>73.56</td>
<td>73.56</td>
<td>5.75*</td>
</tr>
<tr>
<td>Sex X Children</td>
<td>1</td>
<td>7.61</td>
<td>7.61</td>
<td>0.59</td>
</tr>
</tbody>
</table>

*p < .02

Duncan Grouping

<table>
<thead>
<tr>
<th>Children</th>
<th>n</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (no children)</td>
<td>134</td>
<td>9.56</td>
</tr>
<tr>
<td>1 (had children)</td>
<td>64</td>
<td>8.27</td>
</tr>
</tbody>
</table>

Acceptance

A significant difference was noted on the Acceptance scale. The Duncan's Test revealed that people with children were more accepting of infertility than people without children. (Table 22: Means: With=16.47, Without= 14.82; F=8.17; p<.0047).
In summary, more clearly descriptive of these peoples’ profiles is the following listing:

<table>
<thead>
<tr>
<th>PEOPLE WITH CHILDREN</th>
<th>PEOPLE WITHOUT CHILDREN</th>
</tr>
</thead>
<tbody>
<tr>
<td>More accepting</td>
<td>Less accepting of infertility</td>
</tr>
<tr>
<td>Less angry</td>
<td>More angry</td>
</tr>
<tr>
<td>Less shameful</td>
<td>More shameful</td>
</tr>
<tr>
<td>Less stressed</td>
<td>More stressed</td>
</tr>
</tbody>
</table>

Table 22

**Previous Children X Acceptance ANOVA**

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>ANOVA SS</th>
<th>Mean Square</th>
<th>F Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>1</td>
<td>2.60</td>
<td>2.60</td>
<td>0.18</td>
</tr>
<tr>
<td>Children</td>
<td>1</td>
<td>117.38</td>
<td>117.38</td>
<td>8.17*</td>
</tr>
<tr>
<td>Sex X Children</td>
<td>1</td>
<td>2.79</td>
<td>2.79</td>
<td>0.66</td>
</tr>
</tbody>
</table>

*p < .0047

<table>
<thead>
<tr>
<th>Duncan Grouping</th>
<th>n</th>
<th>M</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>(no children)</td>
</tr>
<tr>
<td>A</td>
<td>134</td>
<td>14.82</td>
<td>0</td>
</tr>
<tr>
<td>B</td>
<td>64</td>
<td>16.47</td>
<td>1 (had children)</td>
</tr>
</tbody>
</table>

In general, people without children evidenced more intense and negative emotional reactions to infertility than those with children.
INTERCORRELATIONS AMONG SCALES

Because these scales portray important variables of the psychological impact of infertility, it is assumed that there may be some intercorrelations among some of these scales. It would be important to attempt to clearly acknowledge where such correlations may exist. Therefore a correlation analysis was performed using all of the factorially derived scales in addition to some of the relevant demographic variables, such as age, years of education, Socio-economic Status, years married, months and years trying to conceive and years in medical treatment. Using the entire sample (N=200), the most highly correlated variables are listed below as they provide the most relevant information with respect to the issues involved in the experience of infertility.

Depression is significantly correlated with Negative Psychological Effect (47.9% of the variance), Stress (35% of the variance) and Isolation (33.9% of the variance).

Negative Social View is significantly correlated with Isolation and accounts for 29.8% of the variance.

Months Trying to Conceive is significantly correlated with Years in Treatment and accounts for 29.7% of the variance.

Negative Social View is significantly correlated with Depression (26.3% of the variance), Negative Psychological Effect (22.5% of the variance) and Stress (21% of the variance).
Years in Treatment is significantly correlated with Years Trying to Conceive (26.1% of the variance) and Years Married (22.4% of the variance).

Years Married is significantly correlated with Months Trying to Conceive and accounts for 24.5% of the variance.

Isolation is significantly correlated with Stress and accounts for 18.4% of the variance.
Question 3

GENDER DIFFERENCES

The question of gender differences was addressed both quantitatively through statistical analyses of the questionnaire data and qualitatively using content analysis of the data obtained during the interviews. During the interviews each respondent was asked about his or her personal view regarding a particular issue as well as their view of the opposite sex's perspective on that same issue. The questionnaire data will be discussed first, followed by the interview data.

Questionnaire Analyses

Statistically significant gender differences were noted on five of the factors. These included Stress, Negative Psychological Effect, Physician, Depression and Isolation. Specific factors which evidenced significant statistical differences for the main effect of sex are clearly denoted in Tables 23 - 27.

Stress

While there was a statistically significant sex difference on the Stress factor, it only accounted for 6% of the variance. It, therefore, remains unclear how meaningful such a difference may be. The Duncan's Post Hoc test revealed that women felt more stressed than men regarding their infertility. (Table 23: Means: women=10.5, men=8.8; F= 12.05; p<0.0006)
Table 23

Gender X Stress ANOVA

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Duncan Grouping

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Negative Psychological Effect

The statistically significant sex differences evident on the Negative Psychological Effect factor accounted for 19.7% of the common factor variance. A Duncan’s Post Hoc test demonstrated that women experienced more negative effects from the infertility experience than men. (Table 24: Means: women 19.67, men=13.5; F= 47.11; p<.0001).
Table 24

Gender X Negative Psychological Effect ANOVA

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Physician

Despite the fact that statistically significant sex differences were noted on the Physician factor, they only accounted for 5% of the variance so it is unclear how meaningful these differences really are. A Duncan's Post Hoc test illustrated that women tended to have more critical views of their physicians. (Table 25: Means: women=20.87, men=18.93; F=8.54; p<.004)
Table 25

Gender X Physician ANOVA

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Depression

The two by two (gender and region) ANOVA identified a statistically significant difference for the main effect of sex on the Depression factor. Of particular relevance is the fact that sex accounted for 44% of the common factor variance. The Duncan’s test revealed that women felt much more depressed by infertility than did men. (Table 26: Means: women 35.13%, men=20.87; F= 149.85; p<.0001)
Table 26

Gender X Depression ANOVA

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Duncan Grouping

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Isolation

A statistically significant sex difference was found on the Isolation factor which accounted for 19.46% of the variance. The Duncan’s Test revealed that women experience more feelings of isolation than men. (Table 27: Means: women 16.47, men=12.48; F= 45.98; p<.0001).
Table 27
Gender X Isolation ANOVA

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*p < .0001

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Item by Item Analysis

When assessing each item individually two specific observations became apparent. First, the responses of men and women tended to fall into three categories: major/significant disagreement, minimal difference or extreme similarity. Second, overall, women tended to be the ones who acknowledged more intense emotional reactions. Along those lines, men tended to report, more often that some items were 'not applicable' or not relevant to the issue of infertility. This was quite interesting in light
of the fact that all of the items were derived from the infertility literature and patient report.

The following items demonstrated significant differences in gender responding. Women strongly agreed with the statements that infertility was their fault, that their body image had changed, that their lives were dictated by others and that treatment was stressful for them. Men, however, tended to disagree with each of those statements. They did not feel infertility was their fault, that their body images had changed, that their lives were dictated by others nor that treatment was extremely stressful for them.

Women also noted changes in their level of functioning. For example, women commented that their work performances had deteriorated noticeably, that they were more critical of others and that they had difficulty concentrating on anything but infertility. Men reported they did not notice any of these changes. The one striking observation mentioned by men was that they did feel burdened by having to deal with their spouses infertility. Psychological changes were also frequently reported by women. More specifically, women described crying for no apparent reason, feeling depressed, hopeless, tense and angrier as a result of infertility. All of these emotional changes were acknowledged to a significant extent by women but not by men. Additionally, women described themselves as becoming angry at friends who became pregnant and experiencing intensely negative reactions to seeing pregnant women.

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Finally, women tended to say that they felt that their lives were ruined as a result of infertility and despite how their infertility problems worked out they would always feel differently from the fertile world. Men were essentially unaffected by the news that a friend was pregnant or the sight of a pregnant women. Furthermore, men did not report that they did or would feel differently from the fertile world in the future.

On the positive side, women stated that they felt capable and qualified to be actively involved in the decision-making regarding infertility treatment. Men seemed to be somewhat less sure of their abilities and competence in this area.

In terms of similar feelings, there was a more positive sense to these items reported by both men and women. It also seems that these items were less emotionally charged issues and tended to address more objective concerns. For instance, both men and women felt that their physicians must have initially made a mistake when they told them about their infertility. There was also a united perspective on the role of physicians; i.e., that they tended to not discuss alternatives to family building nor did they address any of the many emotional issues associated with infertility and its treatment. Both men and women felt strongly that their communication patterns had improved directly as a result of having to deal with the issue of infertility. Both partners also remarked that they felt positive about
the decisions they had made related to infertility. The couples also agreed that it was a question of 'when' not 'if' they would have children. Couples also were united in their view that they had realized that they did in fact have more control regarding their infertility than they had previously realized.

Interview Analyses

When directly asked whether people thought that there were gender differences regarding the impact of infertility, there was majority agreement. Most people (N=12) acknowledged that infertility affects men and women differently. A few others (N=5) disagreed and thought that the etiology of the infertility problem was the key factor in differential reactions to the impact of infertility.

There were three others who only indirectly answered this question and as such it was impossible to discern their perspective on this issue.

For those who thought that there were gender differences, the overwhelming majority (N=11) felt strongly that the entire infertility issue was much more devastating for the women to deal with. Respondents discussed a number of important issues where they felt major differences lay. These included: the underlying meaning of infertility, the degree of emotional upheaval, how often the issue was thought about and how verbally expressive individuals were regarding their particular infertility situation. Both male
and female perspectives for each issue will be presented in the following sections.

**Underlying meaning of infertility**

**Female perspective**

When women were asked what they felt was the underlying meaning of their infertility, the responses were quite similar. Most women (N=8) acknowledged some type of loss or lack of fulfillment. For some it was the loss of a life-long dream: "to grow up, get married and have children." These women had part of their identity tied to the idea of motherhood and were devastated by the prospect that it may not happen. For others, it was a more specific loss: the loss of the experience of pregnancy and childbirth. For these women, a significant part of being a women involved these solely female abilities. To not be able to take part in these experiences was a great personal loss for them. One woman reported feeling a strong sense of "guilt" related to her "past promiscuous lifestyle." For her, infertility signified a past she was not proud of and a feeling that she was paying a substantial price for it now. She did not feel overwhelmed by these thoughts but they definitely plagued her at times. Two women in particular stated that infertility "makes you nuts!"

**Male View of the Female Perspective**

When men were asked about the underlining meaning infertility held for women, there was also some commonalty among their responses. The majority of men (N=6) stated
that infertility and the possibility of not having biologic children was a devastating experience for women, largely because they were not fulfilling society’s expectations of a woman’s role. As a result, women felt badly about themselves and were depressed much of the time. Along these lines, one male stated that he felt men "pressurize the situation. They expect to have children and that puts too many demands on the partner. Medical treatment is bad enough without the added psychological aspects." A few other men (N=3) felt that there was an inherent biological need in women to bear children and become mothers. This need went unmet because of infertility. As a result, women often became consumed by their drive to have children and a family. This issue then, took on monumental meaning in the lives of these women. Many women became obsessed and overwhelmed by their infertility. Lastly, one male stated "Women are full of self pity and they dwell on this (infertility issue). There’s an empty space that can’t be filled. That’s the problem."

Male perspective

When men were asked about the underlying meaning of infertility for them, there was one primary viewpoint. Similar to the sentiments of the women, most men (N=7) acknowledged experiencing a loss related to infertility. The specific focus of this loss however, was very different from that expressed by the women. The major concern verbalized was the loss or sadness associated with the fact
that they were not going to be able to pass on their genes or their family name to the next generation. For these men, this seemed to be a major reason for having children. As men described their concerns, they were not overwrought with emotion and devastation as the women were. It seemed to be an area of concern, but not an overwhelming one in any sense. Two men out of the entire ten acknowledged that infertility was a threat to their identities. When their responses were probed further, only one could or would articulate his thoughts. He stated "It makes you feel less of a person, less masculine." He added further that he thought that society fosters this view. One other man described the underlining meaning as "a loss of spontaneity. Everything has to be timed just so. That's what infertility represents to me." He seemed to be describing more a sense of frustration with the whole process of infertility from the surface rather than deriving any deep underlying meaning from it. Along these same lines, two other men shared their perspectives, which were quite aligned. Essentially, they thought that infertility represented a medical problem which prevented them from having children. That was that. There was no deep significance to the issue. They just happened to have some type of medical condition for which they were seeking treatment. It did not present any major concern on their part. Both men were quite matter-of-fact when the interviewer attempted to probe a bit more. They really did
not understand what else I could be looking for in terms of a response.

**Female View of the Male Perspective**

There seemed to be one predominant viewpoint, that infertility presented a threat to a man’s masculinity. Two other points were also expressed. Women commented that men seemed to feel some loss associated with the fact that their family name would not be carried on. The last issue raised was that for many men the issue of infertility was not that traumatic in general. Women qualified their statements by saying that they all agreed that their husbands did, in fact, want to have children, but the possibility that it may not occur was an acceptable outcome for these men. This was in sharp contrast to the views held by many of the women.

It was interesting to note that most women saw a connection between their partner’s feelings of masculinity and infertility. A number of women stated that men seemed to equate “their concept of virility and sexuality to their potency and their ability to reproduce.” As one woman stated, "Men are not psychologically capable to deal with this issue. You start messing with their parts and they go crazy." When asked more about this, the women supported their stance by describing changes in their husbands. For example, one woman stated that for a time her husband would constantly joke about their infertility. Whenever he spoke of it, he would laugh and say he was "shooting blanks."

Another woman described concerns that her husband was
becoming overly stressed by the infertility treatment and the fact that he had to "perform on command." He had experienced an episode of impotence and had found this very difficult to accept. Her worst fear was that he would want to end treatment rather than have to deal with that issue. It was especially interesting that so many of the women noted emotional effects in their husbands and so few of the men were willing to acknowledge any relationship or concern in this area. Obviously the fact that they were being interviewed by a woman may have inhibited any discussion in this area by men who had even the slightest anxiety.

A lesser but still significant issue, according to the women, was the realization by some men that their family name would not be carried on. Several women and men spontaneously commented on it. One man in fact, said that infertility was a "threat to your immortality." When asked to elaborate, he said "I realized that I was the end of my family tree on this earth. What would I have left here? Nothing." It appeared that a child would have been a tangible and important contribution from this man's perspective.

The last category of responses is a compilation of comments offered by women regarding the male's perspective. The major underlying theme was that most men felt comfortable acknowledging the fact that they did want to have children and a family. If, however, it did not work out, they could deal with it. Some women felt that the ease
with which a man could adapt to childlessness was attributable to the fact that creating a family was not a top priority in their lives. Rather, it was one area of interest among others.

Emotional upheaval

The clearest distinction between females and males was evident when the issue of emotional upheaval was raised. Many women and men (N=16 out of 20) believed that "women are women and men are men". When questioned further about the meaning of this statement, most indicated that women, in general, were perceived to be more emotional because of their biological make-up. Regardless of the underlying reasoning, there did seem to be fairly uniform agreement among both sexes that infertility was a much more intensely negative and emotionally devastating experience for women. The following section will elaborate on these points.

Female perspective

Overall, women (N=8) voiced almost unanimous agreement with the idea that facing infertility was one of the most, if not the most devastating experiences of their lives. The intensity and the pervasiveness of the emotional experience was extreme. These women thought that the infertility issue complicated their entire lives. Every aspect of their existence was colored by the reality of their infertility. Things like seeking a new job, taking a vacation or having a drink when out to dinner were all affected by where they were in the treatment cycle. Similarly, spending money on a
new car or redecorating their home took on new meaning in the context of the financial burden of infertility. For many women the additional burden of infertility made almost all decisions major ones, despite how small they may be. When speaking with these women it became evident that all of the emotions associated with infertility and its treatment were negative. Furthermore, it became clear that most, if not all of these women had much difficulty separating out the negative emotions stemming from infertility from other emotions experienced in response to various stressors. As one woman stated, "Infertility makes women nuts. I used to be an agreeable person. Now I snap at people and am a crabby person. I'm becoming an emotional basket case of clinical depression."

Male perspective

Men expressed a much more relaxed perspective and experience of infertility. For men, there was not an all-encompassing aspect to infertility. Rather, it was viewed as one facet of their lives, which most stated that they could fairly easily separate out from the rest of their lives. While many of the men acknowledged that infertility presented numerous difficult issues for them to deal with, none of them felt particularly overwhelmed by having to face this experience. In fact, only one male respondent stated that he felt infertility was a pervasive issue in his life and that it was constantly on his mind to some extent. He did not in any way feel, however, that this fact impeded his
performance at work or that in any area there was a noticeable change as a result of having to deal with the infertility issue.

In contrast, there were two males who were extremely unemotional about the entire infertility issue. Both of these men felt it was a cut and dry issue. There was a problem and they were in treatment trying to correct it. The common sentiment here was that they were doing all that could be done so there was no value in being additionally concerned. One man stated "I deal with emotions mechanically."

Although only directly verbalized by two males, this decreased level of intensity was immediately evident in all interactions with the men. In an attempt to understand this large emotional difference, men were questioned about it. The predominant response was that while they were all sincerely interested in having a family, it was not the sole motivation in their lives. It was only one aspect of their lives, among many, that was important to them. Most reported that they truly did hope everything would work out, but if it did not they were confident that they could adjust to that situation with relative ease. All agreed that this would not be the case for their wives. In fact, the concern for their wife's emotional well-being was one of the most difficult and biggest areas of concern for these men. Many of them spontaneously stated this concern was foremost in their minds.
A slightly different perspective was offered by one man. He stated that he felt the key difference lay in the fact that from the start women are the major participants in family building in that they actually experience pregnancy and give birth. Men are relegated to the role of bystander from the outset. He stated that as a result, he personally felt "emotionally it has less of an effect on me. It's not crippling."

One last viewpoint was expressed by a male. He stated that his motivation for wanting children was not the same as his wife's and therefore he was less emotionally traumatized by their infertility. According to this man, his wife, like other women, had this maternal drive underlying her desire to have children. There was a deep and all-encompassing need within her. This was not the case for him though. His interest was much more superficial. He stated that his motivation was purely to "have fun." When questioned further, he responded that when he was with any of his friends who had children, they always seemed to be enjoying themselves and he thought that he, too, would derive pleasure from that type of experience. He went on to elaborate that he thought having as much fun as possible was what life was all about. Having children was just one of many ways that pleasure could be obtained.

Female View of the Male's Perspective

When women were asked about the male's emotional reaction to the issue of infertility, they offered similar
descriptions as the males. Primarily, they felt that men, in general, were less emotionally invested in most things. Typically, they appeared unaffected by many things that caused the women to feel emotionally devastated. What was especially interesting was the fact that many of the women had given this issue considerable thought and as a result had developed some interesting ideas on the subject. It should be noted that many of the women spontaneously stated that the fact that they were at such different emotional places from their mates only seemed to add to the burden of the entire infertility experience. Of note, though, few women tried to directly address these concerns with their partners. Rather, they chose to suffer often in silence and without the possible support of their partners. When asked more about this approach, some women commented that initially they had made attempts at talking to their husbands but often their responses were so minimal and empty that these conversations were extremely unproductive. As a result, this area was too painful and unfruitful to pursue. Some women even reported that their husbands became angry at these solicitations of emotion and the women felt worse off for having initiated the topic. As one woman stated, "This caused a lot of friction between us for a long time."

Two women developed sophisticated interpretations of their husbands' lack of emotional expression. One woman thought her husband's silence was a protective maneuver. He had not wanted to upset his wife by showing any emotion. He
had felt that if he showed any sad or negative feelings, then it would impact negatively on his wife and, may in fact, cause her to become depressed and/or tearful. What this man did not comprehend was the fact that this avoidance of the issue made his wife feel worse and also caused an emotional distance between them that added a further strain to an already overwhelming concern for his wife. Interestingly, this man, and many others, seemed unjustly to equate an open expression of emotion, especially of a negative one, as a situation which may become uncontrollable. They failed to perceive that such discussions may be quite valuable for some women (and even some men). Having talked something out and even cried about it may actually improve one's emotional state. There is often a tremendous sense of relief derived from this type of cathartic experience. Most men, on the other hand, seemed to view this type of emotional expression as something to be avoided at all costs. It was apparently too difficult for the men to deal with. Perhaps it was a fear that the situation would become uncontrollable if both partners were emotionally open and vulnerable. This potential loss of control, despite how temporary, may have been anticipated as too overwhelming for the men to accept.

Two other women felt that for men the issue of infertility is not necessarily an emotional one. Each offered a different viewpoint as to why this may be so. One woman stated that she felt infertility was more of a
practical concern rather than an emotional one. By this she meant that "men want someone to play ball with or teach how to mow the lawn. If they don’t have children, they’ll miss out on this." She felt that there were basic differences in men’s and women’s perspectives and motivations for wanting to have children. As a result, they handled their feelings very differently.

A second woman felt that because she was the primary focus of the medical treatment and her husband often did not accompany her to the appointments, that he did not truly have a sense of what the experience was like. She agreed that he had an intellectual understanding of what happened at each appointment but had little perspective of the emotional trauma associated with the medical part nor any actual physical pain associated with the treatment. This void only served to heighten her emotional need.

On the more positive side, two women reported improvements in their situations. One stated that over time she had noticed an increase in her husband’s emotional expressiveness. She felt that he had never had to deal with any sort of trauma before and needed some time to identify and feel comfortable expressing what he was actually feeling. She was very pleased to see some gains being made in this area. A second woman reported that she had noted an improvement in her and her husband’s communication pattern over time. Initially she described herself as very emotional and "showing all her feelings" and her husband as
"showing nothing." They had both acknowledged how difficult that was to deal with. Over time, however, she felt she was becoming less emotionally labile and better able to discuss her feelings rather than just show them by crying, yelling or laughing. He, in turn, was able to be more verbally expressive regarding his emotional status. This coming together was deemed by both of them as very positive and productive in terms of the relationship.

Frequency of Thinking About Infertility and Verbal Expressiveness

Female perspective

On this issue there was unanimous agreement among the females. All of them (N=10) stated that they thought about their infertility situation almost constantly. For some it was more often than others, but at the minimum these women thought about infertility at least daily. More typically, however, infertility was something that was more-or-less always on their minds. Numerous situations throughout the day reminded them of their infertility. For example, often at work they were faced with a pregnant co-worker or someone who was at least contemplating beginning a family, so the topic of pregnancy was being discussed. At other times, co-workers who were proud parents would be recounting their child’s latest accomplishment and many of these women felt obligated to listen and respond favorably. In many other settings as well, these women felt constantly confronted by situations which evoked thoughts of their infertility. For
example, often on the way home from work they would stop at a store or the supermarket. The stores, and especially the supermarkets, seemed to be filled with either pregnant women or women with two and three little children at their sides. Finally when they arrived home, it seemed to them that children were playing everywhere in their neighborhoods. The sights and sounds of these children served as constant reminders to these women that their goals and dreams of having a family were as yet unmet. Even watching the evening news was painful for some. They seemed to have somewhat stronger emotional reactions to stories involving child abuse or children with serious illnesses. Most of the women commented that these reminders were present on days which otherwise could have been "good," meaning that they did not have doctor's appointments. Such appointment days were even more difficult partially because they were directly facing the reality of their own infertility as well as because they were often involved in uncomfortable, even painful, procedures.

In terms of verbal expressiveness, there were primarily three categories of responses. Essentially, there was one group of women (N=6) who found it enjoyable and even beneficial to talk about their infertility whenever the opportunity was present. A second group of women (N=3) discussed their infertility with only a few close people, usually select family members. Lastly, there was one woman who shared nothing about her infertility with anyone at all.
An elaboration of each of these styles will be provided in the following section.

For those women who were verbally expressive regarding their infertility, there was a common sentiment that they derived much needed benefit from this approach. For them sharing feelings and experiences offered a catharsis, a sense of relief from keeping all of these emotions pent up inside. Many women stated, "It just helped to talk. Afterwards I usually felt better." There were two women who felt especially strongly about the importance of talking. One stated, "I'd talk to anyone who would listen, often in great detail." She fully realized that this approach was solely for her benefit in terms of helping her to feel better. A second woman stated that as soon as she began infertility treatment she let everyone at work know that she had an infertility problem. According to this woman, "Career-wise it's the best thing. I got more promotions than usual. No matter what top management says, they are always a little worried that they'll invest all this money in you and you'll get pregnant and walk out. It seems that infertility usually helps a woman's career."

Those women who shared their infertility concerns with only a select few people, had a slightly different perspective. For two of them, it was important that both they and their husbands use the same approach. What they could agree on was only sharing information with immediate family members and usually only if it was solicited by those
family members. Despite this agreement, it often turned out that family members sought information solely from the woman. In these two cases, this arrangement was acceptable as it was primarily due to the males’ request that little information be shared with others. The women voiced some concern of their own about sharing too much information with too many people, so this approach offered them a reasonable compromise.

The one woman who refused to share any information with anyone was quite adamant about this. She could not tolerate the idea of constantly being questioned about the status of her infertility treatment. She felt that these additional questions would be unavoidable and would add to an otherwise very stressful situation. She also stated she felt that it was one small way in which she could exert some control over some aspect of her infertility treatment. By this she meant that she would rarely be put in awkward positions by others asking untimely and perhaps even painful questions about her infertility. Interestingly, her husband thought that the amount of effort it took to keep this secret was excessive. As such, he would have preferred that they share some of their infertility concerns with family members and possibly even close friends. He thought, unlike his wife, that these others would be able to provide some much needed support for them. Because of his wife’s strong stance, however, he did not directly discuss this with her, as he felt it would only serve to further burden his wife.
Male perspective

The men provided a very different viewpoint on the issues of how much they thought about infertility and their degree of verbal expressiveness. In contrast to the women's report, only a few men (N=3) stated that infertility was on their minds very much of the time. The majority (N=7) stated that they did not usually spontaneously think about it or if they did, they usually did not allow themselves to think about it for very long.

Of the three men who did think about their infertility, two thought that the fact that they were thinking about it more often was a fairly recent phenomenon. Each directly related this change to a recent event in their lives. One stated that since the death of his newborn baby, he had been more concerned about the possibility of successful infertility treatment as well as the impact it would have on his wife's emotional well-being. He did qualify his statement by saying that although he thought about infertility more now, it still tended to only be when there was a "lull at work." Otherwise, he did not tend to think of it too much. A second man stated that for him the realization that they were going to try the last available treatment option for their infertility problem had forced him to confront the entire issue more directly. He stated, "Lately I've become much more anxious about our infertility and wanting children. I think since this is really our only shot left, I'm having to face the prospect that we'll have
A slightly different perspective was offered by one man. He stated that he felt the key difference lay in the fact that from the start women are the major participants in family building in that they actually experience pregnancy and give birth. Men are relegated to the role of bystander from the outset. He stated that as a result, he personally felt "emotionally it has less of an effect on me. It’s not crippling."

One last viewpoint was expressed by a male. He stated that his motivation for wanting children was not the same as his wife’s and therefore he was less emotionally traumatized by their infertility. According to this man, his wife, like other women, had this maternal drive underlying her desire to have children. There was a deep and all-encompassing need within her. This was not the case for him though. His interest was much more superficial. He stated that his motivation was purely to "have fun." When questioned further, he responded that when he was with any of his friends who had children, they always seemed to be enjoying themselves and he thought that he, too, would derive pleasure from that type of experience. He went on to elaborate that he thought having as much fun as possible was what life was all about. Having children was just one of many ways that pleasure could be obtained.

Female View of the Male’s Perspective

When women were asked about the male’s emotional reaction to the issue of infertility, they offered similar
to make some major decisions in the near future. I find that anxiety provoking." The third man within this category readily acknowledged that he frequently thought about and discussed his infertility. For him this was a typical style of dealing with difficult issues. He tended to derive benefit from talking out his concerns. He stated, in fact, that he tended to do this excessively, i.e., to the point that he often spoke of little else.

The majority of men reported that this issue was not on their minds much of the time. Some (N=3) readily admitted, "Careers come first, then family." They said that it was relatively easy to separate their personal lives from their professional ones. All of these men seemed to believe that men are career-oriented and women are family oriented. This philosophy enabled them to effectively devote themselves to their careers while minimizing the impact their infertility may have had on them personally.

There were a few others (N=3) who stated that they had to make a slightly more conscious effort to avoid thinking about their infertility situation. All three chose the same approach, i.e., they immersed themselves in other activities. Two men stated that they "get lost in hobbies." Each enjoyed woodworking and spent more time in their workshops as a way of avoiding the infertility issue. The third man reported that he had a wide variety of interests and was able to "put infertility on the back burner most of
the time." He spontaneously added that it was not a
difficult thing to do.

One last man reported that his only infertility related
concern was for his wife's well-being. If not for that,
then he would not think too frequently about their
infertility. He did state, however, that he was constantly
wondering throughout the day how his wife was doing. While
he readily acknowledged that for her some days were good and
others were especially bad, he seemed to have little insight
into what may make particular days worse than others. It
was also unclear from his response if he ever openly
addressed this concern with his wife.

Interestingly, none of the men reported having
difficulty dealing with any of the daily situations the
women had spoken of. When specifically questioned about
this issue, none of them reported any emotional reaction to
pregnant women or children playing in the neighborhood. In
fact, not one man could recall any experience where an
external situation caused him to feel badly. This report is
in marked contrast to that of the women.

Regarding verbal expressiveness, essentially the same
categories existed for the men but the numbers within each
were exactly opposite that of the women. The majority of
men (N=7) did not want to discuss the fact of their
infertility with anyone. There were those (N=2) who were
comfortable sharing this information with only a few select
family members. Finally, there was one sole man who stated
that he enjoyed and actually derived benefit from talking with others about his and his wife's infertility.

The common sentiment shared by those men who did not want to discuss their infertility situation with anyone was, "It's a personal thing." Some men (N=3) stated that in general they do not discuss personal matters with anyone but their wives. As one man stated, "Why we don't have children is no one's business but ours. I don't feel any need to discuss it with anyone." These particular men described a consistent stance of not sharing family concerns with outsiders in all areas, only one of which was infertility. Others (N=3) related their reticence more specifically to the issue of infertility. For example, one man stated "For me, it's a masculinity issue. I'm not talking about this stuff to anyone." For another man, embarrassment was the major underlying concern. He stated, "It's embarrassing to discuss semen." One last man stated, "I can't discuss it with somebody else unless they have had a problem too. It's too uncomfortable." He was unable or unwilling to elaborate any further. Within this group of non-discussers, only one man stated that he would have preferred to share some infertility issues with at least family members and perhaps a few friends. He was unable to do so as his wife was adamantly opposed to the sharing of any information related to their infertility. He also qualified his statement by saying "Since she feels so strongly about it, I'll do it her way. It's really not that big of a deal to me anyway. I
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just think it would lessen some of the stress, especially for her, if we talked to someone about it."

There were two men who stated that they discussed their infertility with a few select family members or friends. One man said that he chose to talk to some of his co-workers about it because, "It made it easier to leave work early and with short notice for medical appointments if they knew what was going on." Both this man and the other one in this category stated that they rarely initiated the conversation about infertility. Rather they fairly willingly responded to questions posed by others. They both qualified these statements by saying that they tended to provide answers to the questions asked but rarely offered any additional information to elaborate on the subject.

There was one male who stated that he benefitted from sharing information about their infertility situation. To him it offered a sense of relief to talk about all that he and his wife were going through because of their infertility. Interestingly, his wife preferred to minimize her conversations about infertility, even with him. This reticent reaction from his wife only further fueled his desire to talk to outsiders. He readily admitted that he was seeking support from others as well as addressing his internal need to ventilate. He described getting much relief and comfort from this style of expressiveness.
Conclusions

In sum, gender differences were evident on each of the above described issues; underlying meaning, emotional upheaval, frequency of thinking about infertility and verbal expressiveness. Overall, the majority of infertile people who were interviewed thought that women were significantly more emotionally traumatized by the infertility experience than the men were. A few thought the key factor was not gender, but rather in which member of the couple the etiology of the infertility resided.

For the majority of women, the underlying meaning of infertility was a loss or lack of fulfillment of their idealized female role. For men, their major concern with infertility was the possibility of not passing on their genes or family name to the next generation. The entire issue of infertility was of much smaller magnitude for the men.

In terms of emotional upheaval, most of the women agreed that infertility was one of the most, if not the most, devastating experiences of their lives. Almost every aspect of their lives was affected by infertility. This was not the case for men. The majority of men viewed their infertility as one aspect of their lives. All described it as an important one but also one that could be fairly easily separated out from the rest of their lives.

How often women and men thought about infertility as well as verbally expressed these concerns was also very
different. All of the women reported thinking about infertility almost constantly. This was in marked contrast to the frequency reported by men. The majority of men reported that they rarely spontaneously thought about their infertility. In terms of priorities, they clearly stated "careers came first, then family."

Regarding verbal expressiveness, essentially the same categories existed for both women and men but the numbers within each were exactly opposite. In essence, the majority of women enjoyed and benefitted from talking to others, whereas the majority of men preferred to not discuss their infertility with anyone.
Question 4

IMPACT OF A DIAGNOSIS

As previously discussed, it was not feasible to compare couples with diagnoses to those without since the vast majority of couples (83%) carried a diagnosis. This issue, then, was addressed primarily through information gained during interviews.

From the interviews, it became clear that there were primarily three responses to the question of the impact of having or not having a diagnosis. Overall there was agreement with the idea that having some kind of diagnosis was easier psychologically than not having a diagnosis. Many people, however, qualified their responses. A few people could not decide whether having a diagnosis made any difference or not. Essentially they felt that it was both good and bad. Only one person felt strongly that not having a diagnosis was better (psychologically). His philosophy was "Without a diagnosis at least there is hope."

For the most part people seemed to say that a diagnosis provided them with something concrete; something they could point their fingers at and say "This is the problem." It also seemed to provide some degree of comfort to people in that it gave them some type of framework to help them understand what they were going through. As one person stated "It gives meaning to this madness". The increased level of understanding seemed to also enable the individuals to be more patient while involved in medical treatment,
rather than becoming easily frustrated over the length of treatment as well as the lack of success to date. For one couple, having a diagnosis had a calming effect. Before they had a diagnosis they were expecting to get pregnant with every treatment cycle and were devastated when this did not occur. Once they had a diagnosis they both felt better about treatment and at least temporarily experienced reduced pressure as well as expectations for each cycle. One woman commented that the finality of a diagnosis enabled her to accept her infertility and "get on with life".

Some respondents were unsure whether it was advantageous or disadvantageous to have a diagnosis. This viewpoint seemed to be shared primarily by those people who had nonspecific and/or inconclusive diagnoses. A common sentiment was that with this kind of diagnosis, the good news was that there was hope for success. The bad news was that nobody seemed to be completely sure what was being treated. As a result of this uncertainty, there was a feeling that you could "slip around the problem even if you don’t know what it is". In other words, effective treatment may necessitate both proper medical intervention and a lot of luck. That was especially unsatisfying and difficult for people to accept. For some the lack of a concrete diagnosis offered them additional hope and time which was perceived as helpful in that they could feel like they were pursuing the next aspect of treatment without having to deal with major issues and questions about the future and their treatment.
In retrospect, though, some people did feel that this was a false sense of hope in that nothing productive came of the additional time spent in treatment. Inevitably they were confronted with the frustration of unsuccessful treatment and the uncertainty of their future medical treatment, just at a later point in time. One woman stated, "I think it’s harder since I don’t have some problem that they could either effectively treat or be done with treatment altogether". One woman commented that the uncertainty of their diagnosis prevented her from actually effectively dealing with her emotions. She stated, "I just went through things and never really got to the bottom of how I felt."
Question 5

STAGE VERSUS UNIQUE EXPERIENCE OF INFERTILITY

It should be noted from the outset that there are three predominant perspectives from which to address the question of the existence of common stages in the experience of infertility versus an individualized and unique experience of infertility. These include the general overview, the specific gender approach and third, the couple as a unit perspective. Each of these offers valuable insights into the issue and as such each will be discussed in greater detail.

Typically when a relatively new phenomenon is being investigated, the most common approach is to speak in generalizations. For the case of infertility an example would be how the infertile population at large, commonly referred to as "they," felt. These discussions frequently included multiple emotional positions verbalized by infertile patients. It was essentially a population perspective or a general discussion involving a number of thoughts and feelings expressed by relevant parties. A more specific presentation is that offered by gender. This approach offers a more detailed understanding of the specific issue of infertility. It further enables an understanding of the complexity involved in such an issue. The last approach, that of the couple as a unit, is a very relevant perspective for the issue of infertility. Because infertility affects both partners of the couple, their
unified experience may bring additional issues to the experience of infertility. While it is an important and valuable position to explore, it is also quite complicated. What becomes immediately obvious to any researcher is that in order to accurately assess the "couple as a unit", specific research tools must be developed and utilized. Attempting to get an overview of the "couple's" response to infertility proved to be quite difficult in practice. For example, an attempt was made to average the responses on the questionnaire for both the women and the men i.e., obtain a merge score as an indication of the overall feelings of the couple as a unit regarding specific aspects of infertility. This proved unsuccessful because it tended to mask the true picture of each participant. This was especially so when reactions were quite different. Because the enormity and complexity of this issue was unanticipated, no provisions were specifically made in the context of this research endeavor to undertake such a comprehensive study.

As a result, the major focus of the current research study in relation to the relevance of stages to the experience of infertility is addressed in a two-fold manner, both from the general, population perspective as well as from the differential gender perspective. Both of these perspectives are particularly useful. The general view encompasses the overview of what feelings and thoughts may be relevant to each of the stages previously described in the literature. The gender differentiation explores each of
the relevant stages and depicts the differences by gender. This provides a clearer and more specific description of what issues and emotions are involved in each of the stages.

The interview data reveal clearly that a stage specific analysis of the emotional response to infertility does not have broad applicability. This reflects the very variable and singular circumstances attendant to the experiences of individuals and couples. In essence, this relates to many of the variables which comprise the substance of the questionnaire. No unifying threads could be identified that would link all couples to given stages in the so called emotional continuum. Nevertheless the interviews revealed several important insights.

From these interviews it became clear that there was not a generalizable progression of stages. Rather, people reported that they experienced many of the feelings associated with each stage, at various times throughout their treatment. Some reported that during each treatment cycle they felt many of these emotions. Further, there often seemed to be a progression from one stage to the next within the treatment cycle. Many others, however, described these emotional reactions being evoked by particular events and experiences they had. In fact, many of these emotions were commonly experienced in response to any number of situations, experiences or events people found themselves facing. The findings are, therefore, presented in order of the initially presumed stage theory, which is analogous to
the Kubler-Ross stage theory plus one stage (Rejuvenation/Accommodation).

**INITIAL REACTION**

When interviewees were asked what their initial reaction was to the fact that they may have an infertility problem, slightly more than half of the respondents described denial. Most of the others stated that they did not experience any denial in response to the possibility of an infertility problem. A few seemed to accept the reality and the truth of the information and were "panicked and devastated."

**Denial**

For those people who did acknowledge denial, it seemed to be perceived in predominantly two ways. One group labelled themselves the "eternal optimists." They reported feeling that initially they thought conception would just take longer. The length of time that individuals felt comfortable using this approach varied dramatically. Men especially were capable of allowing this type of thinking to persist for prolonged periods in the absence of encouraging information. The second group tended to deny the existence of a problem through minimization. They reported that if by some remote chance there was a problem, it would not be any big deal and it would be easily and quickly rectified by a physician.
Acceptance of a Problem from the Start

For those who did not report experiencing denial, most stated that they had expected to have some type of infertility problem. Some felt this way because of their family history of difficulty conceiving. One couple stated that they were not surprised at their infertility and that they were sort of expecting to have some difficulty with conception because of their advanced ages and their premarital sexual activity, which involved numerous partners. Another couple felt that their lives were too wonderful to not have to deal with some traumatic issue at some point in time and that they felt that infertility would fit the bill.

These two couples immediately accepted the news of an infertility problem as the truth. As a result they were most concerned. For one in particular this news emphasized the importance of not wasting additional time and a sense of real urgency was imparted to this problem. The second person's response was much less emotionally reactive. He described relief at finally knowing what the cause of the problem was. He felt now a specific treatment could be implemented and resultant progress could be made toward rectification.

In reviewing the interview data it appeared that those people without conclusive diagnoses tended to deny the possibility of an infertility problem longer those who had a specific diagnosis. The lack of a diagnosis seemed to
foster hope and optimism in these people. In this context, people stated that until their physician told them it was impossible for them to conceive, they would remain hopeful.

In terms of gender differences, there did seem to be some particularly striking differences. Women, in general, tended to deny less than men. In talking to these women it seemed that they were the ones who had been most interested in beginning a family and because it did not happen immediately, they were always acutely aware of the possibility of some underlying problem. In keeping with this, women seemed to be the ones who initiated the physician contact with the idea of pursuing their concern that conception had not occurred to date. It seemed that while both women and men may have initially denied the possibility of an infertility problem, women’s denial was shorter lived and they were the ones most interested in taking the next step toward dealing with this concern. Men, on the other hand, seemed less ready to pursue medical treatment and more likely to feel that their wives were over-reacting. Their attitude tended to be more of a "wait and see" one, although they were all willing to participate in the medical evaluation should their presence be requested. This participation seemed to be as much a statement of support for their wives as it was out of personal concern for their lack of conception. As one man stated, "My wife was all bent out of shape at first. She made all of the arrangements and was getting more upset and
angry as time went on. I tried to keep an open mind. I didn’t know what to expect, but I didn’t feel upset or angry. I just figured we should give it some time. I went to the doctor’s with Flo just to hear what they had to say and be there if she needed me." Another man described himself as the "eternal optimist." He added that "Even now, after five years of treatment, I’m still very hopeful. Barb, on the other hand, doesn’t seem to have much hope left."

There was one last area where gender differences were evident. Fairly early on when couples were trying to conceive, sexual relations took on new meaning for many of the women. The majority of men (N=6) expressed little change in their view of sexual relations. They stated that enjoyment for the moment continued to be the primary motivation. Most women (N=8), on the other hand, viewed things differently. Because of their concern with getting pregnant, sexual relations became very goal-oriented. They often focused on the timing of these relations as well as the frequency and were acutely aware of when to target the occurrence of such relations. Spontaneity and the pleasure of the act became secondary considerations.

**THE SECOND PRESUMED STAGE: ANGER**

When responding to the question of whether anger was one of the stronger feelings these people had experienced, responses could be categorized into three areas. One group acknowledged feeling a considerable amount of anger. The
major variable among this group seemed to be where the focus of this anger was directed. The second category of responses seemed to feel that the term "anger" was inaccurate. They chose various other descriptors as more accurately portraying their feelings. The third category of respondents rejected the idea of anger.

Within the group that did experience angry feelings, there were differences in both intensity and focus of the anger. One woman vehemently stated that, "In spite of all other emotions, anger is there all of the time." Two women stated that their anger seemed to be cyclical. They reported feeling anger at a specific time during each treatment cycle. More specifically, they became especially angry the day they got their periods, following the intense treatment month. Typically this anger was quite intense but did not last more than one or two days. For the majority of people within this category, their anger seemed to be highly situational or event related. For example, some women reported that they were angered by other people who felt a need to protect them from the news of someone else’s pregnancy. This approach infuriated some women who felt badly that friends of theirs would think so little of them that they would not be capable of sharing a friend’s good fortune. Many people in this category mentioned that stories of child abuse and unwanted pregnancies were especially difficult to deal with. Their initial response to such situations was one of anger and resentment. Many
responded to these situations with questions of "Why me?" or "How can life be so unjust?". While frequently this anger was directed toward people, this was not always the case. One woman reported channeling her anger toward God. She couldn't understand how God could be so cruel to some people. Further, she felt that if there really was a God he could well handle all of her angry feelings probably better than any human being could. Some women internalized their anger. They tormented themselves with questions of what they could have done to warrant such a severe punishment. For some this was a transient query, while for others this was an additional burden which plagued them fairly regularly. Lastly, one person reported being more easily angered over little things or things out of her control. For instance, if her medical chart was misplaced for an appointment she became furious. Normally she would not react so intensely nor so negatively.

The second group of respondents relied upon terms other than anger. A few people felt that "frustration" was a more accurate descriptor of their feelings. These people tended to be the ones that ascribed to the philosophy that if you try hard enough, you will always get what you want. They reported that for them infertility was the first instance in which this did not hold true. As a result they found the entire situation overwhelmingly frustrating. One man felt that anger was too strong of a term for his feelings. He preferred the word "concern." He defined that as feeling a
little "jipped along the way." One other man could not clearly label his feelings although he denied that they were feelings of anger. He described difficult feelings stemming from "others lack of understanding of infertility as a whole experience." He stated that he became upset by the unending number of irrelevant questions posed by outsiders. Partially this was because these questions were impossible to answer and partly because they reflected such a dearth of insight into the plight of infertility. These questions served as a constant reminder that no one really understood what he and his wife were experiencing, despite many of these people really caring about them. This realization was particularly unsettling for him personally and caused much internal anguish.

The third group of respondents stated that they had not experienced angry feelings. Two men summed up their feelings by saying "What’s to be angry about? This is just something that happens and you have to deal with it." One woman stated that rather than angry she became frantic. Her major concern was finding out what was wrong and where she could receive proper medical treatment. For her, anger did not even enter into the picture.

The gender issue was particularly striking with respect to the question of anger. Women seemed to experience much anger on a fairly regular basis. They offered numerous examples of situations that caused them to feel angry. As an example, one woman who had been trying to conceive for
five years stated, "Despite all of the other emotions, I think anger is there all the time. It never leaves." Men, on the other hand, seemed less intensely emotional about this issue. They tended to express more accepting feelings associated with infertility in general. More specifically, of the ten women and men who were asked about their angry feelings, eight women felt strongly that anger was an integral part of what they had experienced. Only two men discussed thinking about it even fleetingly. The majority of men chose to rename this term or reported experiencing no angry feelings. Interestingly almost all men spontaneously commented on the intensely angry feelings their wives had experienced.

THE THIRD PRESUMED STAGE: DEPRESSION

This question proved to be quite illuminating. Of the 20 people interviewed only four stated that they never had felt depressed. Two of these people, however, admitted they thought that depression was inevitable at some future point, but they were not sure when that would occur. One other questioned if in fact he may be depressed but just hadn't realized it because his schedule was so busy. He did acknowledge feeling tired much of the time, but ascribed this to his hectic pace.

Interestingly the response to this question also strongly divided along gender lines. More specifically, many of the aspects of depression were experienced and perceived differently by women and men. For women the
depression was multi-faceted. There were numerous components to this one issue. Further, this form of depression seemed to permeate most other areas of their lives, and for some it increased as time went on. Some women described the depression as "feeling that you have no future. You don't know whether you should get a job and get on with your life and forget the idea of having children or if things will all work out and you'll have five kids. I could handle either one; it's not knowing what the future holds that is so difficult." Three women stated that their depression was primarily related to being involved in medical treatment. Two of the three stated that going through even the basic procedures was depressing because each had such a low success rate. In addition, they were painful, unpleasant, and required huge amounts of time, money and energy. As one stated "From there it just got more depressing and more depressing." Another reported that after one year of treatment she began to feel the depression. She flatly stated "Every time I thought that I'd been through the worst, they hit me with something much worse." For another woman it was the lack of success associated with each cycle that she found most depressing. She felt that she had totally immersed herself in the treatment cycles and to end up with nothing but bad news was extremely depressing. One woman had miscarried during the time that 7 other women at work were pregnant, some of whom were ambivalent about their pregnancies. This woman was a
supervisor and was often placed in a position of having to listen to these women complain and express their anger at the prospect of having a child. Given her long-standing infertility problems and her current misfortune, she felt that she was barely able to go to work and make it through the entire day. This required every bit of energy she could muster. Consequently when she got home she was exhausted and very depressed. Most of the time she chose to isolate herself as a way of protecting herself from having to deal with the pressures of the outside world. She felt that everyone was pregnant and she couldn't bear to even see anyone who was pregnant, never mind have to interact with them on a voluntary basis. She wanted desperately to quit her job but that was where her medical benefits came from as her husband had just recently started his own business. She felt trapped all of the time. One woman reported that in the midst of her infertility treatment, she was told by her family physician that she was clinically depressed. He had in fact recommended antidepressant medication. She and her infertility specialist decided to try increasing her activity level as a way to initially combat this depression. This helped to lessen her depression. One other woman, who had been in treatment for 5 years, described her feelings of depression as longstanding. She felt that over time, though, she had learned how to better cope with these feelings. Although depressing feelings were still present,
she felt that the really bad depressions were behind her and she was able to get on with her life.

These experiences were not reported by men. Their sense of depression seemed to be quite different from that of the women. Less than half of the men (N=3) did state that they had some 'concerns' but frequently they preferred to call them something other than depressing. The intensity, the focus as well as the duration of these 'concerns' was much less than those reported by women. Among the rest of the males (N=7), five denied any feelings of depression, one acknowledged a long-standing depression and the last attributed the onset of his depression to a specific event; i.e., the death of his newborn following years of infertility treatment. All of the men, however, were acutely aware of their wives' feelings of depression.

Of those who denied any feelings of depression, one man who had only been in treatment for less than a year thought that he and his wife hadn't reached that point yet, although he fully anticipated this would come at some time. The other four men who denied depressing feelings were especially clear and unemotional when responding to this question. They flatly stated essentially the same sentiment: "No I've never had anything like that. She's depressed, not me."

For the three men who preferred to relabel their emotional reaction, they clearly stated that any feelings of "concern, disappointment or frustration" that they may have
experienced were only reactive in nature. They seemed to discount these emotions. Rather, they tended to describe their emotional responses as much less self-directed, much less intense in nature and much easier to compartmentalize than their wives' feelings. These men stated that because their wives were depressed this caused them to feel badly on occasion. A couple of the men admitted that they really only dealt with this issue when they were forced to, typically when they were home in the presence of their wives. Often because they felt ill-prepared to effectively deal with the situation, they gave up and 'busied' themselves with some type of project. Of particular interest is the fact that each man stated that he almost never attempted to openly discuss his concern for his wife's well-being in a direct manner. Rather, they tended to decide what would be best and pursue that strategy without ever conferring with their wives to find out how they may be able to be more supportive and helpful during this particularly difficult period.

There were two men who did acknowledge feeling depressed. One man's description was quite similar to that of the majority of women. He stated "Certainly it's a prolonged depression. I feel I haven't really truly been happy in over a year. Because of the infertility it seems that we face every situation a notch or two below everyone else. We just kind of maintained this low level of depression for a long time. It's hard to go through the day
without thinking about our infertility. You realize you may never achieve one of the things you really wanted to. It's very depressing to think about. It's just so pervasive. So many other problems go with it. I can't separate it out from the rest of our lives." The last male who responded to the issue of depression stated that his depressive feelings surfaced following the death of his newborn daughter. Despite the fact that they had been in medical treatment for over five years and his wife was quite depressed much of the time, "It didn't really bother me til Emily died, and we had to start over again." It seemed that his sad feelings may have been more of a grief reaction to the death of his daughter rather than directly related to their infertility situation. Perhaps the combination was overwhelming enough to cause him to feel depressed for the first time.

THE FOURTH PRESUMED STAGE: HELPLESSNESS

In addressing the question of helplessness, there was much agreement among the types of responses offered by both men and women. Majorities of both sexes (N=13: F=7, M=6) felt that there was a large degree of helplessness inherent in the medical treatment of infertility. Within this group some individuals had developed coping strategies which enabled them to more effectively deal with their feelings of helplessness. Within the minority view, an equal number of both men and women (3 and 3) interviewed vehemently expressed no feelings of helplessness. There were gender
differences, however, regarding the perspectives and rationale underlying these positions.

Basically, the women offered two opposing viewpoints. The overwhelming majority of women (N=7) experienced strong feelings of helplessness. Within this group there were two women who seemed to accept at face value this feeling of helplessness. Their perspective was predominantly one that encompassed the sentiment, "No matter how hard you work, this is one of the few situations in which your goals may not be reached." Although it was difficult, they could accept this result. One other woman who accepted this philosophy further elaborated by saying, "Helpless and hopeless, that's how I feel all the time." One other woman stated that part of her helpless feelings arose from her doctor treating her as if she were not smart enough to understand all of what was going on. He shared very little with her and tended to just provide regular instructions. She reported being very resentful of this style of interaction, but did not feel comfortable discussing this issue with her physician. Two women shared the philosophy that because they were doing all that they could with respect to medical treatment, they did not feel helpless. They could accept that even if it was not successful they had done their share and that was a comfort to them. There were three women who felt that helplessness was not the issue. They felt that they, as individuals, had been asked to take on a great deal of responsibility for their own
infertility treatment. Of interest, all of these women reported feeling comfortable questioning their physician about the rationale for a specific test or procedure. Further, each of these women described their physicians as offering them options rather than dictating treatments. This approach seemed to be quite useful and much appreciated by the female patients.

The overall feelings of the men were quite similar to those expressed by the women, however, their perspectives were somewhat different. Again the majority of men (N=6) reported feelings of helplessness. Within this group, there appeared to be predominantly two responses to these feelings. One group of men stated that this helplessness was extremely difficult to deal with. One man said that "Everyone was dictating to us. I just did whatever they asked and tried to keep the frustration and displeasure to myself, in large part to prevent my wife from getting so upset." This particular man had been withholding his feelings from the outside world for over two years. He did acknowledge that this was his typical approach to dealing with difficult emotional issues. Another man reported that the major impact of helplessness for him was the lack of spontaneity, especially related to sexual activity and the fact that intercourse had to be on a time schedule which was usually determined by someone else. He found this extremely frustrating.
The second group of responses to the issue of helplessness tended to be more accepting and less resentful. While these men clearly acknowledged that feelings of helplessness were present, their perspectives enabled them to cope with these feelings better. Basically these men shared the view that the infertility treatment was only controlling a part, and a small part at that, of their lives. Their rationale was that they had voluntarily given this control to their physicians in exchange for medical treatment. They felt that this was a decision that they had made and were able to change at any time. They had therefore accepted these feelings of helplessness as an inherent part of medical treatment. One man expressed that his initial sense of helplessness was related primarily to treatment taking such a long time. These feelings evaporated once this man came to accept the long time frame of treatment.

In contrast, there were those men (n=4) who did not feel helpless. One man who did not feel helpless in the infertility situation attributed this to the fact that he felt that they still had options to pursue; that they had not exhausted all the alternatives available to them. Further he described an additional role which he felt a need to take on, that of carefully monitoring the care rendered to his wife by their physicians. Because she was seen by one of three physicians and their practice was very busy, they sometimes did not recall all of the details of her
particular situation. As a result the couple felt that she was at risk of experiencing undo side-effects of treatment because of a physician oversight. Two other men reported that they did not feel helpless because they felt that they were doing all they could and that was that. The fact that they were doing as much as they could seemed to give them some reassurance that they were actively involved in their treatment and that was sufficiently satisfying to them. One man denied feeling helpless primarily because he had so much confidence in his wife's ability to thoroughly research the entire area of infertility as well as investigate their specific situation that he felt nothing would be missed.

THE FIFTH PRESUMED STAGE: REJUVENATION/ACCOMMODATION

When couples were asked specifically about this topic, they evidenced much difficulty answering any related questions. This may have had to do with the fact that all were heavily immersed in treatment at the time of the interviews. As a result, they were not seriously contemplating any major changes for dealing with their infertility problems. When this question was being developed, the intent was to try to determine whether people actually experienced this reorganizing burst of energy. For whatever reasons, no one seemed to fully appreciate this as a phenomenon. It had not been written about in the literature but had been experienced to some degree by this researcher. Perhaps it would be more relevant to pursue this area of research with couples who have recently ended
medical treatment and are currently pursuing alternatives to creating a family. As a result of their change in focus, they may be able to delineate the thought processes or events which enabled them to take some action. This was really the initial intent of the question and may best be answered by people who have made changes in their approaches to building a family.

**THE SIXTH PRESUMED STAGE: ACCEPTANCE**

Acceptance was perceived to be the final phase according to the stage theory. When interviewees were questioned about this issue what became immediately obvious was that everyone had a different interpretation of the meaning of the word. For some it meant 'accepting' the fact that you have an infertility problem. It may therefore take longer for conception to occur. For others acceptance meant being comfortable with your current infertility situation and being able to move on from there. In this interpretation the key seemed to be the ability to move forward and take some action. To a few others acceptance connoted a feeling of "loosening up and letting go some of the ideas that were once so important" to them. For example, a few of the women spontaneously commented that they would not allow themselves the pleasure of buying new clothes. They felt a need to hold off until they could buy maternity clothes. For them to actually go out and buy clothes was perceived as overcoming a great obstacle. For a few the term acceptance was largely a negative word. To
them it signified "a giving up on a dream." Inherent in that definition was the feeling that children were an unlikely outcome for them. In order for them to reach the point of acceptance, they felt that they had to be ready to 'accept' living their lives without children.

In contrast to previous responses, this issue evoked minimal gender differences. Most respondents, both male and female, seemed to have given this topic some prior consideration. Everyone, except one person, was able to clearly articulate his or her stance on the issue.

There were basically two schools of thought regarding this issue: either people felt that they had accepted their infertility or they had not accepted it. Only two out of the entire group of 20 felt that their position was ambiguous. One man had really not given this issue much consideration at all. When questioned about this area, he was unable to formulate any type of response. A second male described himself as "straddling the fence on this issue." He had thought about this topic in great detail and had conceptualized the term "acceptance" as being comprised of multiple stages. The first stage involved accepting the fact that there was any type of infertility problem. Once someone had overcome that, they could move on to the next stage which addressed accepting the severity of the infertility problem. This involved the realization that whatever the problem was it may not be effectively treated immediately. More often than not any type of infertility
problem takes a very long time to effectively solve. The third stage involved the issue that despite medical treatment, a couple may remain infertile for the rest of their lives. Currently, this is where he saw himself.

Out of the remaining 18, 11 stated that they felt that they could "not accept" their infertility. Of these 11 respondents, seven were women and four were men. It must be reiterated that the definitions of what "acceptance" meant varied fairly widely among respondents. There was not a uniform definition for this term. One underlying theme for people in this group seemed to be that they derived a great deal of encouragement from their physicians. Many seemed to believe that if their situation were hopeless their physician would level with them and direct them to consider alternatives. This was one way in which patients chose to view the physician's role. It also lessened the burden of responsibility regarding infertility that was often overwhelming to them. It seemed to comfort patients in that they were trying to ensure their physicians had responsibility and were accountable for the medical treatment they were prescribing. One couple stated that the fact that the wife had gotten pregnant and delivered a child only served as a constant reminder and source of motivation to continue with treatment. The fact that she conceived once was sufficient evidence that conception was possible for them again. They could not allow themselves to think that it could not happen again.
A few women stated that they had not reached acceptance yet because in their eyes this meant ending their involvement in treatment. All of them felt that this was a premature move at the current time and in fact, if they did so they would regret it for the rest of their lives. That idea alone prevented them from moving on to acceptance. It also seemed to provide a rationale for continuing in treatment, which was comforting to them.

The second category of respondents stated that they had reached the point of acceptance. This group was comprised of 7 people: 3 women and 4 men. The major underlying theme for this group seemed to be that they had come to the realization that "life goes on" and "what will be will be." As a result, many of them had devised or were in process of devising a plan for the future. The fact that they were able to proceed with such a plan signified to them that they had accepted their current situation and were constructively dealing with it. There were two people who had not gotten to the point of having a plan devised however, they did consider themselves to be in the 'accepted' category. For them, just the fact that they were able to unemotionally and rationally discuss their infertility situation was a symbol that they were comfortable with the reality of their particular situation. As one woman stated, "I may not be tickled pink about it but I can see it for what it is. I still feel a loss." One other woman commented, "After after a while, you begin to see that in spite of the infertility,"
you still have to go to work, eat, clean the house. You get tired of always putting infertility first, especially when nothing positive seems to be happening. Over time, you begin to realize you are doing all that you can and whatever will happen will happen. I have a need to get on with my life." They seemed to have come to the point of acceptance through a laborious and highly emotional process. Each of them described this process and the underlining meaning this issue held for them. It was clearly viewed and experienced as a major emotional breakthrough which signified forward movement in the process of dealing with infertility.

The men shared quite a different perspective from the majority of women. They seemed to have an easier time accepting the fact of infertility than the women, in general. In fact, two of the men were quite casual in their responses. A representative statement was, "Infertility is just something that you have to deal with." Often they had little additional to say and seemed not to appreciate a need for amplification.

In summary, it became clear from the interview data that there was not a generalizable progression of stages. What was clear, however, was that the combination of individual circumstances and widely varying medical management of infertility contributed to the highly variable and diversified reactions described by the interviewees. It should be further noted that the stages described in the literature were extremely applicable to many of the
experiences described by the respondents. The major point of distinction was that there was not a progressive sequence to these emotional reactions. In fact, there was much variability with respect to these emotions in terms of how they were experienced and the impact they had on people facing infertility.

There were primarily two types of initial reactions. There were those people who denied the possibility of an infertility problem. The extent and length of this denial was extremely variable. The contrasting perspective was also noted. There were those who immediately accepted the possibility that an infertility problem existed. There was no surprise or shock. Of interest was the fact that it appeared those people without conclusive diagnoses tended to deny longer than those who had a specific diagnosis. Additionally, gender differences were noted. It seemed that the women, in general, tended to deny less than men.

The second presumed stage was anger. Three types of responses were determined. There were those who reported intense feelings of anger, those that relabelled this term and substituted words such as "frustration" and "concern" for anger and a third group of respondents who rejected any feelings of anger at all. Again, gender differences were evident with regard to the issue of anger. Women seemed to clearly experience much more anger and on a fairly regular basis. Only a couple of men acknowledged any angry feelings and these were described as fleeting ones at best.
The presumed third stage was entitled depression. Most people readily admitted experiencing some form of depression. Interestingly, however, the women described this type of depression as multi-faceted, meaning that it seemed to permeate most other areas of their lives. This did not appear to be the case for the men. Most of them reported that they had "concerns", however, the intensity and focus of them was much less than those described by the women.

Helplessness, the fourth presumed stage, was uniformly experienced by most men and women. The respondents agreed that feelings of helplessness were inherent in the medical treatment of infertility.

The fifth stage entitled rejuvenation/accommodation did not seem to be relevant for any of the respondents. As such its existence and inclusion is questionable.

The final stage, acceptance, provided some interesting insights. Of particular note was the fact that there was wide variability among definitions used by the respondents. As such, there were many interpretations of this stage. For the most part, however, most people associated it with ending treatment. As such, the majority of respondents felt that they had not reached this stage, nor were they ready to do so.

ADDITIONAL AREAS OF IMPORTANCE IDENTIFIED BY RESPONDENTS

During the interviews questions were asked about other areas of possible concern. Some of these issues were
derived from the written literature, while others became evident only during the interviews. Specific areas addressed included decision-making both in and out of treatment, termination of treatment, long-lasting effects of the infertility experience, quality of the relationship with the physician and finally, constructive insights into the infertility experience.

This aspect of the interviews served a two-fold purpose. First, by giving the respondents an opportunity to elaborate on anything they felt was relevant and/or not adequately addressed during the interviews, it helped them to reach some type of closure regarding issues raised during the interviews. For the women this seemed to be especially valuable. Throughout the interviews, they, in particular, discussed very personal and emotionally taxing issues. Secondly, it offered new information and insights into the infertility experience which had not previously been discussed in any of the relevant literature. The following section will elaborate on each of these issues. Although most of the viewpoints were shared by both women and men, notations of the gender differences will be supplied where appropriate.

Decision-making

For treatment-related decisions, there appeared to be three varying levels of responsiveness to the advice of the physicians treating these patients. There were those patients who had utmost faith and trust in their physicians'
knowledge and therefore would do whatever was asked of them. There were those who needed to feel somewhat involved in the treatment decision-making process, but really did not want to play a dominant role. Finally there were those patients who needed to exert as much control in their treatment as possible.

For the people (N=9: F=4, M=5) who placed all their faith and trust in their doctors, the underlying rationale was uniformly consistent. All ascribed to the philosophy that "The physicians are the experts and they know what they are doing." These people felt that they were "at the mercy of the physicians" to comply with their requests.

The next higher level of assertiveness with respect to patient involvement in their own care were those people who wanted to hear and understand what the physician had to say before a new approach was initiated. Basically this group (N=7:F=3, M=4) felt more of a need to understand what was happening and why as a way of being involved in treatment. No one in this group seriously considered refusing treatment based on what they heard, they just wanted to be informed about their treatment.

Finally there was a group of patients (N=4: F=3, M=1) who were the most assertive in terms of demanding time and information from their physicians on a regular basis so they could decide the future direction of their medical treatment. These people tended to ask a lot of questions whenever they met with their physician and ensured that they
had a complete understanding of the plan as well as all of the possible side-effects of the treatment. No decisions would be made on the spot. Rather, they would go home and often do additional research and reading on the subjects which were discussed at the meeting with the physician. They would carefully consider all of the relevant issues and then come to some type of formal decision. When they returned to their next medical appointment they would inform their physician of their decision. This approach was more time-consuming but quite necessary for the comfort of these patients.

Termination

Essentially the same three levels of assertiveness existed for this issue. One group of respondents gave complete control of the length of treatment to their physicians. A second group gave their physicians primary control but they too were contemplating when the end of treatment should come. Finally, the last group of respondents wanted total control of their length of treatment and they had very definite ideas about when to end.

For those people who gave complete control to their physicians (N=7:F=4, M=3), the philosophies were all the same. They felt that their physicians were the experts and would tell them when it was no longer worthwhile to continue in treatment. Many of the women found this approach comforting as it reduced one of the burdens which was
initially on their minds. Interestingly, for most of these people, this issue had never been overtly discussed with their physicians. Rather it was just an assumption the patients had derived. No one, in fact, was even planning to broach the subject with their physicians.

Consistent with this same degree of passivity regarding the ending of treatment, there were two men who gave complete control to their wives. These two men stated that they wished to continue treatment only as long as their wives could handle it. As soon as their wives had enough or voiced any interest in terminating, that would be fine with them. These men saw their role primarily as support givers and as such were waiting for cues from their wives regarding the end of treatment.

A slightly more aggressive group was comprised of those individuals (N=4: F=2, M=2) who were working in tandem with their physicians regarding the issue of termination. Again, however, there was no overt communication between the two parties on this subject. Each party was working independently of the other and was free to raise the issue of termination at any time. The two women in this group were closely monitoring their treatment. Despite the ongoing daily involvement, they were trying to maintain a more global perspective of their treatment and its progress. They were approaching the possibility of ending treatment by gauging their perception of the likelihood of success. One man wanted to stop as soon as possible, but his wife did not
ever want to stop treatment. Rather than address the issue, he chose to remain silent and hope she would change her mind or her physician would end treatment. The second man in this group wanted to have a say in when the end of treatment would occur but had not given the issue any serious consideration, nor did he have any concrete plan to do so.

Finally, the last group (N=6: F=4, M=2) consisted of people who wished to determine for themselves when they would end treatment. For two women in particular there was a fairly clear idea of the endpoint. For one, her next birthday, her fortieth, was a milestone of significance. She thought that at that time it would be a good idea to terminate treatment. A second woman, a teacher, thought that the end of the following summer, just before she went back to work, would be a reasonable time to end treatment. Interestingly, the two men in this group had much less clearly defined endpoints. They were quite clear, however, on the fact that they wanted to be the ones to make the final determination regarding the end of treatment.

**Long-lasting Effects of the Infertility Experience**

There were essentially six types of responses to this issue, ranging from changing one’s personality to having no longterm effects as a result of the experience. Interestingly, gender differences were most prominent in the two extremes of the spectrum; i.e., there will always be persisting remnants of the experience and having essentially no long-lasting effects. The other four responses were
comprised of both female and male viewpoints. Some individuals provided more than one response to this question. Each response will be discussed in more detail in the following section.

The majority female response came from a group of women (N=6) who felt that "While the emotions may fade, there will always be remnants of the infertility experience for the rest of your life." One woman made an analogy to the death of someone. She stated, "It's like if somebody dies, you still think about them occasionally and feel sad. It's just easier as time goes on." Two women could not articulate exactly what they felt. One stated, "I don't know exactly what it is but it's something that you carry with you all the time." The other stated, "I don't think it ever goes away." The other three in this group felt that the emotional residual depends, to some extent, on the ultimate outcome of infertility treatment. Two felt that if they ended up childless, they would throw themselves into their careers and get on with their lives. They both acknowledged that there would be a void that would remain with them forever. At times they felt that this would be especially painful, but that they would learn to deal with those situations as time went on. One last woman stated that if she did have children, then they would serve as reminders of what she had gone through to build a family.

The opposite perspective was offered by the majority of males (N=6) who stated there would be no long-term effects
of having been through the infertility experience. Essentially they felt that the only effect of having had to face infertility was the fact that "we just had to work a little harder." The underlying sentiment seemed to be that while they were in treatment they were doing all that they could to rectify the problem. That was all that could be expected of them. Regardless of the outcome, they would adjust and life would go on. All acknowledged that one of the major difficulties would rest with the adjustments of their wives. Given sufficient time, however, all of the men thought that their wives would do fine.

The middle of the continuum was comprised of essentially four types of responses. The largest group of respondents (N=6: F=5, M=1) stated that as a result of their infertility experience their views of the medical field had changed. A smaller group (N=3: F=2, M=1) felt that any experience of a trauma, such as infertility, was something that shapes one as an individual. Another response was offered by one woman who described the major impact of the infertility experience for her as having changed her views on religion. Another response offered by one male was that as a result of the infertility experience he was more sensitive to the problems others may have.

For the group whose views of the medical field had changed as a result of their infertility treatment, the underlying theme seemed to be a realization that the field of medicine is an art, not a science. As one woman stated,
"Medicine is not what I thought it was nor what I want it to be. Once I realized this I bounced the other way. I became ultra distrustful. Now I don't believe anything they say."

After two years of treatment one man stated, "I just realized that, although they are specialists, they don't know everything. They can't. Nobody is that smart." On the more positive side, two women made the following comments. One stated, "Doctors are trained to make the best possible decisions given the information available. A lot of times with infertility they can't determine exactly what the problem is. Our doctor takes what he knows and makes educated guesses." One other woman stated, "There's a lot of logic and intuition involved in treatment. The physicians are learning all the time." Overall these respondents did not appear overly upset by this realization, however, there was a note of concern and disappointment at this realization. There was a feeling that they were being let down by the entire field of medicine and that was disconcerting.

Within the group of respondents who stated that facing a trauma such as infertility impacted on who they were as people, two of the women felt that they were better people as a result of the experience. One thought that she had become a stronger person. She stated, "I can handle much more than I ever thought I could. That makes me feel good about myself." The other woman described the entire experience as a "humbling" one. She stated, "It makes you a
better person as you realize that you can't always be in control. In society, usually if you work hard enough, you get what you want. Not so with infertility and that's a valuable lesson to learn." One final comment by the third person comprising this group was that infertility as a phenomenon has been incorporated into how she thinks about herself. She stated, "It becomes one of the identifying things for who you are. Infertility is such a part of your life for so long that it just doesn't go away. It becomes part of how you see yourself." In trying to clarify her statements, she did not seem to mean this in any sort of negative way, rather it had just become one of the components comprising who she was.

One woman commented on changes regarding her religious beliefs. She described herself as fairly religious to begin with. As a result of infertility and all its associated trauma, she was now questioning her previously held beliefs. For instance, she constantly asked herself, "If there really was a God, how could he allow such a terrible thing to happen to so many people?" including herself. She further stated that the church had labelled so many of the available treatment options as unacceptable that she had to carefully consider where she stood on these issues as well question her devotion to any church that had such backward and limiting views of ways to build a family. She stated, "How can a group of men who never probably wanted to have children anyway, condemn people like us who can only have
children through such high tech measures and dictate what is right and wrong? That's not fair at all. I've developed a certain level of comfort defying the church rulings." It appeared that religion had once been a very important part of her life but this no longer could be the case. While she did express anger and resentment toward the church, she had given this issue so much consideration that she had developed a certain level of comfort with her position at the current time. She had decided that she needed to do whatever it took in order to build a family, despite the church's dictates.

One male described a heightened awareness of the problems others may have as a result of infertility. He directly related his increased sensitivity for others to the fact that he had actually experienced this trauma. His major point was that, "If you haven't gone through it, you can't really understand how it feels." He added, "If somebody has a problem or wants to talk, maybe there is something I could say or not say that could be helpful." The main premise here was that as a result of dealing with infertility, this man had developed a certain degree of comfort with the issue and appreciation of some of the relevant feelings and thoughts. He, therefore, would be more open and available to help someone else deal with some of their concerns in this area. This was an approach he did not typically use but because of his personal experience
with this issue, he thought that he may be able to help someone feel better about their infertility.

Quality of the Relationship with the Physician

For this question there were primarily three types of responses. Gender did not seem to distinguish the types of responses provided. The two most supported groups of responses concluded that the quality of the relationship was of great importance. There were two specific attributes that these people reported as most desirable. The largest group (N=8: F=4, M=4) described trust and respect for their physicians knowledge as the most important ingredients in the physician-patient relationship. The second largest group (N=7: F=4, M=3) thought that a sense of caring from their physicians was of utmost importance. The third and final group of respondents (N=4: F=2, M=2) stated that they felt they had no relationship with their physicians at all and that the actual relationship was not the key ingredient in their treatment. Each of these positions will be further discussed in the section following.

For the largest group of respondents, the most important qualities in the physician-patient relationship were trust and respect, primarily for the knowledge the physician had. One man stated, "He’s the best. We’ve talked to others and always feel that ours is doing everything that can be done. If he can’t help us it’s doubtful anyone can." One woman held a similar view, stating "I think when he gave us all these research papers
he had written, it really helped. It gave us confidence that he knows what he's talking about. It also makes you feel responsible and mature that he's handing you all these research papers." The people in this category all seemed to share the sentiment that the most important aspect of medical treatment is the quality of medical care, i.e., how knowledgeable the physician was. Within this group, the common sentiment was that the quality of infertility treatment was not affected by the emotional qualities of their physician group. While many commented that their group was "pleasant and nice," these aspects were of lesser importance to these patients. In fact, they were viewed as almost afterthoughts, rather than important variables which would heavily impact on the quality of treatment. When further questioned about this, they stated that their major concern was the quality of medical treatment they received, not whether their physician was supportive of their feelings. Many spontaneously added that any offer of emotional support would be much appreciated, however, they did not truly expect this from their physician. They thought that their physicians were too busy to spend time on these types of issues.

For the group who felt that caring was the key factor in the development of a positive physician-patient relationship, there were specific areas which seemed to be of particular value for these patients. For some of these patients, the fact that their physician could recall all of
the details of their case indicated to them that he cared about them as individuals. It seemed that the physician’s good memory was being equated with taking a special interest in his patients as people, rather than as numbers or nameless cases. One other relevant variable in this caring relationship was described by a number of respondents. They felt that the fact that the doctors offered them time to express their emotional concerns was a genuine gesture of caring. It was a much appreciated part of the total infertility care of these patients. For those who considered the caring quality to be the most important aspect of the relationship, the implicit assumption by these people was that their physicians were quite knowledgeable about the medical treatment of infertility. The primary distinguishing feature, then, was the fact that they encouraged their patients to express their emotional concerns as part of their infertility treatment. One woman summarized it best by saying, "He acts like he has time for you when it’s your turn, even if he has a roomful of patients and he’s two hours behind. It makes a big difference when you’re under all this stress. If he shows some sympathy or taps you on the shoulder, it makes you feel good and that’s important." Similarly, one of the men commented, "It’s important to have a relationship with the physician because you are talking about very personal things with a stranger. After I dealt with the same physician for a while, and we felt comfortable with each other, my
defenses were less." Along these same lines, a couple of men commented that they felt good about the relationship with the physician in large part because of the compassion and great concern he showed for their wives. Sometimes, these men only indirectly were aware of this aspect of the relationship through comments from their wives. Nonetheless, the fact that their wives' emotional needs were being professionally addressed was a great comfort to these men. It may also have been a significant reduction of the burden of having to deal with the very difficult emotional concerns of their wives on such a continual basis. Perhaps any outside help would have been greatly appreciated to deal with what many of the men perceived as a very overwhelming problem.

The last group of respondents was comprised of only two women. They were receiving treatment from two different physicians, neither of whom offered any type of emotional support. As such, both had grown accustomed to this approach to medical treatment. Of interest, however, was the fact that both woman had different feelings about this. One woman was outraged at the fact that there was no provision for even the smallest amount of emotional support within the physician group. She stated, "We had no primary doctor. We just saw whoever was available. We couldn't even get an appointment with a physician to have a pep talk when we really needed it." She added that as a result, in part, of their unmet emotional needs they were seriously
considering ending treatment. Interestingly, they had not considered changing physicians. The second woman was much more accepting of this non-emotional approach to infertility treatment. She felt that, at times, it did make treatment more stressful but she insisted that her needs were met in other ways. She commented that she was fortunate in that her husband was very supportive and encouraging and that made it easier for her when times were very difficult. She also derived much support from other women in the waiting room of the physician’s office. Often there were very open and enlightening discussions on topics of great concern to her. As a result of these discussions, she was better able to deal with the emotional issues that often arose. She, therefore, accepted the fact that the sole focus of her physicians was the medical management of her infertility treatment.

Constructive Insights Offered by Infertility Patients

For many infertility patients, one of the most difficult aspects of dealing with this phenomenon was dealing with issues that were out of their control. While they acknowledged that this was often the case, it was still very taxing. This reflected being thrown into a new and unknown area where medical treatment was sometimes frightening, very time-consuming, often painful and almost always expensive, and also was related to one of the most basic human needs, that of raising a family. As evident from this piece of work and others, it is clear that
infertility raises a number of very difficult issues for patients, as well as friends and families of these patients. Friends and families always want to help in any way they can so their intentions are usually good. Nonetheless, with an issue such as infertility, such people are uncomfortable discussing it and, as a result, often say something inappropriate which causes pain for the other person. In order to address some of these issues, infertility patients were asked to provide constructive information for people in order to help them understand what the experience of infertility is like and what they, as outsiders who care, can offer infertile people, if anything.

This last section, then, is comprised of a compilation of ideas both spontaneously offered as well as solicited from infertility patients. The primary goals were to encourage theses patients to think about their situation and comment on both the positive and negative aspects. My intent was to have them provide a meaningful description of what it’s like to go through infertility treatment. This included their thoughts and feelings regarding specific experiences, what were especially difficult times and why, and what made things better. Finally, they were asked what they, as infertility patients, perceive as the most important information that needs to be conveyed to those people just beginning treatment as well as to the lay public, including family and friends.
The previous sections have described and detailed much of the more typical aspects of infertility treatment. There is, however, another facet. One of the things that became very clear from the initial findings of this study was that there was much variability among types of experiences for people facing infertility treatment. The particulars of each unique situation, combined with the individual personalities of the participants resulted in very complicated and sometimes overwhelming situations for both the infertile people as well as whomever they were interacting with. One of the most striking memories of my initial infertility days was talking to a friend about my initial feelings associated with being in infertility treatment. I can clearly recall the puzzled look on her face as I noted some of my concerns. She was obviously overwhelmed at my story and appeared to be getting increasingly uncomfortable as I proceeded. As a result, I began to feel uncomfortable talking to her and she had no idea how to respond to what I was saying. This incident had a profound effect on both of us, as I had expected something more, although I wasn’t sure what, and she obviously had no idea how to handle what I was saying. The discomfort felt during that interchange stayed with me for a long time. In fact, even today it colors what and how I say things to people. As a result of that experience, I was determined to attempt to make some type of meaningful contribution in the hope of providing some insight into the entire field of
infertility and its impact on those affected. What follows is a compilation of thoughts and ideas shared by infertile people in an attempt to highlight some of the more subtle aspects of the infertility. The overall hope was that by combining the more quantitative data from the statistical analyses of the questionnaire with the interview information, the most comprehensive discussion of the infertility experience could be obtained.

Toward this end people were asked to provide any thoughts or feelings about their experience as infertile people. The resultant responses can be categorized into three broad areas: what not to say or do, constructive comments and some additional insights of importance. A further distinction was made from these responses. One group of comments was primarily focused on the lay public, i.e., family and friends of infertile people. These comments comprised the majority of the responses and as such, will be the major focus of this section. A second and somewhat smaller section will address comments for new infertile patients in an attempt to provide them with valuable information in the hopes of improving their understanding and adjustment to this new area. Obviously, reading this entire document would be illuminating for any new infertility patient. The insights offered in the following section, however, are meant to enhance the qualitative understanding of the infertility experience. It is hoped that they will be especially meaningful primarily
because they were developed by infertility patients who are attempting to offer help to newer patients based on their experience and perspective of how things could have been handled better.

Over half of the respondents (N=12) clearly stated that they did not want to hear specific comments, which were characterized as the "cliches." Basically, there were four commonly heard statements: "relax and it will happen," "go on vacation and don’t worry," "have a glass of wine at dinner" and lastly, "adopt and I bet you’ll get pregnant." Almost all of the people stated that they had heard each of these comments at some point in time. How intolerable they were appeared to be directly proportional to how often they were heard. The more often they were heard, the more disturbed the recipients were. As one man stated, "People say things out of ignorance. They just don’t know what to say but feel that they have to say something." In general, these types of comments seemed to infuriate people, especially many of the women. In addition, the recipients seemed to feel that the comments may have served the needs of those offering them more than anyone else. As one man stated, "People feel better if they say something, sometimes anything at all is perceived as better than nothing."

Another woman elaborated on this same point by saying, "People have difficulty dealing with traumatic situations of all kinds and tend to say anything that comes to mind. They just blurt out anything without thinking."
Along these lines, two men in particular said that comments such as those described above may have an effect on people that no one realizes. To them, these types of comments seem to make light of their infertility situation. Referring to the use of cliches, one said "All those things make it seem like infertility is so easy to treat." In a somewhat increasingly inflammatory tone, he continued, "If there were easy answers, we'd have solved the problem by now." When asked more about this statement, the man stated that he felt these types of comments implied that they, as a couple, were not doing all that could be done to address their infertility problems. Further, it tended to minimize the overwhelming nature of the medical treatment they were receiving at the current time. For many, medical treatment is a significant and often all-consuming involvement, and not something to be taken lightly by outsiders. Similarly, a second man agreed that making light of what he perceived as a most serious subject was very difficult to hear. For him to hear people joke about getting pregnant was devastating. A friend once commented jokingly, "Well, at least you don't have to worry about birth control." This man was extremely offended by this statement.

A second type of comment that infertile people frequently described negatively was those offering "advice." Some people described these types of comments as patronizing and demoralizing. These comments were perceived by many, especially some of the women, as "hurtful" and "burdensome."
As an example, one woman whose son had recently been diagnosed with cancer said, "Don't ever have kids. You don't want to ever have to go through all this stuff." The infertile woman's immediate response was, "What about all those hugs you've had and all the times he's told you that he loves you. Don't tell me I don't want that." Another woman relayed a scenario where she heard an older woman say to a young infertile woman, "You are being so awful to your parents by depriving them of being grandparents. You should think about them for a minute."

Of particular note is the fact that, although family and friends tended to offer advice more freely, a number of total strangers did so too. For many, dealing with unnecessary and unhelpful comments from family members was nothing new. It seemed to be a bit more acceptable for family members to overstep the boundaries of privacy at times. The idea, however, of being forced to entertain comments from people unknown to them about very personal matters, was something they were not prepared to deal with, nor did they feel that they should have to.

Almost all of the respondents stated that they realized that most of the time the "advice" was meant to be helpful or at least not malicious. The fact, however, that most of those people offering comments had never had to deal with infertility nor had any idea of what it was like made their comments even more difficult to accept. As one woman said, "People feel that they a have the right to say whatever they
want, no matter how it affects another person." From this comment and others of a similar nature, it seems that the infertile people as a group feel a sense of being taken advantage of by others or that their personal rights were being infringed upon.

Along these same lines, a woman reported that at work, "People think they deserve an explanation if I miss a lot of work (for infertility appointments). I feel kind of forced to give up some of my privacy as a result of having to deal with my co-workers and with infertility. Otherwise people get offended and that just makes things worse at work." Similarly, another woman described being fairly quiet at work about her infertility, although she had mentioned that she was interested in having children and was going to see a doctor for some help. She described seeking refuge from having to face infertility by the distractions of working which she found to be helpful. She thought that it was her right to determine the amount of information she shared with others regarding her infertility. She found a memo at work which stated, "Ann is infertile." She was horrified, outraged and overwhelmed by this. When confronted, people at work tried to avoid dealing with it. They tried to minimize the intrusiveness of the episode and as a result, even the resolution of this issue was disturbing to Ann. It did, however, add another burden to an already emotionally taxing situation for her.
For a few people, comments from the media were more disruptive than helpful. The media was perceived to exert a great deal of influence on the public especially by providing much information with respect to the latest developments. This includes the strides being made in the field of infertility and its treatment. As such, the infertile population was especially sensitive to media coverage of the entire field. Many people reported being disappointed at the quality of media coverage given to this field and felt it created many misimpressions rather than qualifying information. For example, one woman stated that, "The media lumps all infertile people into one category and says everyone is desperate. That’s not how I feel at all." She was specifically referring to a story of a woman who was unable to have biologic children. As a result, she had stolen a newborn form a hospital nursery. This woman, as the rest of the population, condemned this act but also feared that some people would think that she would consider such an extreme measure if things did not work out for her. One other woman felt that the media slants some information and misimpressions occur as a result. She stated, "The media makes infertility treatment sound like it’s for genetic engineering reasons." This was so far from the truth that she found it appalling. One last man commented that, "It kind of makes us freaks. They say here’s a phenomenon, let’s cover it, like a trend. It’s my life, don’t trivialize it." He felt insulted that the media could
transform such a devastating phenomenon to such a sensational issue just by how they reported the stories.

A couple of women described approaches that some of their friends had taken in interacting with them. The underlying concern for these women was that people were being treated differently. One stated, "It hurts me when we don't get invited to things where there will be lots of children running around because others think it will be too uncomfortable for us." Another woman stated, "If friends stop calling, I know they are pregnant." When discussing these situations in greater detail, what seemed to be most bothersome for these women was the fact that others were determining what would be best for them, in the absence of any input from them. No one openly addressed any of these potential concerns directly with them. Rather, people took it upon themselves to determine what their needs were and how they could best be addressed. What both thought would have been better, would have been an open acknowledgment of concern for their well-being and solicitation of their input as to what would be best for her. This approach would have directly conveyed their interest in their well-being and allowed them to request any specific arrangements which would have alleviated any stresses imposed by external situations.

In terms of constructive suggestions, there were essentially three specific areas mentioned. The first received unanimous support. This was the idea of increasing
the public’s awareness of infertility and its treatment, primarily through the provision of factual information. A second comment was directed at enhancing everyone’s awareness of the emotional impact of infertility and its treatment. Lastly, there was a discussion of concrete suggestions for people who are indirectly dealing with infertility. More specifically, this was directed at what others can do that is most beneficial to those experiencing infertility and its treatment.

The major suggestion offered by people who have been through this experience is that the public needs to be educated about infertility, in its entirety. It was emphasized by many respondents that the current informational void related to infertility is significant and impacts quite negatively on them personally as well as on society, in general. The fact that none truly understands what the issue of infertility means to those affected tends to foster feelings of isolation for the infertile population. This lack of knowledge on the lay public’s part also encourages continued discomfort with the topic of infertility, primarily because it is a relatively unknown area and because it deals with sexual issues. This was perceived by participants in the current study to be unnecessary and easily rectified.

One particular point raised in concert with the issue of educating the public was that it needs to be both on an objective as well as subjective level. More specifically,
what this meant was the information presented to the public needs to provide an overview of the infertility evaluation and various treatments commonly prescribed. This would be one aspect. The second aspect would involve a description of the emotional component. It would be hoped that by addressing both of these issues in detail a comprehensive understanding of the infertility experience could be realistically attained. In support of this approach, one man stated, "One of the things that few people realize is just how continuous the whole infertility treatment is. The actual medical treatment part is often a daily thing and the emotional part is more than a daily phenomenon". Emphasizing a similar point raised by a number of respondents, another man stated, "People need to realize that the two worst traumas in life are the death of a loved one and infertility. Both are bad, but infertility may be worse. With death you know you’ll get over it. With infertility, you never know if it’s gonna be over or not. If people could remember how bad they felt when somebody died, that’s kind of what we are going through." Along these same lines another man stated, "Infertility is like a chronic illness— we deal with it differently at different times, so if you see a change in us, you’ll understand and may give us some space." To each of these men, their ideas addressed areas not often considered by the public to be major concerns for people involved in infertility treatment. It is this type of deep level of understanding that the
infertile population believes will improve, at least in part, the experience of infertility for those facing it.

For those people just beginning the infertility treatment phase, a number of people offered the suggestion that they need to realize early on that they must become their own advocates. The common feeling was they, as patients, need to be actively involved in their treatment and any decisions that need to be made. While they may not always feel comfortable in this new role, they need to force themselves to understand as much as they can and they need to ask as many questions as necessary to feel comfortable that every avenue is being explored by their physician. Additionally, they need to constantly be evaluating their progress in treatment. They need to talk to other infertility patients as well as other physicians in an attempt to get a second opinion of the approach that is currently being pursued. Perhaps one of the most difficult aspects they need to contemplate is when to change physicians. For most of the people interviewed, a change of physicians was necessary at some point during their treatment. All emphasized how difficult the decision to change was for them. For most people, the physician’s help is requested by the patient and his/her advice is rarely questioned. For those in treatment of infertility, the standard approach is not ideal, nor should a typical patient-physician relationship exist. What further complicates this picture is the fact that there are rarely
any clearcut correct answers to the treatment of infertility. As such, it is difficult to have complete confidence in any approach being utilized and just as difficult to get a second opinion which is consistent with the current treatment approach being utilized. Often, what happens is one is left with a compilation of various opinions, many of which may sound reasonable, but few of which provide the direct support for which one was seeking. This is often an overwhelming situation.

In terms of reducing some of the stresses associated with facing infertility, a few people commented that contact with other infertility patients was a big plus. Many felt that, "You can’t understand what it’s like unless you’ve been through it." As such, interacting either with people who are currently in treatment or who have been there, can be very beneficial. Most people felt an immediate level of comfort, even in the initial discussions with other infertility patients, primarily because there was an immediate understanding between them.

The final comments that people made related to how the lay public could be more responsive to the needs of the infertility population as a whole. There was essentially unanimous agreement with regard to the identification of the major issue. Everyone agreed that comments that other people made were very difficult to accept. What they wanted conveyed was that the most important thing an outsider could do for someone facing infertility was to offer them a
"listening ear." These people strongly felt that they did not want any advice nor did they appreciate unnecessary comments from others. When asked what kinds of comments had been helpful, the overwhelming majority stated that they could not recall any comments which were helpful, although most of the comments were probably meant to help in some way. Two people said that statements such as "We wish you the best" or "We feel for you" are sufficient to convey sincere concern and that there really was little else that people could offer them. Emphasizing this point, one man stated, "The best comment I received was from someone at work who actually said the least. All he said was, "I'm really sorry." I knew he meant it sincerely and that really made me feel good. Along these same lines another man elaborated that it was not so much what was said but rather what the underlying motivation for the statement was. He described often feeling that people were asking questions purely to "get the inside scoop. They were just being nosy." This infuriated him. Conversely, if people had a sincere interest in his situation as friends or even for their own personal situation, then he was more than willing to share whatever information was relevant and helpful.

What was evident throughout all of the interviews was that people facing infertility tend to become very sensitive to comments made to them. It is not only the content of the comment, but often who is making the comment and what is expected of these people given their relationship with the
infertile people. Other variables such as the emotional state of the infertile person at the time the particular comments are made impact on how they will be taken by this person.
CHAPTER V

Discussion

STAGE VERSUS UNIQUE EXPERIENCE OF INFERTILITY

One of the major areas of investigation of this piece of work involved the assessment of the presence or absence of specific and generalizable stages which followed some type of progression. While several reports in the literature proposed such a theory, no objective data had been provided to substantiate this concept. In the absence of any research documentation, the validity of such ideas is wholly untested. What was needed then was a research based assessment of whether or not there are clearly defined stages relevant to the experience of infertility or whether the experience of infertility was just too personal and unique to be characterized into discrete stages which would be generalizable to the infertile public at large.

Often when this study was being conducted, respondents spontaneously made references to the similarities of infertility and the death of a loved one as discussed by Kubler-Ross. In addition, some of the more recent literature makes an analogy between the experience of infertility and Kubler-Ross’ death and dying theory. The theory that death and dying incorporates specific stages which are experienced in an ordered and progressive manner was related to the experience of infertility by some of the more recent writers. What was missing was the research based documentation to validate its accuracy and relevance.
to infertility. As a result, this was an area which warranted further investigation.

One of the major aspects of this study directly addressed this issue. The questionnaire and the interview format were developed specifically in an attempt to assess the validity and relevance of such a stage theory to the issue of infertility.

Findings from this current study clearly demonstrated that the idea of a stage theory relevant to the experience of infertility did not pertain. None of the data collected could be construed to be consistent with this theory. What the results did demonstrate, however, was that each of the proposed stages provided useful and meaningful labels for many of the emotions involved in the infertility experience. These findings, then, directly support previous works described in the literature which discussed the emotional effects of infertility. For example, in 1984, Leader described infertility patients feeling vulnerable and losing personal control in their lives. Other articles reported feelings of hopelessness, depression and despair (Farrer-Meschan, 1971). Feelings of anger and shame (Menning, 1977; Rosenfeld, 1970) were also found in the literature.

These emotional reactions were deemed relevant and reliable by respondents in the current research endeavor. Regarding each of the stages offered, there was some variability however, by and large, there was uniform agreement on the specific components comprising such a stage.
theory. What was lacking was any support for an ordered progression of these emotional reactions. The absence of any such ordered timeline, then, totally refutes the applicability of a stage theory to the issue of infertility. This finding does not support any of the previous work described in the literature. Rather, it directly refutes many of these works. It should be noted that while many previous claims supported the relevance of a stage theory to the issue of infertility, none of them had documented their claims with research based data. For example, Berk and Shapiro (1984) clearly stated that "emotional responses to infertility tend to follow a fairly predictable pattern for most couples" (p. 160). They then go on to describe a number of relevant emotional responses to infertility, i.e., denial, helplessness, anger, depression, etc., but do not provide any documentation for the progression aspect they had described.

One of the most enlightening discussions of stage theory related to infertility was presented by Shapiro (1982). Essentially this involved an adaptation of Kubler-Ross' theory of death and dying to the experience of infertility. She offered a fairly detailed presentation of each of the stages, i.e., denial, anger, depression and acceptance, of the mourning process described by Kubler-Ross and related it to the experience of infertility. Again, as with others writers, she describes movement from one stage to the next but does not provide any substantiation for
these claims, i.e., research based documentation. What she does do is effectively relate the emotional experiences of death and dying and infertility in a nice, clear and theoretical package. It is a succinct and seemingly reasonable presentation of ideas. While this is a valiant attempt, she offers no data to substantiate her theory.

There is no doubt that if this theory were true, it would be easily understandable in the context of a commonly referred to format, namely that of the Kubler-Ross theory of death and dying. Findings of the current research, however, do not support the application of this theory, in its entirety, to the experience of infertility. Rather, support for the specific emotions discussed was found, but the progression aspect was not clearly documented.

The current research study offered these findings. Early on in the infertility experience, the majority of people acknowledged some type of denial that an infertility problem may exist. This form of denial seemed to serve the purpose of providing the individuals some additional time to get used to the idea that some type of extra measure may be needed in order for them to become biologic parents and to move onward with their plan. The length of time that denial was utilized was widely variable. Interestingly, men evidenced more denial and for longer periods of time than women. Anger was a very common reaction once the reality of an infertility problem was accepted by these people. Depression was also one of the most common emotional
response to the entire experience of infertility. Acceptance, the final stage was deemed something that everyone was aware of but not sure how they felt about from a very personal point of view.

Again, it should be noted that while all of these stages provided labels for many of the emotions experienced as a result of infertility, what did not ring true was the progressive nature discussed in the literature. There was no reproducible and/or generalizable progression identified by the respondents in this research. While there was some mention of cyclical emotional reactions associated with the monthly treatment cycles, even this was not generalizable. Rather, what did seem to be relevant was the fact that many of the emotions were experienced regularly in response to the many demands of infertility treatment. Additionally, people seemed to move at their own unique paces regarding their experience of these emotional reactions. Even the frequency with which these emotions were experienced within individual couples varied dramatically. This variability seemed to be dependent on a number of factors, including presence or absence of a diagnosis, individual personalities and the treatment approach of the physician.

COMMONALITIES OF THE INFERTILITY EXPERIENCE

Despite the fact that there does appear to be some similarity of experience, in general, to the issue of infertility, this does not seem to accurately portray the true picture of the infertility experience. For example,
while many people stated that they felt angry and depressed by their infertility, the specific underlying meanings of these feelings were often quite unique. What became readily apparent from this study is that there is so much variability among patients, their infertility problems and physicians that little commonalty of experience can be demonstrated. It is therefore unlikely that one general description of the experience will adequately document the experience of infertility. In light of this finding, it seemed that perhaps a better way of approaching an understanding of the experience of infertility would be to document what respondents described as the key issues for them in this process. This was effectively done through the research tools used in this study. This was primarily the questionnaire which was developed for this study and included items described in the literature as well as those offered by patients.

The resultant factor analysis allowed the identification of variables which were deemed relevant by statistical criteria. Twelve factors were specified by this means. They included: stress, anger, depression, negative psychological effect, shame, no control, control, physician, negative social view, hope, isolation and acceptance. These were all felt to be very important variables comprising the infertility experience.

The stress described in this study was of a global nature. While there was unanimous agreement that stress was
an integral part of the infertility experience, the particulars making up this factor were highly individualized. Depending on the couple this involved the long waiting at the physician’s office, the anticipated pain associated with medical treatment, the realization that an infertility problem existed, or the fact that they had been in treatment for so long and either they still did not have a diagnosis or despite following the prescribed treatment, they remained unsuccessful. For most, the stress was an inherent part of infertility and its treatment. People described the stress as continuous, although of varying intensity.

From the original category entitled Emotional Reactions two factors evolved, anger and depression. Anger was a commonly experienced emotion. For some it seemed that it was more apparent at the beginning when they first were made aware of their infertility problem. The overwhelming majority, however, stated that some degree of anger was present much of the time. It appeared that as time went on angry feelings surfaced easier and more frequently for some people. These people readily acknowledged that at times it seemed to be out of their control. Some of the smallest incidents would cause them to flare up unexpectedly.

Depression was attributed primarily to the women. Men relabelled feelings along these lines as disappointment, rather than depression. For the women, it seemed that the realization that a possibility existed that they may not
have biological children was devastating for them. Many readily acknowledged that part of their identities were involved. More specifically, one of their main goals in life was to become a mother and raise a family. The idea that this may not be in their future was often an unbearable thought for them. Men, on the other hand, readily admitted that they wanted to have a family, however, if it did not work out as hoped for, they were quite confident that they could fairly easily adapt.

The category entitled Psychological Considerations was found to have four factors. They were negative psychological effect, shame, no control and control. Negative psychological effect was essentially the idea that infertility raises a number of personal issues that often become internalized. These included guilt feelings associated with thinking that infertility was one individual’s fault or a lowering of one’s self esteem as a result of infertility. It should be noted that this was particularly true for the women and essentially untrue for the men.

Shame was also found to be a significant factor for many experiencing infertility. This factor addressed the concerns of secretiveness and a desire to withhold information from others regarding their infertility. Some of the underlying feelings relevant to this factor included embarrassment, discomfort and inferiority. As an example, a
few of the men stated that they were uncomfortable discussing their sexuality with strangers.

Concerns related to losing and maintaining control were also deemed important. Concerns with losing control primarily focused on the realization that in order to be in medical treatment they, as patients, had to surrender much of their freedom and be willing to follow a prescribed plan which dictated what could be done and when. Attempts at maintaining control were related to active participation in medical treatment and relevant decision-making. This included such activities as questioning the physician regarding the treatment plan and ensuring that one had a clear understanding of what was being done regarding treatment.

Social issues were also evident and two factors were identified, negative social view and physician. Negative social view was defined as the fact that many lay people were perceived as insensitive when it came to the issue of infertility. Friendships changed as a result of infertility, not necessarily for the better. The role of the physician was also perceived as an important area. Many people reported that their physician's optimism and sensitivity were key factors for their own sense of well-being.

Within the category of Current Feelings, issues of hope, isolation and acceptance were discussed. Hope was an important consideration throughout this entire experience as
it had a sustaining effect. It was deemed by many patients as a key factor in maintaining their participation in treatment, especially at times when it was very difficult to continue.

Isolation was something many reported almost unexpectedly. There was a sense that their lives were dramatically changed as a result of infertility. As such many of their interests had also changed and they tended to drift away from friends whose interests were unchanged. This combined with the fact that so few people really understood what the experience of infertility was like only served to heighten these isolating feelings. For many this was very uncomfortable and threatening as it added another dimension to the already significant isolation they were experiencing.

Acceptance was the last factor that was identified by the respondents. To most respondents this signified either ending treatment or at the least being comfortable making alternative plans for building a family. This seemed to be something in the back of many people's minds, however, few of them had actually reached that point. Interestingly, not many felt they were ready to face that issue head on. Most preferred to continue in treatment for an undetermined period of time. This essentially enabled them to hold off dealing with this issue.

The identification of these factors provided an overview of what infertility patients felt was relevant to
their experience of infertility. These twelve factors comprise the overall experience of infertility. They represent the key emotional issues facing infertile people.

Differential Gender Effects

Another major finding of this research study was that of differential gender effects related to the emotional responses to infertility. These findings, in many respects, were striking. Overall women tended to report more intense and more negative emotional reactions. This initial disparity was quite obvious to both men and women right from the beginning. For women this enormous difference served to heighten their feelings of anxiety and helplessness. Perhaps the best way to understand the differential impact of infertility is to focus on the major areas of difference.

Initially many women reported feeling overwhelmed by the prospect of an infertility problem. As time went on these feelings intensifiesed and progressed to the point that infertility related thoughts and feelings seemed to permeate their lives. These were constantly on their minds. Every decision, regardless of how small or insignificant it may have been, was contemplated in terms of its impact on infertility and its treatment. This was noted both internally and externally. Outwardly, women reported a noticeable deterioration in their work performance and occasional crying spells for no apparent reasons. They perceived constant reminders of their infertility in everyday activities. For example, at work people frequently
spoke of their children or the supermarkets seemed to be filled with pregnant women trailing two or three little children behind them. Attending medical appointments involved especially strong reminders of their infertility predicament. Inwardly, the experience of infertility was even more pronounced. Women reported feeling depressed, having difficulty concentrating and being constantly plagued by thoughts that infertility was their fault, even when there was no concrete evidence to support those ideas. In addition, they felt a decrease in their self-esteem and a negative change in their body images. For example, some reported feeling ugly.

The emotional reaction of men was quite different. Initially, they were not very concerned about the possibility of an infertility problem. Rather, they assumed that there may be a temporary obstacle that the physicians would rectify in rather short order. Over time, they did acknowledge some noticeable concern but, in general, preferred to let their physicians manage the medical treatment. They felt that by being in medical treatment they were doing all that they could and they hoped for the best. The majority of men reported none of the intensity that the women did. None of the internal or external signs and symptoms were relevant for the men. In clarifying their specific concerns, they tended to relabel their thoughts and feelings. For example, most men stated that they were disappointed about their infertility, not depressed.
Another major difference between women and men involved
the intensity and pervasiveness associated with dealing with
infertility. Men were not overwhelmed by their infertility,
nor was it something that constantly preyed on their minds.
Rather, they were able to easily and effectively
compartmentalize the entire issue of infertility. The
overwhelming majority of men reported their major area of
infertility related concern was that of their wife's well-
being. In fact, many men stated that they felt burdened by
having to deal with their spouse's emotional response to
infertility.

Given these differences in how men and women reacted to
the issue of infertility, it was deemed useful to pursue a
better understanding of how these differences evolved
through the use on interviews. Both women and men were
directly asked what the underlying meaning of infertility
was for them. Their responses were very different. To
women, infertility signified a loss and a lack of
fulfillment of their idealized female role. This had an
especially deep and strong meaning for the women as it
addressed very core needs and desires. For the men, it was
much less of an emotional issue. Rather, it seemed to be
one of loss, focused on the reality that they would not be
able to pass on either their genes or their family name.
This presented an area of concern but it was not a
monumental one for them.
How women handled their infertility and the related emotional issues also was dramatically different from the approach used by men. Overall women seemed to be most comfortable sharing some of their trials and tribulations related to infertility. When they were able to talk about what they were going through, women often reported feeling a sense of relief and a reduction in the overall stresses related to infertility. Women also acknowledged that at times they tended to go overboard and would talk to anyone and in great detail about their infertility.

This was in marked contrast to the perspective offered by men. Men were much more comfortable sharing nothing with anyone except their wives. The common sentiment was that infertility was a very personal thing and it was no one’s business but their own. Those men who were more expressive of their feelings basically did not share much information with outsiders but did seem, at least, willing to respond to questions posed by close family and friends regarding their infertility and its treatment.

Interestingly, there were some positive outcomes, primarily for the women. It seems that as a result of the women’s reported intensity related to infertility, they became extremely knowledgeable about the entire field. In addition, they tended to do extra reading to enhance their level of understanding and seek second opinions about treatment options and alternatives. They were, therefore, better able to understand their treatment and ask relevant
questions as well as investigate meaningful alternatives to their current treatment. This enhanced knowledge base offered them some degree of confidence and self-assuredness. These also seemed to help women to feel more actively involved in their treatment and better about themselves.

This was not the case for many men. They did not seem interested in extending themselves. Rather, they tended to go to the medical appointments whenever possible but rarely at these appointments did they speak to anyone. Occasionally, they would ask the physician a question or clarify a point made by one of the staff. This difference was poignantly evident when couples were asked for their input in making some major treatment related decisions. The women, more than the men, wanted to either be included in the decision-making or actually make the decisions themselves, whereas the men preferred to leave the major decisions up to their physicians, the so-called "experts."

As a result of the women's intense involvement with their infertility and the more casual involvement of their partners, women also reported strong feelings of isolation. This was primarily related to the fact that they could not talk to their husbands about their infertility and treatment.

In addition to the significant differences in the underlying meaning infertility held for women and men, the respondents noted another area of significant difference. It was commonly agreed upon by both women and men that their
perceptions of infertility were different both on the surface and internally. In addition to the previously described reasons, everyone readily agreed that the specific experiences of women were dramatically different from men. In reality, the majority of times it is the women who are the foci of treatment. They must faithfully attend all of the appointments, undergo most of the procedures and take the medications prescribed. Additionally, much of this involves stress and discomfort, if not actual pain, and inordinate amounts of time are needed to comply with medical treatment as well as energy and money. Women are the ones on whom the major burden of treatment rests in that they have to do the most amount of accommodating to their treatment schedules in order to ensure everything can be fit in.

The emphasis on the female’s role in infertility treatment is consistent with the overall emphasis on females within the entire field of infertility as a whole. Females and their reproductive systems have long been recognized as the primary focus of researchers, who were predominantly males. Although this might be perceived as an overtly chauvinistic attitude, it is grounded in objective and technical reality. The fact that the female reproductive system is better understood than that of the male as well as the reality that the turnaround time for egg development is approximately 10 days versus 75 days for appropriate sperm development, supports the idea that it is inherently easier.
and perhaps more productive to emphasize the female reproductive system when evaluating infertility and attempting to develop new and effective treatment options. As a result of the additional time and energy focused on the female reproductive system, more and better treatment options have become available for women rather than men.

It is understandable too that women may feel a significant amount of frustration by being in infertility treatment. Typically, in spite of strict adherence to the prescribed treatment plan and despite achieving goals, often conception does not occur. As a result of such an intense involvement, women often become overly invested in their treatment and are personally devastated by its perplexing lack of success.

Even if things do work out for them; i.e., they become pregnant, their degree of responsibility continues on. If they go on to have a child, it is their lives primarily that will be the most dramatically affected. They will have to make the most amount of decisions related to how to have a family and a career if that is an area of interest.

For men, all of these considerations are minimized. During the treatment phase, the most that they can do is attend the medical appointments and offer support and encouragement to their partners. Rarely are they asked to participate in any major way except to occasionally produce a sperm specimen. If they were unable to attend one of the medical appointments, they would not be jeopardizing their
treatment. Treatment could still proceed, which would not be the case should the woman be unable to make a medical appointment. Should the treatment be successful, the lives of men would change but only to a minimal degree. Regardless of the outcome, most men would still have to go to work as they had all along. Few changes in their lives would be necessitated as a result of a positive outcome of medical treatment. Thus the different emotional reactions between men and women can be understood better in terms of the underlying meaning of infertility to each and also in terms of its impact on their day to day existences. Both of these are so different for women and men that there can be little question or surprise that the experiences should be so dramatically different, both externally and internally.

By identifying and describing what the infertility experience was comprised of it is hoped that both new infertility patients as well as those people who are only indirectly affected by infertility will develop a new understanding and appreciation of what it means to those more directly experiencing infertility. If everyone had a better understanding of the relevant issues associated with infertility and its treatment then perhaps the lay public would be more aware and sensitive to the needs of those experiencing infertility. An additional benefit of such an educated understanding by the lay public would be a decrease in the feelings of uniqueness and isolation associated with infertility. Also if infertile couples could enter the
treatment phase of infertility with a better understanding of what to expect they may have an easier time dealing with many of the emotional factors previously delineated. It seems that a little bit of knowledge could serve to enhance the experience of everyone involved, whether directly or indirectly.

INFORMATIONAL VOID

It is clear from the findings of this research that the informational void is significant. The results of this study further state that this informational void is two-fold. On one side is the lack of information for the public and secondly there is a lack of information for the new infertile patient. Both of these gaps in information weigh significantly on the infertile people and are perceived as unnecessary by those currently involved in infertility treatment. Providing this information to all could dramatically improve the situation for everyone who either directly or remotely are faced with infertility. This would allow insight regarding what to expect from the infertility experience, including its medical management and psychological components. In addition, it is felt by most of the respondents that these are key areas which can be addressed relatively easily. Improvements in these particular areas would have long-lasting ramifications for the majority of people. If people had a better understanding of the relevant issues related to infertility they would be less likely to make insensitive and hurtful
comments to those faced with infertility. Additionally, they may feel more comfortable discussing some of the issues with people faced with infertility. This would perhaps be perceived by the infertile population as a welcome additional area of support which was not available previously.

It seems that all infertile people realize, quite early on, that infertility is a very horrible thing to have to face. Further, there is little that anyone outside of the medical community can do to improve one’s situation. The majority of infertile respondents acknowledged that there were, however, some areas where improvements could be made. One was the informational void previously described. A second area was the need for the lay public to realize that infertile people do not expect them to have any answers. Rather, it seems that the ability and desire to listen meaningfully would be quite helpful. In fact, this is perceived as something that could vastly relieve some of the stress associated with infertility.

POTENTIALLY HELPFUL INSIGHTS FOR THOSE FACING INFERTILITY

In terms of what would be helpful for the newly diagnosed infertility patient, it remains unclear. Because infertility is such a personal and variable entity, there is no uniform prescription that would be applicable to all. For example, for many people in the current study deciding how much information to share with others was a very difficult thing to do. There were those who felt better if
they had someone to share their latest trials and tribulations with. The sharing of information provided them with a sense of relief from having to keep all of this contained within themselves. In contrast, there were many who felt that it was an invasion of their personal privacy to have to divulge any information related to their infertility and its treatment. Regarding each of these perspectives there were people who felt strongly that one or the other was best for them. Each person had his or her own rationale. The take home message then appears to be that this is just one of many issues on which those involved in the treatment of infertility vary. As adults and individuals they should be granted the right to deal with their infertility in the way that best suits them. There is in fact not one best way, especially when you look at the results of this study.

Because of the tremendous variability associated with infertility, its medical management and the reactions of patients to it, perhaps the best way to offer these patients some help is to have a comprehensive guide available to them which would highlight the findings from this study. More specifically, if they could read about the experiences of others who have faced infertility, the fact that experiences are widely divergent would become evident. By providing them with such a comprehensive overview, they may be comforted by the fact that almost anything they are feeling about their infertility is within the spectrum of emotions.
documented amongst respondents in this study. Further, there is not one way to feel regarding infertility, nor is their one best way to deal with any of these feelings or issues. Perhaps what is key is that many aspects of infertility are very personal and every individual needs to make his or her own assessment regarding the best way for them to deal with the various feelings and issues elicited by it.

ADDITIONAL AREAS OF IMPORTANCE

The section entitled Additional Areas of Importance Identified by Respondents provided some very useful and enlightening information. Issues addressed within this section were derived from comments of infertility patients and respondents of this research study. The issues identified by these people were not commonly discussed in the relevant infertility literature. It became clear, however, that they were important aspects of the overall infertility experience and as such warranted further elaboration and discussion. These issues included decision-making, termination of treatment, long-lasting effects of the infertility experience, quality of the physician relationship and finally, constructive insights into the infertility experience.

Regarding decision-making and termination, three similar types of responses were offered for each. First, there were those people who felt most comfortable letting their physicians determine the direction and length of
treatment. They believed that their physicians were the experts and as such were the best prepared to make these important decisions. A second group of respondents wanted to feel involved to some extent with both decision-making and termination issues. This level of involvement, however, was only to the extent that they had a clear understanding of relevant issues impacting on the decisions being made, including when treatment should be ended. The last group of respondents felt that they, as the patients, should be in charge of all decisions being made and they alone should determine when treatment should cease. This group, more than either of the other two, was motivated to become as educated as possible so that they could make informed decisions regarding their infertility treatment.

It was interesting to note the fact that there was a fairly even breakdown amongst respondents within each of these categories. This suggests there are essentially three types of philosophies ascribed to by patients involved in infertility treatment.

In terms of long-lasting effects related to the experience of infertility, the most striking finding was the gender differences related to the two most extreme responses. The feelings of the majority of females could be summarized by the statement, "While the emotions may fade, there will always be remnants of the infertility experience for the rest of your life." Analogies were made to feelings evoked when someone has died, i.e., feeling sad when you
think about them. Although not all of the women could articulate their thoughts regarding the long-term effects of the infertility experience, all of them agreed that there were indeed enduring effects from this experience.

This was in marked contrast to the sentiments offered by the majority of men. They basically stated that there would be no long-term effects of having been through the infertility experience. The underlying sentiment seemed to be that by being in medical treatment they were doing all that they could to rectify their infertility problems. That was all that could be expected of them. Regardless of the outcome, life would go on.

Of particular note is the fact that this disparity in feelings and intensity is reflective of the larger and more global gender differences noted in regard to the overall experience of infertility. The women tend to have more intense and more negative reactions to many of the related issues. The men on the other hand, seem to approach many of the issues from a very relaxed and practical manner. They seem to be more accepting of infertility and its ramifications and generally believe that they will always be able to find something in their lives to compensate for the possibility of not having children. Women, on the other hand, see this as an enduring loss that will always play a prominent negative role in their lives. Interestingly, all of the men acknowledged that one of the major difficulties would rest with the adjustments of their wives.
In terms of quality of the relationship with the physician, there were two attributes that people felt were key to an optimal relationship. These were respect and trust in their physician's level of knowledge and a sense of caring from their physicians. Of note also, is the fact that both women and men were united in their perspectives of what was important. It seemed that most of the patients perceived the treatment of infertility as something that was not as straightforward or as clear as they would have hoped it to be. In light of that, they wanted to be treated by the most informed person available. Knowing that their physician was an expert in the field of infertility offered these patients a degree of comfort and reassurance that they deemed very desirable. In addition, because the entire issue of infertility and its treatment was so overwhelmingly emotional, especially for the women, any open acknowledgement by the physician of the emotional needs was greatly appreciated by both the women and the men. This, many felt, directly impacted on the ability of the women in particular to deal with the many stresses and demands inherent in the treatment of infertility. Of note was the fact that since their wife's emotional needs were being professionally addressed, this served as a great comfort to many of the men. Perhaps any outside help would have been greatly appreciated as an aid to what many of the men perceived as a very overwhelming problem, namely that of their wife's tenuous emotional status.
CONSTRUCTIVE COMMENTS

Throughout all of this research, one of the major goals was to be able ultimately to offer some constructive comments to both new infertility patients as well as those people indirectly affected by infertility. As such, this was an area that was directly addressed during the interview portion of the study.

One of the foremost sentiments of the majority of respondents was that they did not want to hear certain comments, which were characterized as "cliches." More specifically, there were four commonly heard statements: "Relax and it will happen," "Go on vacation and don’t worry," "Have a glass of wine at dinner," and lastly, "Adopt and you’ll get pregnant." The infertility patients clearly realized that these comments were not meant to be malicious, rather, they were offered either in an attempt to support and encourage or as a result of the individual’s discomfort with the topic and the need to say something, rather than nothing. Despite this intellectual understanding of the comments, many infertility patients, especially women, found them disturbing. Some people, in fact, were infuriated by them. In part, this seemed to be due to the increasing frequency with which they were hearing such comments. A second and more important reason seemed to be the underlying meaning associated with these comments. Infertility patients interpreted these comments in many different ways, many of which would have never been considered by the people.
offering them. For example, some people were angered by the thought that outsiders were making value judgments about the intensity with which these patients were approaching treatment. They felt that these types of comments implied that the patients were not doing all that could be done to effectively deal with their infertility problems. The anger seemed to be related to the fact that the people making the comments really did not know the first thing about infertility and its medical treatment so, it was felt, they had no right of make any kind of value laden judgments.

Secondly, patients reported that these types of comments tended to minimize the overwhelming nature of their current medical treatment. For many patients medical treatment is an all-encompassing and often all-consuming experience; not something to be taken lightly. Patients seemed to be quite sensitive to the comments from others. Often, they interpreted them in ways which may not have been intended, frequently in very negative ways. It is important for all to realize that the heightened sensitivity of the infertility patient is not always something that is obvious, objective and rationale. It is usually very subjective and highly individualized. The perspective developed by these patients evolves over months and sometimes years of intensive treatment, which is often not successful, despite strict adherence to the treatment plan. This is often a very frustrating, difficult and emotionally stressful experience. The reality of this type of existence in
combination with unhelpful, often hurtful and almost invariably unnecessary comments by outsiders, can be perceived as intolerable by those facing infertility.

It appeared that there were specific types of comments that were deemed more difficult to deal with. These included jokes about infertility but more importantly, advice from lay people was perceived as especially unnecessary and very difficult to accept. Interestingly, infertility patients often commented that they had expected this "advice" from family and sometimes friends. Rarely, however, did they expect to hear it from total strangers. The fact that this was not an uncommon occurrence was very disturbing and irritating to these people. Such advice placed an additional burden on these infertile people and, in addition, was perceived as a gross invasion of their privacy.

Along these lines there was one other area which plagued the infertility population. This was the approach the media had taken regarding the issue of infertility. Essentially, it was felt by a number of people that the media was a great potential source of information for the lay public. Rather than providing useful information, though, it was felt that the media tended to create numerous misimpressions regarding the latest developments in the treatment of infertility as well as sensationalizing particular stories; e.g., of people stealing babies because they were not able to have their own. Infertile people took
many of the publicized stories in a very personal manner and were quite bothered by their inaccuracy. Reports of recent breakthroughs were skewed such that the average person thought that infertility could be rather easily treated and cured. Often, these treatments were experimental or addressed only a very small percentage of the infertile population. Furthermore, it was felt that the media tended to categorize all infertile people under one rubric, namely that of people desperately doing what they had to in order to build a family. This was in marked contrast to what the patients actually felt. Many of them felt that infertility had forced them to seriously consider their situation and make some important decisions regarding life goals and how to best obtain them. Rather than feeling desperate and willing to do anything, they felt that they had given this matter careful consideration. As a result, their strategy was well planned and they were slowly moving toward that end.

In light of the many emotional highs and lows experienced by patients and because of the fact that they felt that their needs could and should be better met, these people offered some constructive suggestions. It was hoped that these suggestions would aid in improving the situation of new infertility patients as well as those people indirectly facing infertility.

The major suggestion offered by people who have been through the infertility experience is that the public needs
to be educated about infertility. This concern stems from the perception that the lay public is relatively uninformed regarding the overall picture of infertility and this void of knowledge negatively impacts on the experience of those people who are dealing with infertility. The fact remains, however, that currently one in six couples is affected and these statistics are expected to continue to rise. As such, it is likely that almost everyone will either be directly or indirectly affected by infertility. People offering these suggestions felt that increasing the knowledge base of the public regarding infertility would benefit society in two ways. It would educate people who only indirectly are in contact with someone experiencing infertility. Secondly, it may encourage people who are considering starting a family to do so sooner or they may at least entertain the possibility that an infertility problem may be found. Furthermore, if people are more aware of this possibility, then perhaps they would seek medical intervention at an earlier point in time. From the people currently involved in medical treatment, many stated that they delayed in seeking the initial evaluation, in part because they did not fully appreciate the field of infertility and its ramifications. In retrospect, most thought that earlier intervention on their part would have been advantageous because it may have saved them a great deal of time, unnecessary worry and emotional turmoil.
Respondents also emphasized the need for such educational attempts to address both the technical aspects as well as the psychological sequelae of facing infertility and its treatment. It was hoped by many of the respondents that by addressing both of these components in detail a comprehensive understanding of the infertility experience could be attained.

Respondents also offered concrete suggestions for new infertility patients. The major point was that the patients themselves must become their own advocates. Everyone agreed that if patients took this stance from the beginning, much time, energy and emotional pain could be spared. Additionally, almost everyone thought that patients naturally come to this point at some future time anyway given the natural evolution of involvement in infertility treatment. All readily acknowledged how difficult it was to do this, especially in the area of infertility. Specific suggestions as to how to best do this included doing additional reading on particular subjects, seeking opinions from other physicians and most importantly developing contacts with other infertile patients. Most of the respondents seemed to feel that the key to understanding infertility and all that is associated with it was to be able to share or at least hear what others had to say and how they felt about certain experiences and issues related to infertility and its treatment. Interestingly, few people in the current study had actually taken their own advice.
These ideas seemed to be more retrospective in terms of what would have been helpful for them.

What seems most evident from this study is that there are a number of needs that infertile patients have which are going unmet. Some of these are truly unnecessary and as a result attempts could easily be made to rectify these concerns. It seems clear that education of the lay public is necessary. This could, perhaps, be done through the medical field contacts. For example, family practice practitioners could routinely assess potentially at risk people for infertility related problems given their knowledge of their patient’s history. Similarly gynecologists and urologists could each incorporate a brief inquiry into the status of the patient’s interest in conception and follow-up with a brief history related to possible areas of concern related to infertility. These are professionals who would be knowledgeable in the area of infertility. In addition, since they would have access to patients prior to the point where infertility may be suspected, they could play a more comprehensive and proactive role in health care management of their patients. An additional benefit of such a routine approach to at least the discussion of conception and a brief assessment of potentially at risk people is that it puts infertility in general in the awareness of people. This would substantially contribute to the familiarity of the topic for the lay public and would also perhaps motivate anyone who
suspected they may have an infertility-related problem to seek evaluation at an earlier time. One additional advantage of this approach would be that should someone be found to have an infertility problem, there would certainly be much less mystery associated with such a problem. As such, it is likely that others would feel more comfortable and knowledgeable discussing some of an individual's concern and may even be capable of displaying genuine understanding and compassion.

Along these lines it should be noted that infertility-related information could be encompassed within a sex and health education program. The issue of infertility could easily become part of any sex education program. The issue of infertility has direct relevance to such a program. Currently, one focus is on the idea that frequent sexual partners may lead to a higher rate of infection, which could result in future infertility problems. Therefore to combat such a possibility, abstinence is recommended. While to some extent there may be a potential relationship between numerous sexual partners, a higher infection rate and infertility, this does not accurately portray the issue of infertility. As such a sex education program would be one ideal setting in which to offer a factually based discussion of infertility. This would be an important first step in accurately educating the lay public about infertility and what it involves, both medically and psychologically. It would have a two-fold benefit of providing accurate
information to a target population, i.e., the general public at large, at a very early age and secondly, dispelling many of the current myths associated with infertility and sexuality. One added benefit would be the demystification of the entire subject of infertility.

Once any type of infertility problem is found and people enter the treatment phase, it seems that their needs change. They are thrown into a new and unknown area where they are forced to face many frightening and threatening issues as well as be exposed to numerous treatment procedures, which typically only have a relatively small chance of succeeding. A common sentiment in the current study was, "You can’t really understand it if you haven’t gone through it." At this time it seems that what is most needed is support, encouragement, someone to talk to who understands what you are going through and information about the future, including what one can expect given their particular situation. It seems reasonable to assume that one way of addressing many of these needs would be through the participation of some type of infertility focused group. This type of arrangement would allow for the give and take of information as well as the sharing of thoughts and feelings of those people dealing with issues relevant to infertility and its treatment. It would appear that this type of forum would offer much to those people facing infertility.
Because many of the current respondents did not participate in such a group, they were unable to comment on the specifics of such an experience. Accordingly this remains an area for future exploration. There are many possibilities which would address some of the needs of these patients. More specifically, because so many of the concerns seemed to be gender related, it seems feasible that perhaps single-sexed groups would offer a particularly valuable resource to both women and men. It seems that while there are many needs in common, many of the most important ones are solely female or male. For many men this would be their first group type of experience and as such perhaps it would be less threatening if it were an all male group. They may be more willing to express their true thoughts and feelings as well as share some of their deeper concerns if they did not have to worry about the impact their comments may have on someone’s feelings, especially a woman’s. Furthermore, they may feel more comfortable with their own difficulties if they were able to hear that other men shared some of the same concerns.

To complement these groups and to effect a better understanding of what each sex’s experience of infertility is, a couple’s group would also be important. This may be especially useful for the men to be able to hear what women think and feel about their infertility. It may also be enlightening for men to see how other couples handle the emotional aspects of infertility, and for them to realize
that what they are experiencing is not unique. There could also be advantages for an all women's support group. This arrangement may provide a forum for women to openly express emotions and ideas without fear of burdening their spouses. In addition, by having a place to ventilate their feelings, these women may experience a sense of relief as well as a decrease in feelings of isolation since they are in an environment where everyone is facing the same general issue, namely that of infertility. Perhaps best through this type of co-educational group experience could both women and men derive the most amount of understanding and support for infertility related concerns.

LIMITATIONS OF THE CURRENT STUDY

It was anticipated that subjects who participated in this research project would illustrate how infertile individuals and couples experience and perceive infertility. One limitation of this study was the fact that subjects came predominantly from middle to high socioeconomic strata. Because of the escalated high cost of infertility evaluation and treatment, respondents typically were couples with "good" medical coverage. As such the sample utilized in this study was representative of only those individuals involved with RESOLVE and/or able to afford medical treatment in the Philadelphia or Indianapolis area. The current sample was comprised of predominantly white people (98%) and only one percent were Black. The remaining one percent were self-described as "Other." Because information
regarding the racial composition of the infertile population in the United States is not readily available, it is impossible to know how representative the current study population is. One would anticipate that there would be significant difference. Further, and perhaps more relevant to the current investigation, is the representativeness of the study population to the infertile population at large, which seeks medical treatment. Again, information on this population is not available for comparison.

Similarly, in this study, the overwhelming majority of participants were very close in age. For example, 51% of subjects were between the ages of 30 and 34 years. Eighteen percent were younger (24-29 years old) and 31% were older (35-45 years old). Because few studies of this nature have been undertaken, there is no way to know how these age ranges compare to the infertile population at large. This is information that would be available primarily from physicians treating infertile patients and as such, quite difficult for an independent researcher to obtain.

The fact that participation was voluntary may have also affected the results. It was hoped that because of the voluntary nature of this study respondents would be inclined to discuss their perspectives and feelings in an open and honest manner. Nonetheless it is possible that respondents withheld certain information and/or denied other feelings/thoughts that they either found difficult to accept in themselves or were uncomfortable sharing with others.
While these responses may have been on a conscious level, others may have been less obvious to the participants. It is possible that individuals and couples may have restructured their perspective on various parts of their infertility in order to better deal with their situation. For the purposes of this research study, however, this information was invaluable. Because this study sought to delineate a subjective perception of the infertility experience, these considerations may in reality have served well the purposes of this proposal.

One additional unexplained category involves the assessment of the impact of infertility on the couple as a unit. As such this remains an area for future investigation. It is clearly an important aspect of the experience of infertility and as such needs to be addressed. Particular attention should focus on the actual assessment tools which need to be developed specifically in the attempt to clarify the couple as a unit in terms of their reaction to infertility.

Another limitation involved the use of self-report and self-report data. Inherent in this form of data-gathering is the possibility of distortion or overt mistruth. There was, however, no way to definitively address such considerations within the structure of this study.

One final issue relates to the statistical analyses performed. Throughout the current study, Analyses of Variance were routinely utilized. When statistical
differences were obtained they were highly significant. Despite this, there is an ongoing relationship between the women and men included in this study, namely that of wife and husband. By performing Nested Analyses of Variance, it would be possible to assess any impact this ongoing relationship may have had on the results of this study. In consultation with a statistician, it appeared unlikely that performing Nested Analyses of Variance would have changed any of the current results. Regardless, for the sake of completeness, Nested Analyses of Variance could be included in future research endeavors of this nature.

SUMMARY

In summary, it is clear from the current investigation that infertility presents an emotionally agonizing situation for those directly facing it as well as those people only indirectly involved with it. Throughout this research endeavor it became readily apparent that infertility is comprised of many commonalities of experience. These similarities offer people facing infertility some consolation in that they are not alone nor is their experience so unique that others cannot relate to much of it. It should be recognized that the individuals as well as the couples do bring their own set of unique backgrounds, issues and relevant particulars to the infertility experience itself. Despite these inherent differences among people facing infertility, there are many generalizable concerns which unite this group of people.
While numerous relevant emotions were identified, there does not seem to be any generalizable ordered progression to these. As such, the idea of a stage theory relevant to the issue of infertility does not pertain. One of the most striking findings from this research endeavor was the fact that the experience of infertility is so different for women and men. Throughout this entire endeavor, it was readily apparent that women are much more devastated by the infertility experience than men. As such their needs are quite different. At the current time, while new technology is continuously being developed to help with the medical treatment of infertility, little attention has been focused on the psychological component of the infertility issue. In addition, there is a significant informational void which impacts negatively on both patients and society, at large. Both of these areas are ripe for further investigation in an attempt to address many of these unmet needs.

While this study offers only preliminary information and suggestions regarding coping strategies, it sets the stage for future research endeavors. It is evident from the current investigation that infertility is an issue that affects a large number of patients directly and also affects many more people indirectly. Because the incidence is expected to increase, it is apparent that this area will continue to warrant investigation. Further, it is hoped that future research endeavors will be able to develop and refine effective coping strategies for infertility patients.
as well as identify additional needs of those people involved with the issue of infertility.
References


Appendix A

I am currently working on my PhD at the University of Pennsylvania and I am requesting your participation in my project. Through my own experience with infertility, I became very interested in the psychological impact of infertility on those individuals involved in medical treatment.

I have developed this questionnaire in an attempt to get a better understanding of other people's experience with infertility. It is important that both husband and wife each complete a questionnaire since this study requires information from both spouses. I would ask that you take 20 minutes to answer the questions as accurately as possible. I realize that this is a long questionnaire but I am interested in getting as much information as I can about your particular experience with infertility.

To date, there has not been an in-depth attempt at understanding the infertility experience nor has anyone directly requested this information from the most reliable sources--the women and men undergoing treatment for infertility. I hope that this information will help other couples going through this pain by letting them know they are not alone and there are valuable resources available to them. It should also enhance the knowledge of physicians, nurses and all other staff who regularly interact with infertile patients and may, therefore, lead to an improvement in the overall quality of the experience for those people receiving medical treatment.

The first part is the questionnaire; please complete this.

The second part involves interviews. If you would be willing to be interviewed please complete the last page of the questionnaire with your first name and phone number.

It must be stressed that your participation in this research project is totally voluntary and can in no way affect your medical treatment. It is completely anonymous and your physicians will have no knowledge of your participation. You may withdraw from participation at any time.

I thank you in advance for any time or effort you may expend in answering this questionnaire. Should you have any questions or desire further information, please don’t hesitate to contact:

Patricia Ferguson, M.A.
Doctoral Candidate, University of Pennsylvania
7301 N. Pennsylvania
Indianapolis, Indiana 46240
(317)253-6749

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Appendix B

1. Age
2. Male  Female
3. Occupation
4. Total income range:
   below 9,999  50-59,999  100-119,999
   10-19,999  60-69,999  120-139,999
   20-29,999  70-79,999  140-159,999
   30-39,999  80-89,999  Over 160,000
   40-49,999

5. Cultural identity: Caucasian
   Afro-American
   Hispanic
   Other (please state)

6. Religion: Roman Catholic
   Protestant
   Jewish
   Other (please state)

7. Highest grade completed

8. How long married?

9. How long have you been trying to conceive?

10. Do you have any other children? No  Yes:
    If yes, please check appropriate descriptor: biologic
        adopted  step-children  other (please state)

11. How long have you attended RESOLVE meetings?

12. How did you hear about RESOLVE?

13. How long have you been in medical treatment?

14. Currently how long do you expect to continue in medical
    treatment?

15. Do you have a definitive diagnosis? Yes  No
    endometriosis  male factor
    history of miscarriage  tubal problem
    other (please state)

16. What procedures have you had done?
    sperm analysis  laparoscopy
    hysterosalpingogram  endometrial biopsy
    inseminations: husband  and/or donor
    other (please state)

17. What percentage of infertility costs does your medical insurance cover?
The next 6 statements ask questions about levels of stress associated with particular situations or issues. The choices include:
NA=Not Applicable;
NS=Not Stressful or usually not stressful;
SS=Somewhat Stressful or occasionally stressful;
MS=Moderately Stressful or frequently stressful;
ES=Extremely Stressful or almost always stressful.
Please circle the response which best reflects the degree of stress you feel regarding the issues identified.

STRESSFULNESS

1. Being around people while they talk about their children is: 0 1 2 3 4
2. Holidays are: 0 1 2 3 4
3. Interacting with friends who have children is: 0 1 2 3 4
4. Financial considerations of infertility are: 0 1 2 3 4
5. Responding to questions about why we have no children is: 0 1 2 3 4
6. Being involved in medical evaluation and treatment is: 0 1 2 3 4

For the remaining questions, please circle the amount of agreement or disagreement which best reflects how you feel at the current time. The choices are:
NA=Not Applicable;
SD=Stronally Disagree;
MD=Moderately Disagree;
MA=Moderately Agree;
SA=Stronqly Agree;

EMOTIONAL REACTIONS

1. The absence of grandchildren has strained relations with our parents. 0 1 2 3 4
2. Treatment is more stressful for me than my spouse. 0 1 2 3 4
3. As a result of our infertility, my work performance has deteriorated a little. 0 1 2 3 4
4. Finances enter into treatment decisions to some extent. 0 1 2 3 4
<p>| | | | | | |</p>
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<th></th>
<th></th>
<th></th>
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<tbody>
<tr>
<td>5. At times I find myself crying for no apparent reason.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>6. I am depressed much of the time because of our infertility.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I find my sleep pattern has changed.</td>
<td>0</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. As a result of the medications that I take for infertility, I feel depressed much of the time.</td>
<td>0</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I feel hopeless about the future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. At times I feel that my life is ruined because of our infertility.</td>
<td>0</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. One minute I am happy and the next moment I am very sad.</td>
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<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. My emotional fluctuations are normal.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. With every new treatment cycle, our hopes are raised.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. After each unsuccessful treatment cycle, we are devastated.</td>
<td>0</td>
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<td>2</td>
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<td>4</td>
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<tr>
<td>15. As a result of our infertility, I am more critical of others.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. As a result of the infertility, I have more difficulty making decisions.</td>
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<td>3</td>
<td>4</td>
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<tr>
<td>17. I feel tense much more of the time since I have been dealing with infertility.</td>
<td>0</td>
<td>1</td>
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</tr>
<tr>
<td>18. I have difficulty concentrating on anything but infertility.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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</tbody>
</table>
NA=Not Applicable;  
SD=Strongly Disagree;  
MD=Moderately Disagree;  
MA=Moderately Agree;  
SA=Strongly Agree;  

19. I am angry that we have to deal with infertility.  
   0 1 2 3 4  

20. I am angry at my friends when they become pregnant.  
   0 1 2 3 4  

21. I have an intensely negative reaction to pregnant women.  
   0 1 2 3 4  

22. I am angry at my spouse for burdening me with infertility.  
   0 1 2 3 4  

23. I am angry at the medical community for not successfully treating our infertility problem.  
   0 1 2 3 4  

24. At the present time, I feel helpless to deal with the infertility problem.  
   0 1 2 3 4  

PSYCHOLOGICAL CONSIDERATIONS  

1. It's been a long haul, but I still expect that we will get pregnant.  
   0 1 2 3 4  

2. Initially I thought the physician must have made a mistake.  
   0 1 2 3 4  

3. At first I thought that it would just take longer for us to conceive.  
   0 1 2 3 4  

4. It took us a while to fully accept that we had an infertility problem.  
   0 1 2 3 4  

5. Initially we were very secretive about our infertility.  
   0 1 2 3 4  

6. I have experienced physical side-effects from the medications I am taking.  
   0 1 2 3 4  

7. I feel like my life is totally dictated by others.  
   0 1 2 3 4
NA=Not Applicable;  
SD=Strongly Disagree;  
MD=Moderately Disagree;  
MA=Moderately Agree;  
SA=Strongly Agree;  

8. We do not hesitate to question our physicians when we do not understand what is to be done or why.  

9. Deciding when to finally terminate treatment is something my spouse and I will have to determine.  

10. I do not feel that I can refuse a test or procedure recommended by our doctor.  

11. I feel that I am controlled by a strong inner drive to remain in infertility treatment.  

12. I feel capable and qualified to be actively involved in the decision-making regarding my infertility treatment.  

13. I prefer to let our physician make all the decisions for our treatment.  

14. Despite infertility, I feel good about myself.  

15. I view myself more negatively as a result of our infertility.  

16. As a result of our infertility, my body image has changed.  

17. I feel ugly because of our infertility.  

18. Through the infertility process, I have come to realize some of my strengths.  

19. It is embarrassing to discuss our infertility situation with others.  

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NA=Not Applicable;  
SD=Strongly Disagree;  
MD=Moderately Disagree;  
MA=Moderately Agree;  
SA=Strongly Agree;  

20. I am open and honest with friends about our infertility.  

21. I think our infertility is my fault.  

22. Nothing I did in the past has caused me to have to deal with infertility at the present time.  

23. Sometimes I think our infertility must be punishment for some long-ago wrong that we committed.  

24. I cannot control my emotions when I am faced with pregnant women or women with young children.  

SOCIAL ISSUES  

1. Our sex life was not affected by our infertility.  

2. As a result of our infertility, communication between me and my spouse has improved. Please briefly describe any changes in communication patterns.  

3. Our marriage has been strained as a result of our infertility.  

4. I am unsure if our marriage can survive the stress of infertility.  

5. If I could do it over again, I would still marry the same person, in spite of our infertility.  

6. I feel closer to my spouse because we have had to deal with infertility.  

7. I feel I have lost my sex appeal as a result of our infertility.  

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NA=Not Applicable;  
SD=Strongly Disagree;  
MD=Moderately Disagree;  
MA=Moderately Agree;  
SA=Strongly Agree;  

8. Sometimes I feel burdened by having to deal with my spouse's emotional needs.  

9. Our physician is meeting our needs adequately.  

10. Infertility has negatively affected my relationships with friends. Please briefly describe any effects on relationships.  

11. I believe that people are basically insensitive to the issue of infertility.  

12. Physicians are sensitive to the psychological needs of their patients.  

13. Only people who have been through this can understand how I feel.  

14. Most of my friends understand how I feel about infertility.  

15. Our families are understanding of our infertility and its emotional aspects.  

16. Our physician openly discusses the emotional difficulties related to infertility.  

17. Our physician discusses alternatives to biological children with us.  

18. Our physician's optimism keeps us motivated to return to treatment the next month.
NA=Not Applicable;
SD=Strongly Disagree;
MD=Moderately Disagree;
MA=Moderately Agree;
SA=Strongly Agree;

19. Our physician is so optimistic about our chances for a successful pregnancy.

NA SD MD MA SA

0 1 2 3 4

CURRENT FEELINGS

Although you may have felt different ways at different times, I am now interested in how you are feeling at the current time. In responding to the next set of statements, please provide answers which reflect your current feelings.

1. I am shocked that we have an infertility problem.

0 1 2 3 4

2. I can not believe this is happening to us.

0 1 2 3 4

3. I don’t think it is a question of ‘if’ so much as ‘when’ we will have children.

0 1 2 3 4

4. I honestly don’t know what I’m going to say to my spouse if we have a medical problem.

0 1 2 3 4

5. I can accept that we may never bear biologic children.

0 1 2 3 4

6. I view myself as one partner of an infertile couple.

0 1 2 3 4

7. The fact that we have a specific diagnosis makes it easier to accept our infertility.

0 1 2 3 4

8. If I never have a biologic child, I will feel incomplete as a person.

0 1 2 3 4

9. I now realize that I have much more control over this situation than I ever thought I could.

0 1 2 3 4

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NA=Not Applicable;  
SD=Strongly Disagree;  
MD=Moderately Disagree;  
MA=Moderately Agree;  
SA=Strongly Agree;  

10. I realize that despite our infertility there are still a number of viable options to pursue.  

11. I have the energy to pursue alternatives to biologic child-bearing.  

12. I can once again get excited about what the future may hold for me and my spouse.  

13. We are considering other options for building a family.  

14. I feel good about the decisions that we have made regarding building a family.  

15. I will always view myself as an infertile person.  

16. In spite of the trauma of infertility, things are working out well for us.  

17. I will always feel different from the fertile world.  

18. Women spend more time thinking about their infertility problem than men.  

19. Women have an easier time discussing infertility with others.  

20. It is more humiliating for a man to say he is infertile than for a woman.  

21. I, as an individual, could have used more psychological assistance dealing with the issue of infertility.
The next series of questions are open-ended. Please provide as much detail as possible regarding your particular circumstances and perspective.

1. To date what has been the most difficult aspect of the infertility treatment for you? Why?

2. Approximately how many hours per week or month do you spend involved in infertility treatment? ___________
   In percentages, how is this time spent?
   - Waiting in doctors' office __
   - Having procedures __
   - Driving to and from appointments __
   - Meeting with physician __
   - Discussing infertility with spouse __
   - Receiving psychological help __
   - Other (Please specify) ____________________________

3. How was the information about your infertility first conveyed to you? (i.e.; who told you, what did they say, etc.)

4. When you tell people about your infertility, what do you say?

5. Did you seek outside psychological assistance in order to deal with the issue of infertility? Yes ___ No ___

6. If yes, how did you find this help? What type was it? What was helpful? What was not?
7. Of the alternatives you and your spouse have discussed for building a family:
   On which alternatives do you agree?
   On which alternatives do you disagree?

8. In what ways has infertility changed your life?

9. Please feel free to comment on anything I may have omitted or on anything you feel strongly about regarding your experience with infertility.

I am attempting to get as broad and complete an understanding of the experience of infertility as possible. Because it is not always feasible to fully describe/understand one's feelings or perspectives solely from questionnaire responses, I am hoping to gain additional information through selected interviews of willing participants. In this manner, I hope to gain a deeper understanding of how infertility affects both individuals and couples. If you would be willing to be interviewed or would like more information about the interviewing process, please print your first name and telephone number on the space below.

_______  _______  best time to call ______
    name      tele #

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I will contact interested individuals and/or couples to describe the interviewing process in greater detail.

Your participation will remain confidential and your physicians will have no knowledge of your involvement in this study. Participation in this study will, in no way, affect your infertility treatment. You may withdraw from participation at any time and for any reason.

Thank-you for your participation in this study.
### Appendix C

**Duration of Marriage of Respondents**

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### Appendix D

**Educational Background Comparison of Subjects**

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### Appendix E

#### Age Comparison of Subjects

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#### Variances

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**Note:** $F' = 1.06; \ df = 103.95; \ Prob > F' = 0.79$
# Appendix F

## Socioeconomic Comparison of Subjects

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^aThousands of dollars per year

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Note: F' = 1.12; df = 102.95; Prob > F' = 0.57
Appendix G

Guidebook Outline

I. Overview of Infertility
   A. Two-fold phenomenon
      1. Medical
      2. Psychological

II. Medical Components
   A. Possible etiologies
   B. Evaluation process
      1. Review and describe typical tests, procedures.
      2. Discuss rationale.
   C. Treatment options
      1. What is available
      2. Effectiveness rates

III. Psychological Considerations
   A. As a result of infertility, not causal.
   B. Analogies to death and dying experience.
   C. Different components
      1. Information from the Factor Analysis
   D. Dyspelling myths
   E. Gender differences
   F. Additional areas of importance identified by respondents: decision-making, terminating treatment, long-lasting effects.
G. Constructive insights
   1. How to cope with infertility
      a. What helps
      b. What doesn’t
      c. Developing and maintaining a perspective

IV. Summary