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THE EFFECTS OF SUPPORT GROUPS
ON INFERTILITY PATIENTS

by

Elizabeth Grace Popovich Monteverde

A Thesis Submitted to the Faculty of the
DEPARTMENT OF COUNSELING AND GUIDANCE
In Partial Fulfillment of the Requirements
For the Degree of
MASTER OF ARTS
In the Graduate College
THE UNIVERSITY OF ARIZONA

1986
STATEMENT BY AUTHOR

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ABSTRACT

Infertility is a major life crisis situation that affects at least 20 percent of the population in this country. Historically, religious and mythological references have shown the isolation and emotional distress that infertile couples endure.

Support groups for infertile couples and individuals were established in 1973 by Barbara Eck Menning who called the organization Resolve. Members are provided with information, education and support. A Tucson group of this type was begun in 1981. This thesis surveys the need for an infertility support group and the effects on infertility patients in the Tucson area.
CHAPTER 1

INTRODUCTION

Infertility affects at least 20 percent of the population in this country. Statistically it is due to a female problem 40 percent of the time, a male problem 40 percent of the time, and the remaining 20 percent of the time is either combined causes or unknown. Rarely, if ever, is infertility due to psychological or sexual problems. It can, however, cause undue stress and emotional problems as well as sexual problems, but not vice versa. Even those couples with unknown infertility causes usually have a medical cause that is discovered sooner or later because medical science continually makes new advances in this field (Menning, 1977).

Many mythological, religious and social explanations for fertility and infertility have evolved. The early civilizations of Asia Minor, Syria, and Libya worshipped a mother-goddess rather than a father-god. Even though the man was stronger and more dominant, the woman with her monthly cycles corresponding to the cycles of the moon was seen as an awe-inspiring mystery. At first
it was believed that conception occurred parthenogenetically, or by the spirit of the wind or waters of the streams or from the gods on high. At some point the connection between a man and a woman joining to make a child was made but the strength of worship of the mother-goddess still persisted to some degree. Even today, for example, a childless Catholic woman will pray to the Virgin Mary for assistance in conceiving a child (Menning, 1977).

In the book of Genesis, Adam and Eve were told to "Be fruitful and multiply" (Genesis, 1:27). A childless woman was seen as being as useless as a piece of empty land yielding no crops. Both were called the same -- BARREN. Practices which were later prohibited by religion, such as incest, adultery, polygamy and religious prostitution, were excused in the Old Testament as being necessary to produce children. Abraham and Jacob were encouraged in the book of Genesis to beget children by their servants when their wives were unable to provide them (Menning, 1977).

And when Rachel saw that she bare Jacob no children, Rachel envied her sister; and said unto Jacob, Give me children, or else I die. And Jacob's anger was kindled against Rachel: and he said, Am I in God's stead, who hath withheld from thee the fruit of the womb? And she said, Behold my maid Bilhah, go in unto her; and she shall bear upon my knees, that I may also have children by her (Genesis 30:1-3).
There seemed to be a connection made in the Bible between fertility and worthiness. Infertility was seen as a punishment. Sarah, Rachel, Leah, Hannah and Elisabeth, five of the better known childless women in the Bible, finally did conceive after finding favor with God (Menning, 1977). "And God remembered Rachel, and God hearkened to her, and opened her womb. And she conceived and bare a son; and said God hath taken away my reproach" (Genesis, 20:22-23).

Even today women and men feel that their infertility is a form of punishment and search for reasons for their unworthiness. One woman felt that if she had just been a better person this would not have happened. "We were good children, hard workers, and would never hurt a fly" (Kraft, 1980).

Motherhood is also seen in the Bible as purging women of their evilness since Eve's transgression. "And Adam was not deceived, but the woman being deceived was in the transgression. Notwithstanding she shall be saved in childbearing" (Timothy 2:14-15).

In some religious teachings, children must be born for the woman to reach heaven, to free souls from bondage, or to permit souls to go their own way in a cycle of transmigrations. In some religions a marriage can be annulled
if a woman is infertile, but not if a man has an infertility problem. In polygamous marriages an infertile woman is soon replaced by a new one and relegated to the level of a servant. This religious influence over fertility accounts for a large share of the attitudes displayed toward a couple who are childless (Menning, 1977).

In addition to religious teachings, most psychological theories make reference to having children in terms of normal growth and maturity. In psychoanalytical psychology, for example, parenthood is viewed as the normal outcome of development to adulthood. Freud saw childbearing (preferably of male children) as the way women compensated for "penis envy" (Menning, 1977). Erikson introduced eight basic stages of development each building on the last and progressing to adulthood. The stage of generativity is described as "primarily the concern of establishing and guiding the next generation, although there are some individuals, who through misfortune or because of special and genuine gifts in other directions, do not apply this drive to their own offspring" (Erikson, 1950). If generativity is not achieved, stagnation results. Without progressing to this stage, successive stages cannot be achieved. Therefore, Erikson saw infertility as a developmental crisis (Menning, 1977). Society, in general, often views infertile couples in much the same way as these theorists.
When a couple is childfree, whether by choice or not, they are seen as "materialistic, selfish, and irresponsible". If it's learned that this is not by choice the resulting emotion is pity. Without children couples are seen as having less value to society. They are seen as incomplete. Without children they have not completed the transition to adulthood (Menning, 1977).

**Purpose of the Study**

The purpose of this study was to define infertility and how it is determined, assess the available treatments, and evaluate the emotional stresses and resultant coping strategies of individuals dealing with these issues. Two questions were posed:

1. Is an infertility support group needed in the Tucson community?

2. Do support groups decrease the negative feelings associated with dealing with infertility?

This study surveyed members of a community to determine the need for an infertility support group. In addition, members of the resulting group were surveyed to measure the degree of negative feelings associated with being infertile before and after participating in an infertility group for at least six months.
Limitations of the Study

This study was limited to the infertile population in the Tucson, Arizona community. In addition, it was limited to those patients who were either members of national Resolve, patients of one participating physician or those patients who had heard of the group by word of mouth. Infertility is a sensitive issue and anonymity was an essential element in the study. This may have influenced responses to the survey which may have biased the results. Other limitations of the study include possible discrepancies between actual and reported feelings/behaviors, and possible misinterpretations of the wording of statements/questions. Finally, during the forming of the support group, personal friendships developed between the members and the researcher. This was unavoidable and it is hoped that this did not unduly influence the results of the study.
CHAPTER 2

REVIEW OF THE LITERATURE

This chapter will discuss infertility, its definitions and causes, medical tests and treatments, emotional needs of infertile couples, and infertility as a major life crisis.

Infertility: Definitions and Causes

Infertility is defined as "the inability to conceive a pregnancy after a year or more of regular sexual relations without contraception, or the inability to carry pregnancies to a live birth" (Menning, 1977, p. ). It is not the same thing as sterility, which is permanent, and implies no hope. Over 50 percent of the couples who seek medical treatment for infertility can be "cured". The causes of infertility are numerous and more are being discovered and helped all the time.

Some of the female causes of infertility include: anovulation, systemic disorders, endometriosis, post-oral contraceptives, delayed marriage and child-bearing, sexually transmitted diseases, adolescents having sexual relations earlier and more frequently, intra-uterine device infections, pelvic inflammatory disease, repeated abortions,
cysts, malformations of the reproductive organs, other structural problems sometimes induced by in-vitro exposure to the drug D.E.S. or diethstilbestrol, excessive radiation, some drugs, alcohol and causes unknown (Menning, 1977).

Anovulation, or failure to ovulate, is the cause of infertility in 20 to 30 percent of infertile women and can be caused by a number of factors (Katz, 1983). These can include a lack of estrogen, a lack of gonatropins, luteal insufficiency, increased prolactin secretion, and other hormonal imbalances. Excessive exercise such as that done by joggers or professional dancers can decrease fertility by disrupting the balance of estrogen which is stored in the fatty tissue thus affecting ovulation. Failure to ovulate regularly may be due to problems in the function of the ovaries, pituitary, hypothalamus, thyroid, or adrenal glands. Sometimes one or more of these organs may be malfunctioning. Any disruption in the delicate hormonal balance of the body can affect ovulation and determining the cause of infertility can be complicated. Sometimes women who have taken oral contraceptives will fail to resume ovulation after stopping the medication. It occurs in less than one percent of such women but it can occur (Katz, 1983).

Sometimes high prolactin levels can cause anovulation. The cause of these increased levels can be small
tumors in the pituitary, breast feeding or some medications. Drugs that can cause anovulation include tranquilizers such as Thorazine, Reglan, Reserpine, and Aldomet, anti-depressants such as Elavil and others, amphetamines and narcotics (Katz, 1983).

Endometriosis is a cause of female infertility in approximately 15 percent of the cases (Fertility Review, November, 1985). It is particularly common in women over the age of thirty. This condition is characterized by the endometrium (the normal uterine lining) implanting itself into abnormal places, such as the tubes, the ovaries or the peritoneal cavity. This tissue then responds to the woman's hormonal levels just as her uterus does and it "bleeds" at the time of menstruation as well. This can cause scarring and adhesions as well as extreme pain. In addition ovarian cysts can form preventing ovulation (Resolve Fact Sheet, 1979).

Delayed marriage and childbearing past the most fertile years of the mid-twenties is another cause of infertility, although the importance of this is a controversial issue. Many women in their 30's and 40's successfully deliver healthy babies. However, if a couple had an infertility problem that was undetected in their 20's while they deliberately prevented conception it will become apparent later on when they decide they are ready
to have children. Endometriosis is also more common past the age of thirty as previously mentioned. It is significant to remember that the only true test of fertility is to become pregnant and to carry to term. It is a common lament of infertile couples who make the discovery after years of responsible contraception only to learn it was never necessary, "All those years of contraceptives! All that wasted money!" (Resolve member, 1982).

The degree of significance of age on infertility varies among physicians. It is known that fertility decreases slightly after the age of thirty, again at 35 and also after the age of forty. If a woman menstruates irregularly or has a history of a sexually transmitted disease, or other infection or inflammation of the reproductive system she is at a higher risk of being infertile at any age (Menning, 1977).

Sexually transmitted diseases, particularly if undetected for extended periods of time, can cause irreparable damage to the reproductive system. As a result of some sexually transmitted diseases scarring and tubal blockage can occur. Tubal adhesions account for 30 to 40 percent of the cases of female infertility (Fertility Review, November, 1985).

When a woman has earlier and more frequent sexual experiences with a variety of partners she not only
increases her risk of a sexually transmitted disease but she may develop sperm antibodies. Her cervical mucus can actually kill the sperm before they have a chance to reach the ovum (Resolve Fact Sheet, 1980).

Intra-uterine devices (I.U.D.'s) can harm fertility through the possibility of pelvic inflammatory disease (P.I.D.), perforation, embedding or ectopic pregnancy. They may even lead to hysterectomy (removal of the uterus). One of these intra-uterine devices, the Dalkon Shield, was responsible for at least 17 deaths. This device was taken off the market in 1974 and there are over 1500 lawsuits pending (Women's Health Book Collective, 1984).

Pelvic Inflammatory Disease (P.I.D.) is a general term for an infection that affects the fallopian tubes, ovaries, both tubes and ovaries and/or the uterus. Many cases are undiagnosed. P.I.D. can cause chronic pain, infertility and even death if untreated. Once diagnosed the disease can be treated with antibiotics much the same as a sexually transmitted disease. The partner must also be treated. Sometimes the organisms are difficult to culture. Persistence is necessary when P.I.D. is suspected (Women's Health Book Collective, 1984).

Abortions, if done badly, or not properly followed up, can cause infections which if not treated, can affect
fertility. While having an abortion does not decrease the chances of having a healthy baby in the future, there is some indication that having several abortions may slightly increase the chances of miscarriage or premature birth. More research needs to be done in this area (Women's Health Book Collective, 1984).

Cysts on the ovaries prevent or cause irregular ovulation. Stein-Leventhal syndrome, or polycystic ovaries, is characterized by a tough, fibrotic covering and multiple follicular cysts on the ovaries. Sometimes malformations of the reproductive organs or structural problems are discovered in infertility workups. A condition known as ovarian dysgenesis, or Turner's Syndrome, is a congenital absence of ovaries which is rare and uncorrectable. This is the result when a woman receives only half of her sex-chromosome complement resulting in XO instead of XX. The counterpart in males is Klinefelter's Syndrome. Other reproductive malformations include premature ovarian failure, surgical removal of the ovaries, multiple large fibroid tumors, congenital malformations of the uterus or extreme malposition of the uterus. The most common malposition is a sharp backward flexion (or retroversion) of the uterus accompanied by adhesions in the pelvic area that prevent the free mobility of the uterus. A common congenital malformation of the uterus is a "heart-shaped" or bicornuate uterus where the uterus is divided to some degree
by a septum in the middle. It is also possible, though rare, for there to be duplicate uteruses. The result of these congenital problems is usually miscarriage rather than failure to conceive. The abnormal uterus does not allow for the normal growth and expansion of pregnancy. Hysterectomy or congenital absence of a uterus is a cause of absolute sterility. A weakened or incompetent cervix is a common cause of miscarriage in midtrimester (Menning, 1977).

Some structural abnormalities were caused by exposure to DES (diethylstilbestrol) in utero (in the womb before birth). This drug was ironically given to the mothers of many of today's women of child-bearing age to prevent miscarriage, or so it was believed, during the 1950's and 1960's. Uterine factors account for female infertility problems about one percent of the time (Fertility Review, November, 1985).

The effects of large amounts of radiation on the ovaries appear to be more of a danger to the offspring of someone exposed than a factor affecting conception (Menning, 1977). It can be a cause of miscarriage or conceptual problems in the offspring.

Excessive use of alcohol or drugs can reduce sexual desire (libido) to the point where relations cease. These can be dangerous to a developing fetus (Menning, 1977).
Some medications can interfere with fertility by preventing ovulation, or affecting cervical mucus consistency. If the cervical mucus is too thick, sperm can't penetrate into the uterus.

Luteal insufficiency is another cause of infertility. It appears to be related to development of the corpus luteum. The corpus luteum is a special gland that forms in the ovary at the site of ovulation and produces the hormone progesterone in the second half of the normal menstrual cycle. If this delicate hormonal balance is not achieved then a pregnancy cannot be supported (Menning, 1977). Luteal phase defects account for approximately four percent of female infertility cases (Fertility Review, November, 1985).

Male infertility also has a variety of causes which include: varicoceles, hydroceles, hypogonadism, tubular obstruction, previous infections, mumps, drug induced impotence, alcohol, sexually transmitted diseases, excessive radiation, excessive heat, and unknown causes. Male infertility requires an interplay between the hypothalamus, pituitary, testicles and sperm production. A workup on the male is easier since the organs are more accessible for study. Yet less is known about male infertility than female infertility. But it is a growing area of research (Katz, 1983).
A varicocele is a varicose vein of the testicle which causes a rise in temperature resulting in less sperm. A hydrocele is a small bag of fluid in the scrotum. Mumps can cause impairment and atrophy of testicular tissue.

There are two categories of male infertility, azoospermia and oligospermia. Azoospermia is a total lack of sperm and is seen in 20 percent of infertile men. Unless it is drug-induced there is usually no treatment for this condition.

In oligospermia there are too few, but some sperm. The most common cause of this condition is a varicocele. Some men have antibodies against their own sperm. In 40 to 50 percent of men with oligospermia a cause is never found (Katz, 1983).

Hypogonadism is a term used to mean failure of the testicles to produce testosterone or failure of the hypothalamus to produce gonadotropins. This is sometimes treatable with medication (Katz, 1983).

Obstruction of the vas deferens which carries the sperm from the testicles to the penis can cause blockage, usually from infection. This is usually treated surgically but sometimes antibiotics can help.

Many drugs can induce infertility in men. Cancer drugs affect all rapidly dividing cells in the body. Reversible infertility can occur in low doses, but permanent
effects may occur with long-term or high dose therapy. There is also a risk of birth defects from chemotherapy drugs. The use of saving sperm in a sperm bank prior to undergoing therapy is recommended. Some of these drugs include Cytoxan, chlorambucil, busulphan and methotrexate (Katz, 1983).

Sulfasalazine (trade name Azulfidine) is used to treat ulcerative colitis. This drug may cause low sperm counts, abnormal motility or abnormally shaped sperm. In one study, 71 percent of the men on this drug had some sperm abnormality. Return of fertility sometimes takes months after the drug is stopped (Katz, 1983).

Spironolactone (trade name Aldactone) may cause infertility in both men and women. This drug is used to treat hypertension and remove fluid. It affects hormone production in the ovary or testicle (Katz, 1983).

Cimetidine (trade name Tagamet) is a commonly used drug to treat ulcers. It depresses sperm counts and studies are still being done to determine its other effects on infertility (Katz, 1983).

Large doses of marijuana (more than ten joints a week) can cause a depressed testosterone level and low sperm count (Katz, 1983). Alcohol, while it can reduce sexual inhibitions and stress, is actually a depressant
and in quantity can impair erection ability, arousal, and orgasm thus affecting fertility (Crooks, 1983).

Sometimes there appears to be no problem with the sperm in shape, quantity, or motility. Recently it has been discovered that some sperm are unable to penetrate the ovum or egg. A test called the hamster egg test has been developed for testing this condition. The sperm is mixed with at least 50 hamster eggs (which are similar in structure to human ovum) and are later evaluated to check for signs of penetration (Resolve, 1983).

This is but one example of how previously termed "normal infertiles" (unexplained causes) are now explained. The theory today is that if a cause is unknown it does not mean that psychological reasons are the explanation, merely that medical science hasn't yet discovered the cause. Once a cause is found there are a number of treatments available.

**Medical Tests and Treatments**

To find the reason for a couple's infertility a variety of tests are performed. These tests take a considerable amount of time, money, and emotional stress to complete. Most couples are desperate so they commit themselves to these willingly.

One of the most basic tests is the Basal Body Temperature chart, or the B.B.T. chart as it's called (although
many infertiles have less polite names for it). The temperature of a woman throughout her cycle varies according to the hormonal changes that occur in her body. If her temperature is taken consistently every morning before rising with a special thermometer made to record minute changes in temperature and charted on a special graph, an ovulatory curve (or non-ovulatory) can be seen. Many other factors are also recorded on a B.B.T. chart including whether alcohol was consumed (this can affect temperature), drugs that were taken, sleep of less than four hours, illness, and, of course, sexual relations. The chart is viewed as a sexual report card, and self-conscious couples frequently "cheat" on their charts recording relations as often as they think they should be having them and not necessarily as often as they actually did. The charts are kept for several months to show a pattern, to predict ovulation, to determine if a pregnancy occurred, and to aid in scheduling other tests (Menning, 1977).

The postcoital test, also called the Huhner test or P.K. test, is a test of the cervical and vaginal secretions which are analyzed under a microscope within several hours of sexual relations to check for the number of live, motile sperm. This test should be done near the time of ovulation when the cervical mucus is thin and most abundant, and thereby most receptive to sperm.
Tubal insufflation or the Rubin test, which is not used as often today as a decade ago, is still in existence. The woman's uterus receives carbon dioxide gas blown into it under pressure which will escape out of the fallopian tubes if they are open (Menning, 1977).

A hysterosalpingogram (also called a tubogram, or uterotubogram) is an X-ray study in which dye is injected into the uterus to show the delineation of the body of the uterus and the patency of the fallopian tubes. This test in most medical circles has replaced the Rubin test as it not only shows whether the tubes are open (patent) but also provides additional information (such as the shape of the uterus) (Menning, 1977).

The laparoscopy provides similar information when dye is injected while direct visualization of the ovaries and the exterior of the tubes and uterus is performed. This is a surgical procedure where the woman is put under general anethesia and an instrument is inserted through a small incision at the navel for viewing purposes. An incision is sometimes made in the lower abdomen at about the hair line for inserting instruments to manipulate the organs for better viewing. In addition the abdomen is filled with carbon dioxide to make the organs stand out. This is a one day out-patient procedure, but nevertheless, carries with it the risks of surgery and general anethesia (Menning, 1977).
Other infertility tests for women include a variety of blood and urine studies for estrogen levels, progesterone levels, and tests to indicate LH surges. LH or luteinizing hormone peaks in the body just before ovulation and can be chemically induced. An LH surge indicates that ovulation has occurred. Endometrial biopsies can also be performed to determine ovulation. In addition, cervical mucus is evaluated as ovulation approaches. At the optimal time for sperm penetration the mucus can be drawn into long elastic threads which is called the spinnbarkeit phenomenon. As one woman stated after dealing with infertility and its tests:

There is no inner recess of me left unexplored, unprobed, unmolested. It occurs to me when I have sex that what used to be beautiful and very private is now degraded and terribly public. I bring my charts to the doctor like a child bringing a report card. Tell me, did I pass? Did I ovulate? Did I have sex at all the right times as you instructed me? (Menning, 1977).

The most important infertility test for men is the semen analysis. The man produces a specimen by means of masturbation into a small clean jar after abstaining for several days. In cases of the man's religion forbidding masturbation, the postcoital test must be used, although this is not as desirable for accuracy. Sometimes a special condom without spermicides can be used to collect the specimen during intercourse. If contraception is absolutely forbidden as well than a small pinhole in the
sheath about halfway down can be made to satisfy religious dictates (Menning, 1977).

The semen analysis must be done at least twice to obtain accurate results. The following factors are looked for: count, motility, morphology, total volume, liquefaction, and the presence or absence of seminal fructose. Any count of 20 million or over if other factors are good can be considered in the normal range, although the higher the better. Motility includes the number of active cells as a percentage of the total number of cells and the quality of the movement of the cells. As far as morphology goes, at least 60 percent should be normal in structure. A total volume of between two and five cc of ejaculate is considered normal, and more or less may indicate a problem. Semen is ejaculated in a liquid state, immediately coagulates and then liquifies in 15 to 20 minutes. Failure to liquify may impede motility. Seminal fructose is normally produced by the seminal vesicles. Its presence or absence may indicate a blockage. Other tests include a testicular biopsy, or a vasography (an X-ray study of the vasa deferentia), or various blood tests for hormonal levels, and X-rays of the pituitary (Menning, 1977).

Sometimes a couple's infertility problem results from a combination of factors, some male and some female.
If either was with a "normal" partner they would probably produce children. By performing these tests often some or all of these defects can be identified and treated.

Once the infertility problem is identified a variety of treatments are available depending on the specific malfunction. These treatments can include medications, surgery, and education for one or both members of the couple.

If the problem is anovulation, one or more of the so-called "fertility" drugs can be given to the woman. Even though the publicity in the media gives the impression that multiple births are the norm, rather than the exception with these drugs, the statistics are as follows:

Clomiphene citrate (also known as Clomid or Serophene) is given for five days during the cycle, and results in single births 90 percent of the time, twins results 10 percent of the time, and less than one percent are triplets or more. Clomiphene is effective in 75 to 80 percent of anovulatory women in producing ovulation. It works by stimulating the ovaries to release eggs. The cost is approximately $25.00 per cycle (Facts and Comparisons, 1985).

Pergonal, the trade name for Human Menopausal Gonadotropin, is given by injection and results in single births 80 percent of the time, and multiple births 20 percent
of the time. Of these multiple births, 15 percent are twins, and five percent are three or more, with 20 percent viable (living). Pergonal is effective in aiding conception about 40 percent of the time overall, but in women who have failed to respond to clomiphene the success rate is only 20 to 25 percent overall. The cost of this medication is approximately $30.00 per two ml vial with some women requiring two daily injections for several weeks per cycle. Risks can include dramatic enlargement of the ovaries, abdominal pain, pelvic pain, and increased risk of miscarriages (Facts and Comparisons, 1985).

In addition, Human Chorionic Gonadotropin (HCG) may be given as a one time injection after Pergonal is given to release the eggs produced. The side effects are similar to Pergonal and the cost is about $25.00 per dose. (Facts and Comparisons, 1985).

Clomid and HCG are also sometimes given to men. Clomid acts on the hypothalamus to increase secretion of FSH (Follicular Stimulating Hormone) which in the male plays an important role in sperm production. HCG appears to stimulate the interstitial cells of the testicles to produce testosterone which may improve motility (Menning, 1977).

Sometimes high prolactin levels can cause anovulation. The cause of these can be small tumors in the
pituitary, breast feeding, or some medications. The drugs that can cause this include tranquilizers such as Thorazine, Reglan, Reserpine, and Aldomet; antidepressants such as Elavil and others; amphetamines and narcotics. A drug called Bromocriptine is effective in 50 to 75 percent of patients with non-drug induced high prolactin levels (Katz, 1983).

Doctors frequently prescribe other medications such as Vitamin E or Thyroid for both men and women with infertility problems. However, the benefits of either of these drugs as well as other vitamin supplements are questionable.

If the problem is diagnosed as endometriosis sometimes the drug Danazol is prescribed. Danazol works by altering the normal and ectopic endometrial tissue so that it becomes inactive and atrophic. In addition it suppresses ovulation. In many cases the endometriosis is completely resolved after treatment which lasts from three to six months usually. Some side effects may include masculinizing effects such as facial hair, deepening of the voice, etc. (Facts and Comparisons, 1984)

Surgery is sometimes done for endometriosis as well, particularly in the advanced stages. Sometimes the adhesions can be clipped and sometimes lazer beams are used to destroy the offending tissue. In 1980 the
Endometriosis Association was founded in Milwaukee, Wisconsin. Its goal is support and education of the public and medical community regarding this disease (Women's Health Book Collective, 1984).

In cases where sperm antibodies have developed in the woman's cervical mucus the temporary use of a condom or the use of some medications may be helpful. Stein-Leventhal syndrome is treated sometimes with one of the fertility drugs or by surgical wedge resection (Menning, 1977).

Surgical repair is sometimes possible in cases of congenital malformations of the uterus, such as a bicornuate uterus. Medical intervention is also possible in cases of an incompetent cervix. Unfortunately these conditions are frequently not discovered until a pregnancy has already been lost.

If the cervical mucus is too thick or too scanty, medications can sometimes be prescribed. For example, estrogen supplements may be helpful (Katz, 1983). The cough syrup Guaifenesin (trade name Robitussin) is sometimes diluted and used as a douche to thin out the mucus. In other instances mucus donors exist in some areas.

In cases of luteal insufficiency supplements of natural progesterone can be effective 50 percent of the time (Katz, 1983). But achieving the proper delicate
balance of hormones can be complicated and sometimes involves guesswork.

For men with oligospermia, a varicocele repair may be the required treatment. To reverse a vasectomy a vaso-vasotomay can be done. Where azoospermia is not drug-induced there is usually no treatment. Donor insemination for the female partner or adoption for the couple is recommended.

In cases of hypogonadism, or failure of the testicles to produce testosterone, or failure of the hypothalamus to produce gonadotropins, medications may be helpful. If the problem is testosterone production, then testosterone supplements often are effective. If the problem is gonadotropins, Clomiphene or Pergonal can be used. The success rate of Clomiphene is about 40 percent, while Pergonal is successful about ten percent of the time (Katz, 1983).

Obstruction of the vas deferens which carries the sperm from the testicles to the penis can be treated surgically but sometimes antibiotics can help (Katz, 1983).

Other procedures available to infertile couples include G.I.F.T. and I.V.F. G.I.F.T., Gamete Intra-Fallopian Transfer is the procedure by which ovulation is stimulated with Clomid, the egg is harvested by means of laparoscopy, mixed with the husband's fresh semen, and then inserted into the fallopian tubes. Invitro Fertilization, or the media's test-tube babies, is when the egg is retrieved
and mixed with the sperm but inserted into the uterus 38 to 48 hours after being allowed to incubate for 18 hours. In G.I.F.T. the mixture is reinserted at the same time as the laparoscopy. The success rate of harvesting ripened egg(s) from the ovary is about 90 to 100 percent. The fertilization rate after being put with the sperm after it has been washed is also quite high. But the success of the transfer of the embryo and the implantation rate is only about 20 percent. G.I.F.T. costs about $3,000 per attempt, and I.V.F. runs about $4,000 and up per cycle. Both procedures are considered only after all other possibilities have been attempted (Clapp, 1984).

Other alternatives, less expensive and complicated than G.I.F.T. or I.V.F., include A.I.H. or A.I.D. Artificial Insemination by Husband (A.I.H.) is sometimes used to improve chances of conception. A variation of this is I.U.I., or Intra-uterine Insemination where the husband's sperm is washed and spun down then mixed with some of the woman's serum and directly inserted into the uterus. Artificial Insemination by Donor (A.I.D.) is used with a donor's sperm where azoospermia or severe oligospermia exists. I.U.I. can also use donor sperm, however, it often is not necessary as only one million sperm are necessary for I.U.I. as opposed to higher counts necessary in A.I.H., A.I.D. or normal sexual relations where pregnancy is the goal.
There are many new developments in this field. Only a few of the treatments available have been mentioned. As new treatments become available old ones will become obsolete. Medically speaking this is an exciting time for infertile couples offering new hope and new discoveries.

**Emotional Needs of Infertile Couples**

Infertility is a blow to my self-esteem, a violation of my privacy, an assault on my sexuality, a final exam on my ability to cope, an affront to my sense of justice, a painful reminder that nothing can be taken for granted. My infertility is a break in the continuity of life. It is above all, a wound -- to my body, to my psyche, to my soul (Resolve newsletter, December 1981).

Most couples naturally assume that they will be able to have children if and when they choose to. When it becomes apparent that this will be a problem, both husband and wife go through a series of emotional changes. Major decisions concerning careers, going back to school, moving, job changes, even vacations are affected. Their lives are put on hold indefinitely as they pursue this life crisis of having a child.

As the couple continues with endless medical investigations and treatments they feel helpless and out of control. They are experiencing severe emotional losses, although society does not acknowledge these losses because they seem intangible. They are, nevertheless, real and include:
1. The loss of individual genetic continuity and an unbroken family blood line.
2. The loss of a jointly conceived child.
3. The loss of the pregnancy/birth experience.
4. The loss of the emotional experience of bonding and breastfeeding.
5. The loss of the possibility of parenting.
7. The loss of self-confidence.
8. The loss of spontaneous sexual intimacy.
9. The loss of control.

In dealing with these losses the couple goes through several stages just as other losses are dealt with. These include:

**Surprise or shock** -- This may be the first time in their lives that life has not gone according to their plan.

**Denial** -- Couples may deny that the problem exists or that they ever "really" wanted children.

**Isolation** -- Couples may experience isolation between themselves and they may isolate themselves from people who are pregnant or who have children. If they have received poor or little support they may withdraw from family and friends.
Anger — This is a common feeling associated with loss of control. The anger may become focused on doctors, nurses, or adoption workers, or even counselors, as these are the people who represent having control over their lives.

Guilt — In an effort to find a reason for why this has happened to them, individuals review their lives looking for any guilty deeds to which they can attribute their infertility. When and if they identify them, they may try to atone for whatever the real or imagined deeds were.

Grief -- Often spouses experience this at different times and feel alone at this stage. It is a difficult process to start to acknowledge as the object of the grief is not tangible. Society generally does not respond to this kind of grief, and it is hard for the couple to know when to start grieving in the face of all the new technologies and the treatments they present.

Resolution -- Resolution is usually characterized by feelings of renewed energy and focuses on other aspects of their lives. The question of the importance of the pregnancy experience is weighed against the desire to parent. Decisions regarding options such as A.I.D., adoption or child-free living are explored. This is
not to say that the infertility experience is gone forever; often the anniversary of pregnancy loss, or other life crises, in the years to come will stimulate the feelings associated with the infertility experience (Diane N. Clapp, Serono Symposia, 1985).

Couples become focused on the act of procreation rather than the expression of closeness or pleasure in their sexual relationship. The experience becomes routine, mechanical and unpleasureable. Many admit to feeling like brother and sister. The entire relationship changes.

Every medical test and appointment is a reminder of these losses. The Basal Body Chart, one of the most common tools used with infertility patients, is seen as another control and intrusion on the couple's lives. It has an adverse effect on the enjoyment and spontaneity of sex. Couples begin to view their instructions as "sex on demand", "programmed sex", "ugly sex", and in general as another aspect of their lives that is being controlled (Resolve members, 1981).

Self-image suffers as a result of infertility. If a woman has a poor self-image from a previous time in her life such as feeling too thin, too fat, ugly or whatever, these feeling are reactivated. She may feel ugly inside because of damaged reproductive organs. She often may report feeling empty. Two fairly common reactions
include the "Happy Hooker" phase or the "Baby Shower Queen". In the Happy Hooker phase the woman may deliberately dress sexy and try to attract men. She may think, "Well, at least I still have that." The Baby Shower Queen may overcompensate for her own loss by always offering to give the baby shower for friends, family and co-workers, and usually quite elaborate ones. This is to prove to people that her infertility doesn't bother her (Menning, 1977).

Men may react by picking up women in bars or having affairs to reinforce their manhood. If he has frequent sperm analyses this can cause low self-esteem. He feels as though he's being graded. His manhood is threatened because of his inability to father a child. Impotence is a frequent result. "Why bother?" "I'm shooting blanks anyway." With sex on demand, some men report feeling like a "stud service". As a couple they may deliberately use birth control just so they can say they are in control over their fertility. To put themselves in control psychologically they may tell friends and family "We don't want children", or "We haven't decided yet" (Menning, 1977).

Aside from the tests and medications, even their sexual technique is under scrutiny. The missionary position is usually suggested, with pillows propping up the woman's hips. Afterwards the woman is told to remain there with her legs up like a roach for 20 to 60 minutes. Each monthly
cycle is seen as a reminder of another failure. It is a continuous loss. And others offer useless advice that often hurts. "Relax", "Don't think about it". If relaxation had anything to do with pregnancy, pregnancy could be prevented by mere thought! This advice is actually counter productive and merely drives anxiety higher (Menning, 1977).

If a couple is finally able to have a child, the feelings associated with infertility are never forgotten. The pregnancy does not "make everything OK." The couple often reports feeling as though they were "walking on eggshells." Everything must be perfect or feelings of failure result. The feeling of "this is our only chance" is common and often true. Over protection of the child is common. The couple experiencing secondary infertility has special needs in that their pain, loss and frustration is often minimized by society because they already have "been blessed". Or others may say, "You did it once, you can do it again". These comments do not help and only result in further isolation and increase the possibility of depression and unresolved grief (Menning, 1977).

Each month the couple is reminded of their imperfection and failure. The individual who is infertile may feel that they are depriving their spouse of a child and this can trigger fears about their relationship. Frequently
they will say, "Find someone who can give you a child". Infertility affects all aspects of a couple's lives. Each test, treatment, and inappropriate comment from someone who doesn't understand, only adds to the feelings of helplessness and being out of control. It is a major life crisis (Menning, 1977).

**Infertility as a Major Life Crisis**

Infertility is a major life crisis that causes stress and anxiety to those affected (Menning, 1977). Gerald Caplan defines the normal pattern of any event termed a crisis as:

1. A stressful event occurs that poses a problem that is insoluble in the immediate future.
2. The problem overtaxes the existing resources of the persons involved because it is beyond traditional problem-solving methods.
3. The problem is perceived as a threat to important life goals of the persons involved.
4. The crisis situation reawakens unsolved key problems from both near and distant past (Caplan, 1964).

People cannot stay in a state of crisis indefinitely. Crisis is usually time-limited and pushes toward resolution within six weeks or less. The outcome can be one of three possibilities: the couple may emerge as stable as they were previous to the crisis; the couple
may emerge with increased strength and emotional insight; or the couple may regress to a less stable level of functioning (Menning, 1977).

Infertility patients who are in crisis are particularly vulnerable and can be gravely hurt by the indifference of family, friends and peers, lay psychiatric advice or platitudes. The man and the woman often have little help to give each other, as they are both in a state of turmoil. Their feelings may seem confusing and exhausting, even though they are normal and predictable (Menning, 1977).

Since this state of crisis suspends the couple's usual coping patterns, they are especially open to learning new ways of coping. This can lead to new insights, changes in patterns, and tremendous growth. There is also a rise in energy level in time of crisis -- signified by the emotional turmoil. If this energy can be focused and directed by someone skilled in crisis intervention, it can be used toward resolution of the crisis (Menning, 1977). An infertility support group led by trained professionals can provide some of the missing emotional support needed by infertility patients while coping with this life crisis.

The Chinese use two characters for crisis which signify danger and opportunity (See Illustration 1). This has become an inspirational symbol of the infertile community. Infertility, although dangerous to a couple's mental health
Illustration 1. The Chinese symbol for crisis, danger and opportunity (Courtesy of Frank Chan)
due to extreme and prolonged stress levels, also provides the opportunity to learn and to grow. Infertility support groups can provide the environment for growth by providing a safe, supportive environment offering educational information, coping strategies, and peer support. The couple becomes more informed and more in control of their lives. This group can become the social support system which is lacking in their lives, allowing a place to grieve and providing a place to grow.

For couples who share a strong religious faith, the infertility group may provide another alternative to the support of their church which may be lacking. A woman raised in the fundamentalist Christian church found that help of this nature was seen differently by members of her church.

There have been many times when I have reached out to my fellow church members, wanting their help and prayers in dealing with this situation. Once, I requested prayer from a woman's prayer group and was promptly told by these women that maybe it was not God's will for me to have a child, therefore, they were not going to pray for me. Since my religious beliefs and convictions are based on the power of prayer, I was devastated! (Mary Smith, Resolve, December, 1981).

An infertility support group would not criticize or judge the couple's motives as this woman experienced. Members would be able to empathize and offer hope as well as providing an outlet for the frustrations involved.
The healing power of a group of patients who share a common problem was discovered almost fifty years ago by Dr. Joseph Pratt of Boston, who treated a group of patients suffering from tuberculosis. The preferred treatment at the time was to send patients to fancy, expensive sanatoria in Colorado or the Adirondacks, which not everybody could afford. Dr. Pratt assembled some of those left behind in the slums of Boston and organized his Classes for the Treatment of Tuberculosis in the Homes of the Poor. The topic to be discussed was how to make the most of the meager fresh-air resources of the city.

To everybody's surprise these patients did as well as, or better than, those who went to the mountains. Since the Boston air was not all that good, it was concluded that the patients profited from the healing power of what came to be called "a common bond in a common disease". This was the beginning of group therapy (Decker, 1978).

Today there is increased recognition that all patients who share any kind of serious problem profit from sharing their fears and frustrations with others who are in the same situation. Infertility is no exception.

These group members are at various stages of their battle with infertility. Some have just begun to face the fact that they may never bear their own children. Others have been coming to the group for nearly two years,
all the while undergoing various therapeutic procedures, hoping, praying, crying, raging and eventually coping (Decker, 1978).

It's important to remember that grief, once the process begins, does run a predictable course and does end eventually.

People describe the feeling of having grief resolved in some of the following ways: There is a return of energy, perhaps even a surge of zest and well-being; a sense of perspective emerges; optimism and faith return and also a sense of humor -- and some past absurdities may even become grist for story telling; self-image is again perceived correctly (I may be short and nearsighted, but I'm NOT defective); self-esteem returns (good things can happen to me; I deserve to do well); sexuality can be forever disconnected from thoughts of child-bearing and enjoyed in its own right, for its own sake. Plans for the future can be made again with confidence (Menning, 1979).

In order for grief to run its course it must be expressed. With infertility, beginning this process is the most difficult part. Infertility Support Groups offer a safe place for the grief process to evolve. "A support group is able to offer, as no other form of therapy can, a validation of feelings, thoughts and actions" (Menning, 1979).

Another skill taught in support groups of this type is that of coping with the insensitive comments of others. Physicians can offer medications and treatments that help the physical problems. Having the fact that
it is a physical problem validated can be a tremendous relief to an infertile person who frequently fears there is some psychological problem as others imply. However, only peer support and trained professionals in this field can offer the specific coping skills necessary in dealing with people who are not infertile in the meantime. Merle Bombardieri has developed the Pressure Victim's Bill of Rights which can be applied to the infertility situation.

You have at all times the following rights:

1. The right to choose whether or not to discuss your situation with a particular person.
2. The right to be heard if you wish to explain your situation to chosen people.
3. The right to cut conversation short or change its direction.
4. The right to point out and object to the techniques a pushy person is using on you (Bombardieri, Resolve, September 1984, Reprinted from The Baby Decision).

It is also suggested that an infertile person have a repertoire of well-rehearsed answers in mind ahead of time in dealing with pushy people. Humor can help tremendously. Some possible answers suggested by infertile people include:
Q - "have you tried boxer shorts?"
A - "My husband loves them, but frankly I can't get used to them."
Q - "Everyone I know who adopted got pregnant. It can't be a myth!"
A - "I understand what you're going through. I still want to believe in Santa Claus."
Q - "Maybe what you need is a real man." (leer...lear)
A - "Then you won't mind me calling the clinic and scheduling a macho-oscopy for you?"
Q - "Aren't you ever going to have children?"
A - "What is it about my not having children that bothers you?" (Otterstrom, Resolve, September, 1984)

The goal/objective is to steer the direction of the conversation in another direction and to put the other person on the defensive. The infertile person is once again in control. This is important and is a skill not taught elsewhere in a world that often doesn't even acknowledge the problem. Another way to deal with uninformed people is to memorize the facts so that they come out automatically. When a person confronts an infertile with "Oh, you're taking fertility drugs! That means you'll have six babies!" The patient can reply, "In only ten percent of the women who take these medications do they have more
than one baby and usually it's just twins." It's also a good thing to recognize those people who really care and to have a choice of whether or not to explain the situation to them. Again, the skill taught involves that the choice is possible and that the infertility patient is in control.

An infertility support group should have certain guidelines to be of the most service to infertile couples and individuals. Resolve, the national organization begun by Barbara Eck Menning in 1973 has certain standards they suggest. These groups are nationwide and community sponsored, yet they all have a link to the national organization in Boston. Resolve suggests that the group be facilitated by trained professionals with backgrounds in nursing, social work, or counseling, and trained to the master's degree level. Groups are set up on a geographic basis depending on public demand. Meetings last about two hours and from 15 to 20 sessions, but this is flexible, and is determined by the needs of the group. The leader's role is to facilitate discussion and to keep it at a feeling level. The emphasis is always on the present and the immediate future. In addition to support from each other, members also receive negative feedback, which can result in self-scrutiny and growth (Menning, 1979). The people in support groups are at different levels in the grieving process and offer a
different perspective to the other members. Members dis-
cover that their feelings are normal and that an end is
in sight even if pregnancy is not the result. The crisis
will not last forever.

This chapter has discussed an overview of infer-
tility, its definitions and causes, medical tests and treat-
ments, emotional needs of infertile couples, and infertility
as a major life crisis. From this overview the need for
support groups to help these people can be recommended.
Chapter 3 will discuss how a support group was founded
in the Tucson area.
CHAPTER 3

FOUNDING A SUPPORT GROUP

Infertility affects one fifth of the population. Considering the tests and treatments involved and the resulting emotional stress, the need for support is suggested. The benefit of support groups is well established for groups of people who share a common problem (Decker, 1978). Resolve, the national organization established by Barbara Eck Menning for infertile couples, has successfully been aiding people with infertility since 1973. In 1980, having gone through a long-term personal infertility crisis, the researcher began to explore the need for a support group in the Tucson area. This chapter deals with the procedures that were used in founding a support group.

Letters which suggested the need for a support group and asking for professional support and referrals were sent to physicians, clinics, adoption agencies, and anyone who might be interested and who might deal with infertile people. Although there was no immediate response, about a year later, Dr. Diane Fordney, of the University of Arizona Medical Center, replied that she would be willing
to support such a group. In addition she provided the services of two social workers, Marilyn Hauer and later Charlotte Emery to offer professional assistance. The group officially began in 1981. There was some brief publicity in the local newspaper and the group was called the Tucson Infertility Support Group (T.I.S.G.).

In the next two years, the group remained small and the word was still not getting to the medical community and, most important, to the patients. This was in spite of the fact that meeting notices and fliers were distributed to physicians and clinics on a regular basis. To determine the extent of the need for the group, the Infertility Support Questionnaire was developed. The questionnaire follows in Illustration 2. A copy of the cover letter can be found in Appendix A. Of all the physicians who were asked to allow their patients to participate, again it was only Dr. Fordney who agreed to offer the survey to her patients.

The questions on the Infertility Support Questionnaire were the researcher's and based on personal experience as well as suggested by current literature on the subject. It consists of a series of 20 multiple choice questions dealing with common aspects of an infertility experience and ending with an invitation to join the support group.
Please circle the response which best answers the question.

1. I have been aware of my infertility for
   A. One year or less
   B. Over 1 year
   C. Over 3 years
   D. More than 5 years

2. The problem seems to be caused by
   A. Female problems
   B. Male problems
   C. A combination of both

3. So far, I have sought the help of
   A. One physician
   B. More than one physician
   C. Physicians and other professionals

4. If you circle "C" on question #3, the other professionals were:
   A. A nurse
   B. Psychologist or psychiatrist
   C. Social worker
   D. Other, please state _______________________

5. Have you ever been pregnant before?
   A. Yes
   B. No

6. Do you now have
   A. One child
   B. More than one child

7. Have you ever considered adoption?
   A. Yes
   B. No

Illustration 2. Infertility Support Questionnaire
Illustration 2 (Continued)

8. I feel that my emotional needs regarding this problem are being met
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

9. Have you ever heard of Resolve?
   A. Yes
   B. No

10. Have you ever heard about a support group for infertility patients in the Tucson area?
    A. Yes
    B. No

11. If you have heard of such a group, was it from
    A. Your doctor or someone in their office
    B. The newspaper
    C. A friend or relative
    D. Other, please state _____________________________

12. Have you ever attended an infertility support group?
    A. Yes
    B. No

13. If you answer "Yes" to question #12, was the group
    A. In Tucson?
    B. Elsewhere? Please state where _____________________________

14. If you have attended a support group, was it
    A. A positive experience?
    B. A negative experience? Why?

15. Would you be interested in attending an infertility support group?
    A. Yes
    B. No
Illustration 2 (continued)

16. If you would be interested, should it meet

A. One day per week
B. One day per month
C. Two times a month
D. Only occasionally
E. Other__________

17. Would your partner be interested in joining such a group?

A. Yes
B. No

18. Would you be interested in hearing speakers on (Circle all that apply)

A. Medications used in the treatment of infertility
B. Adoption
C. Religious angles
D. In-Vitro fertilization
E. Other topics, please state__________

19. Would you prefer the time of day for these meetings to be

A. In the morning
B. In the afternoon
C. In the evening
D. On the weekend

20. Do you wish to receive more information about joining an infertility support group?

A. Yes
B. No, not at all
C. Not at this time

If you answered yes, please fill in the information below, and I will contact you. Your help is appreciated, thank you.

NAME__________________________________________

ADDRESS________________________________________

TELEPHONE______________________________________
Illustration 2 (Continued)

Notices of our meetings with speakers on various topics of interest to infertility patients are printed in The Tucson Citizen's "Bulletin Board" section from time to time. The Tucson Infertility Support Group also has recently begun a monthly newsletter. Your doctor should be receiving this. Thank you.
With the help of Jamie Carrier, Dr. Fordney's receptionist, 70 surveys were distributed over one and a half years. Fifteen were returned, and of those returned, only seven offered their name, address, and phone number. However, the remaining eight suggested an interest at perhaps a later time. Despite the low return (21%) of the surveys and the even lower response of those interested in joining a support group (10%) this survey is still considered to be important for the following reasons:

1. It provided information about the Tucson Infertility Support Group in a non-threatening manner to those who needed it.

2. It provided suggested topics that would interest members and prospective members (When speakers were presented on these topics larger groups attended the meetings. They were allowed to remain anonymous to respect their privacy but it is suspected that some of these people had been exposed to the Infertility Support Questionnaire at their doctor's office prior to attending these meetings).

3. It showed that the medical community, family and friends were not providing all of the support necessary for infertile people.
4. It conveyed to even those who chose not to answer the survey that the group existed and was there if they or others like them needed it.

Since 1985, the Tucson Reproductive Institute has become involved with T.I.S.G. Various members of the Tucson Reproductive Institute (T.R.I.) have attended meetings and spoken on various topics of interest to the group. T.R.I. is open for the use of all physicians in the Tucson area and thus provides T.I.S.G. with further exposure.

The Tucson Infertility Support Group was accepted as a provisional chapter of Resolve in 1985. A monthly newsletter was established in the Fall of 1985 to supplement the bi-monthly meetings. Other services that have been established at that time include a crisis support call list, Resolve Fact Sheets, and telephone counselors available on a 24 hour basis. Local physicians send referrals. In November 1986 a regional symposium co-sponsored by Serono (drug company) and National Resolve will be presented in Tucson.

A typical T.I.S.G./Resolve meeting might include the following:

1. Greetings and refreshments
2. Update from the President on current issues from National Resolve taken from the Presidents' Newsletter distributed to all chapter presidents.
3. Discussion of the Tucson group's current plans.

4. Update from committee chairmen: Adoption Coordinator, Publicity Chairman, Newsletter Coordinator

5. Treasurer's report

6. Symposium update of plans

7. Individual member's update on their current situation (open and completely voluntary). Support from other members is freely given. Facilitator (a trained counselor) leads the discussion and tries to keep it at a "feeling" level. The emphasis is kept on the present and the immediate future, although a release of past events also occurs.

Some meetings do not follow this format because a speaker has been asked to talk about a certain topic or a film is shown. These are open to the public. Regular meetings in the Tucson area are always open to new members, although in some parts of the country Resolve has a screening process for new members first. In Tucson the group is small and includes infertile people with all types of infertility problems mixed together. In other parts of the country there are separate groups for specific problems, such as secondary infertility, endometriosis, those
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7. Individual member's update on their current situation (open and completely voluntary). Support from other members is freely given. Facilitator (a trained counselor) leads the discussion and tries to keep it at a "feeling" level. The emphasis is kept on the present and the immediate future, although a release of past events also occurs.

Some meetings do not follow this format because a speaker has been asked to talk about a certain topic or a film is shown. These are open to the public. Regular meetings in the Tucson area are always open to new members, although in some parts of the country Resolve has a screening process for new members first. In Tucson the group is small and includes infertile people with all types of infertility problems mixed together. In other parts of the country there are separate groups for specific problems, such as secondary infertility, endometriosis, those
undergoing donor insemination, those undergoing in-vitro fertilization, etc. Membership in the Tucson group is not large enough for these divisions to be practical.

It was hypothesized by the researcher that participation in an infertility support group can reduce the negative feelings associated with being infertile. To support this hypothesis the Infertility Appraisal Survey was developed (See Chapter 4). This survey consists of 15 negative statements developed from personal experience and the current literature that are believed to express some common sentiments of infertile people. Participants were asked to rate the statements from: a) All of the time, b) Most of the time, C) Some of the time, to d) None of the time. The population was taken from members of the Tucson Infertility Support Group/Resolve of Tucson who had been members for at least six months. They were asked to take the survey twice, once as they would have answered it a year ago (pre-support group) and once as they felt at the present time (Post-support group). Each statement was then evaluated for significant change using a t-test for paired samples. Data and findings can be found in Chapter 4.
CHAPTER 4

FINDINGS

The Infertility Appraisal Survey consists of 15 statements regarding some of the negative feelings associated with infertility. Participants were asked to rate their responses from: a) All of the time, b) Most of the time, c) Some of the time, to d) None of the time. The survey follows in Illustration 3. Each member and each statement were evaluated for significant change from one year ago (pre-support group) to the present (post-support group). The t-test for paired samples was chosen for analyzing the results which can be found in Table 1.

The population participating in the survey consisted of members of the Tucson Infertility Support Group/Resolve of Tucson who volunteered to take part. Sixteen surveys were distributed, and eleven surveys were returned. Each participant filled out a pre- and a post-survey. All participants had been in the support group at least six months and some longer than this, were Caucasian, ranged from 25 to 40 years, had long-term infertility problems (more than three years), five were male and six were
Please rate the following statements regarding infertility as they best apply to you. Circle the appropriate response.

1. Infertility makes me feel alone and isolated.
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

2. Being around pregnant women upsets me
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

3. Being around children upsets me
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

4. Not understanding the required medical tests and treatments upsets me
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

5. My partner doesn't understand my needs
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

6. I feel rejected by my family and friends
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

Illustration 3. The Infertility Appraisal Survey
Illustration 3 (continued)

7. Infertility makes me have low self-esteem
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

8. Infertility causes me to have financial worries
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

9. Infertility causes me to have low self-confidence
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

10. I feel unsure of my career plans because of infertility
    A. All of the time
    B. Most of the time
    C. Some of the time
    D. None of the time

11. My partner and I have sexual problems due to infertility
    A. All of the time
    B. Most of the time
    C. Some of the time
    D. None of the time

12. I feel helpless because of my infertility
    A. All of the time
    B. Most of the time
    C. Some of the time
    D. None of the time

13. I feel angry about being infertile
    A. All of the time
    B. Most of the time
    C. Some of the time
    D. None of the time
Illustration 3 (continued)

14. I feel out of control because of my infertility
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time

15. I want answers and feel that I'm not getting them, regarding infertility
   A. All of the time
   B. Most of the time
   C. Some of the time
   D. None of the time
Table 1. Evaluation: Infertility Appraisal Survey

(Scale and Pre- and Post-Means and SD's for N-ll subjects)

Rate the following statements regarding infertility as they best apply to you. Circle the appropriate response.

A. All of the time = 4. B. Most of the time = 3. C. Some of the time = 3. D. None of the time = 1.

<table>
<thead>
<tr>
<th>Statement</th>
<th>PRE:Mn/SD</th>
<th>POST:Mn/SD</th>
<th>Significant?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Infertility makes me feel alone and isolated.</td>
<td>2.45/.934</td>
<td>2/.447</td>
<td>ns</td>
</tr>
<tr>
<td>2. Being around pregnant women upsets me</td>
<td>1.9/.831</td>
<td>1.9/1.04</td>
<td>ns</td>
</tr>
<tr>
<td>3. Being around children upsets me</td>
<td>2/1</td>
<td>1.64/.674</td>
<td>ns</td>
</tr>
<tr>
<td>4. Not understanding the required medical tests and treatments upsets me</td>
<td>2.09/.831</td>
<td>1.81/.751</td>
<td>ns</td>
</tr>
<tr>
<td>5. My partner doesn't understand my needs.</td>
<td>2.27/.786</td>
<td>1.9/3.0</td>
<td>ns</td>
</tr>
<tr>
<td>6. I feel rejected by my family and friends.</td>
<td>1.9/1.04</td>
<td>1.72/.904</td>
<td>ns</td>
</tr>
<tr>
<td>7. Infertility makes me have low self esteem.</td>
<td>2.18/.873</td>
<td>1.54/.522</td>
<td>p .05</td>
</tr>
<tr>
<td>Statement</td>
<td>PRE: Mn/SD</td>
<td>POST: Mn/SD</td>
<td>Significant?</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>------------</td>
<td>-------------</td>
<td>--------------</td>
</tr>
<tr>
<td>8. Infertility causes me to have financial worries.</td>
<td>2/.632</td>
<td>1.81/.404</td>
<td>ns</td>
</tr>
<tr>
<td>9. Infertility causes me to have low self-esteem</td>
<td>2.27/.786</td>
<td>2/.774</td>
<td>ns</td>
</tr>
<tr>
<td>10. I feel unsure of my career plans because of infertility.</td>
<td>2.72/1.10</td>
<td>2/.632</td>
<td>ns</td>
</tr>
<tr>
<td>11. My partner and I have sexual problems due to infertility.</td>
<td>2/.774</td>
<td>1.72/.646</td>
<td>ns</td>
</tr>
<tr>
<td>12. I feel helpless because of my infertility.</td>
<td>2.54/.934</td>
<td>1.81/.602</td>
<td>p .01</td>
</tr>
<tr>
<td>13. I feel angry about being infertile.</td>
<td>2.81/1.07</td>
<td>2.18/.602</td>
<td>p .05</td>
</tr>
<tr>
<td>14. I feel out of control because of my infertility.</td>
<td>2.54/.934</td>
<td>1.63/.494</td>
<td>p .01</td>
</tr>
<tr>
<td>15. I want answers and feel that I'm not getting them regarding infertility</td>
<td>2.63/.924</td>
<td>1.81/.602</td>
<td>p .01</td>
</tr>
</tbody>
</table>

t-test for paired observations, two-tailed, 10 df
female. The population is limited to those people who are infertile, members of the support group for at least six months, and willing to participate in the survey. The support group itself was limited to those infertile individuals who either heard of the group through their physicians, the press, national Resolve, word of mouth, and who chose to join and continue to participate. Over the time that elapsed between the two surveys friendships developed between the participants and the researcher and might have affected the validity of the study.

Since each statement required an answer regarding time relationships a number value was assigned to each. For example, a value of 4 was assigned to "All of the time", a value of 3 was assigned to "most of the time", a value of 2 was assigned to "Some of the time", and a value of 1 was assigned to "None of the time". It must be made clear that these numbers are purely arbitrary. That is a "4" response for "All of the time", does not mean twice as much as a "2" response for "Some of the time".

The data were analyzed in the following manner. Each pair of statements for each member were totaled using the number value assigned as described. Then these totals were evaluated and compared using a t-test for paired samples as shown in Table 1. While ten of the 15 statements
were not found to be significantly different using this test, five of the statements were found to be significant. The five statements which showed significant change were:

- Infertility makes me have low self-esteem.
- I feel helpless because of my infertility.
- I feel angry about being infertile.
- I feel out of control because of my infertility.
- I want answers and feel that I'm not getting them regarding infertility.

From this data it can be suggested that participating in an infertility support group reduces the feelings of low self-esteem, helplessness, and anger, and makes one feel more in control as well as providing some answers regarding infertility. Since the purpose of Resolve as a nationwide organization is to provide information, education and support for infertile people it can be suggested that the Tucson group is following these guidelines.
Infertility affects at least 20 percent of the population. It can be from male, female and combined causes. The necessary tests and treatments involve considerable time, emotional stress and money. The many mythological, religious and social explanations involving infertility and fertility have led to misunderstandings and more emotional pain. It is a life-crisis situation that affects an individual's entire lifestyle. It is long-term and can continue indefinitely. It involves very real losses which are not often acknowledged by society and therefore are difficult to grieve and to resolve.

Support groups for infertile couples and individuals were established in 1973 by Barbara Eck Menning who called the organization Resolve. Members are provided with information, education and support. A Tucson group of this sort was begun in 1981. This study surveyed the need for such a group and tested the effects of a support group on infertility patients. The results suggest strongly
positive findings implying that support groups can reduce some of the negative feelings associated with infertility.

Infertility affects people of all cultural backgrounds. Yet the majority of Resolve members nationwide are well-educated, middle-class Caucasians. This is not because minorities and lower income people are excluded but because of cultural differences and attitudes towards counseling. They may find a group of predominantly upper- and middle-class Caucasians to be threatening and may feel that they cannot identify with their particular problem. The Fact Sheets developed by national Resolve are written by professionals (nurses, doctors, counselors, etc.) and may be difficult to understand even by some English speaking natives. At the present time they are only written in English.

Recommendations for the future would be to make Resolve and other infertility support groups available to more people. Efforts should be made (and are being made currently) to translate the Fact Sheets into other languages as well as being rewritten in more simplified language for some of the English versions, (i.e. less technical). Public awareness should be increased through increased publicity in the media and directly to physicians. There are still many people who are unaware of the services that are available. Counselors, nurses, physicians, and other professionals
working with infertiles, or who might someday have an infertile patient, need education and training regarding their special needs. With a fifth of the population having this condition it should be recognized as a significant problem in our society and one that can and should be dealt with in a positive manner.

Groups such as Resolve offer education, information and support and are available to anyone needing their services. They not only help by increasing public awareness of the situation but can offer strategies to help infertile people cope. It seems obvious that there is some benefit to joining such a group for most people. It is up to the infertile patients to decide to help themselves. "It is our task to heal ourselves so that these losses and their mourning process can become a rich source of blessings rather than unproductive suffering. We cannot forget, but we can be healed." (Panuthos, Romeo, 1984)
APPENDIX A

COVER LETTER FOR

INFERTILITY SUPPORT QUESTIONNAIRE

I am a graduate student in Counseling and Guidance at The University of Arizona. In addition, I am an infertility counselor and have organized support groups for infertility patients for four years. I would appreciate your help in answering a few questions. You do not need to sign your name unless you would like more information about joining a support group. All responses are confidential.

Thank you.

Lisa Monteverde, M.Ed.
REFERENCES


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