

**PRACTICE GUIDELINE**

# Counseling in Infertility

**Maninder Ahuja**

President FOGS (Faridabad Obst and Gynae Society), Ahuja Nursing Home and Infertility Center, Faridabad, Haryana, India

**Correspondence:** Maninder Ahuja, President FOGS (Faridabad Obst and Gynae Society), Chapter Secretary IMS Faridabad chapter, Chairperson Public Awareness Committee of IMS, Chairperson Geriatrics Gynaecology Committee of FOGSI, Ahuja Nursing Home and Infertility Center, 526, sector 17 Faridabad, Haryana-121002, India, Mob:9810881048 e-mail: mahuja@gmail.com

## INTRODUCTION

*“It’s like I’m a nothing...I really kind of feel like part of me has either died or given up. I guess the thing that has bothered me the most is the kind of emptiness. There is this hollowness about your life. It’s like you thought you were this solid chocolate bunny and you’re not. You’re the hollow chocolate bunny, which is the less expensive version, not quite as good and not what everybody really wanted at Easter.”*

These are the thoughts of women in study done by M Patrice McCarthy, RN, CNS, PhD and this sums up the psychological problems being faced by women and couples and even by families of those infertile couples.

Wish to have a child of own comes from development and is increased by psychosocial factors like the development of individual personality, sociocultural processes, economic factors, individual biographical changes, fate, interpersonal processes between partners and family pressures especially in Indian scenario where pressure from family to have one’s own child is tremendous.

Science of infertility has advanced, as treatments such as *in vitro* fertilization (IVF) and microinjection (ICSI) have given new hope to many infertile patients. But the fact is that the *emotional impact of infertility has been neglected and that the problem is “reduced to a biological or medical one”*. If the wish to have a child is not fulfilled and an infertility problem becomes apparent, this may result in reduced self-esteem, hopelessness, and feelings of guilt and added desperation and grief. The problem of infertility becomes a problem within the relationship of the partners (Menning, 1980; Golombok, 1992; Möller and Fallström, 1991).

Since the time when first infertility services became available various studies have shown that psychological problems are a big issue, despite advances in treatment of infertile couples, these problems have remained the same and they are:

1. The psychological burden of infertility, it was and is still cause for psychological distress for the couples.
2. Risk of clinical depression and anxiety following failed treatment.

3. Subclinical levels of depression, anxiety and distress over time (Verhaak et al 2007).
4. Six months post-treatment 26% of women showed no recovery (Smeenk 2005).
5. After 20 years follow-up it is found that there is reactivation of personal and social problems linked to grandparenthood in peer group (Wirtberg 2007).

Hence counseling services are needed and they are a continuous process beginning with information to the couple before starting interventions to even after exit with unsuccessful treatment.

## What has Changed Over the Years?

- Public anxiety and unease about new reproductive technologies has reduced as most couples are now familiar with IVF and it is now a generally a well-accepted treatment
- Instead of limited patient support groups or networks, now we have extensive support networks nationally and globally
- Previously we had uninformed patient population, and now we have highly aware patient population
- During the period from 1984 to 1990 we had limited counseling and training, but now we do have counseling in most centers. But there are still so many areas where we have to be clear and there is need to form new guidelines and laws.

So question now is—

- Who needs counseling and who should counsel?
- Physicians treating infertility, i.e. should it be part of Patient Care system
- Or separate professional counseling should be there
- Should it be mandatory for every one to go to the counsellor or
- They should be referred to counsellors or psychiatric health professionals.

There is need for Infertility consultants and specialist to understand infertile couples. Infertility consultants have to be competent to understand the following fields.

- Understanding feelings of being childless
- Giving information and ensuring it is understood

- Implications counseling
- Support counseling and/or
- Therapeutic counseling.

### DEFINITION OF INFERTILITY COUNSELING

Infertility counseling deals primarily with the psychosocial impact of infertility, in terms of intervention, treatment and the aftermath of both successful and unsuccessful treatments. Infertility counseling deals with implications, that is, helping patients to understand and contemplate their treatment options and the short and long-term implications of treatment, these are especially relevant in cases of donor gametes. It also involves therapeutic work to help patients cope with the consequences of infertility and treatment.

The counseling and psychological support is a continuous process and has to be given through out treatment and may be required after treatment is terminated. It is important for health care professionals to be sensitive and to understand how infertility influences a woman's life, how she responds to subsequent life events, and the meaning that she attaches to life stage transitions, when she grows up and is in contact with peer group grandparents.

Following are to be understood and practiced:

### Counseling Guidelines (ESHRE)

1. How infertility consultations differ from other medical consultations in obstetrics and gynecology.
2. Fundamental issues in counseling, such as what is objective of Counseling.
3. Who should counsel? What should be training and qualification of counsellor?
4. How to integrate patient-centered care and counseling into routine medical treatment.
5. Some of the special situations which can provoke the need for counseling (e.g. facing the end of treatment, sexual problems).
6. Counseling in third party reproduction and the psychosocial implications of gamete donation, surrogacy and adoption for heterosexual and gay couples and single women without partners.
7. Psychosocial services that can be used to supplement counseling services in fertility clinics: written psychosocial information, telephone counseling, self-help groups and professionally facilitated group work.

*The infertility consultations differ from other disease consultations in the following manners.*

- Main focus of consultation is just an unfulfilled wish to have a child and not a specific disease.
- This wish involves a third party who is not even born or is nonexistent at the present time and so what ever decisions

persons are taking at this time that nonexistent person is at this time not included into this process and into the treatment. But by this decision later on whose wishes may be in conflict with the decision of family at this time.

- The treatment and many interventions which are done may not be successful and may end in failure and this may lead to depression, desperation and emotional problems
- Because of diagnostic procedures and medical treatment in infertility the intimate life of the patients is effected and the couple's relationship in sexuality, ability to cope with the psychological and emotional effects are changed and all these can be cause of interpersonal relationship problems and physicians should be aware of these problems.

### Objective of Counseling and Who Need Counseling?

Enhanced and informed consent is one of the main objectives of infertility counseling. It allows clients to be fully informed about the procedure and the psychosocial issues.

- The objective of infertility counseling is to help the couple, offer coping strategies, offer preparation for procedures, facilitate decision-making, explore options and implications of family building and to explore the impact of infertility on people's lives as well as on the lives of significant others.
- Ultimate goal of counseling is to help the patient achieve a better quality of life.
- The type of counseling offered to patients (e.g. individual, couple, and group) will depend on the patient and the cause(s) of their distress as well as the resources of the clinic.

Objective of counseling is expression of emotions, identify the cause(s) of distress and provide interventions whenever required. Some of the patients need specialized psychosocial care and they are:

- Patients who experience distress and it shows as depression or anxiety and interferes with their day to day activities about 15-20% of infertile patients are expected to experience this level of distress at some point in their infertility work-up experience (Boivin, 1999).
- Patients considered being at risk because of their psychological history or presenting profile, drug abuses, schizoprenics, and patients with history of child abuse. All these patients and patient with mental problems would need pretreatment counseling by professional counsellors (Leiblum and William, 1993).
- Patients who require some form of genetic counseling as part of their fertility treatment (i.e. preimplantation genetic diagnosis). These situations arise when we use donor gametes or when there is family history of some inherited genetic disease. These patients may wish to avoid transmitting a genetic disorder to their offspring, to screen donated embryos and/or to acquire information about a future child (e.g. sex selection). All of these procedures

may raise psychological issues that need more exploration than might be available as part of routine clinic psychosocial care.

- Some people advocate that involvement of counsellors should always be integrated into the patient care from first consultations and presented to couples in a positive light.
- Success means treatment of infertility to achieve pregnancy and the birth of a child. But however success can also mean that not having children is accepted and/or that couples are well-adjusted with their childless nests and change their lives to achieve satisfaction and happiness from other channels and they don't feel distressed (de Parsevale, 1992; Kemeter, 1998).
- Women coping with infertility may be at risk for self-depreciation and isolation because of their choice of coping strategies and the meaning they ascribe to the infertility. As a result, *women are likely to experience more heightened distress than men* who are also infertile. Counseling that is specific to gender-needs is indicated.

### **Who should Counsel and Training of Counsellors**

There are different opinions about who should counsel.

“Medical treatment and counseling are not separate but interlinked and equally important.” Kemeter, 98.

According to BFS RCOG, standards in the care of Infertile 2006.

- Core standard should be that “complete counseling should be available throughout all stages of infertility investigation and treatment and also after the treatment process is complete”.
- AND aspirational standard should be that “counsellors should be part of the staff complement at all fertility centers.”

There is as yet no agreed set of professional criteria for the mental health professional working with this patient group. However, at the least it would seem that counsellors should have professional training in mental health and training in the medical and psychosocial aspects of infertility.

### **Qualification of Counsellors**

Various fertility organizations are advocating that the following should be the requirements of infertility counsellors;

- A graduate degree in a mental health profession
- Licence to practice
- Training in the medical and psychological aspects of infertility
- Clinical experience
- Continuing education.

So far different countries have different guidelines as infertility counseling has not yet completely evolved and

different associations and countries are still in the process of formulating their own guidelines.

### **Guidelines in Different Countries**

In ASRM no government regulations exist but they formed their own group and guidelines

- The mental health professional group (MHPG) was formed in 1987 by 10 mental health professionals and physicians interested in the psychological aspects of infertility. According to their guidelines they have to be member of ASRM. The American Society for Reproductive Medicine and mental health professional group defined the qualifications guidelines for mental health professionals in reproductive medicine in 1995: “A qualified infertility counsellor should be able to provide the following services: Psychological assessment and screening; diagnosis and treatment of mental disorders, psychometric testing (psychologist); decision-making counseling; couple and family therapy; grief counseling; supportive counseling; education/information counseling; support group counseling; referral/resource counseling; staff consultation, crisis intervention; sexual counseling; psychotherapy; and psychopharmacological treatment (psychiatrists and qualified psychologists and nurses).” Additionally, qualified counsellors should have: (1) a graduate degree in a mental health profession; (2) a licence to practice; (3) training in the medical and psychological aspects of infertility; (4) clinical experience, and (5) continuing education.”

### **Australian and New Zealand Infertility Counsellors Association (ANZICA)**

- In Australia and New Zealand with Fertility Society of Australia (FSA) started as group of 10 and it is a two-tiered membership system
- The require four years tertiary education and should hold positions such as academics or conduct research in the field of infertility
- The state of Victoria is unique in that counseling is mandatory for all recipients and donors (and their spouses) involved in assisted human reproduction procedures (whereas in the rest of Australia, clinics must provide counseling for all participants in third-party conception as a condition for accreditation by the Reproductive Technology Accreditation Committee (RTAC).

### **New Zealand**

No legislative law is there for offering mandatory counseling for all.

However all clinics offer counseling to anyone experiencing infertility and seeking treatment. All clinics insist that anyone

involving a third party (donor/surrogate) and all donors have a minimum of one session with a counselor.

The Reproductive Technology Accrediting Committee (RTAC) of the Fertility Society of Australia (FSA) licenses New Zealand clinics that voluntarily apply for a licence and also insists on the provision of information/support/and preparation counseling for participants of assisted reproduction. All clinics choose to abide by this recommendation.

### *Germany, Switzerland*

In these countries patient-centered care is more formally integrated in medical treatment through the application of psychosomatic or psychosocial models which propose that the person who treats (e.g., doctor, nurse) integrates both medical and emotional care in their exchanges with patients, but qualified for this job. So during their medical curriculum they are trained for these services.

### *United Kingdom*

- New code of practice published by the UK's Human Fertilization and Embryology Authority (HFEA) distinguishes between implications advice and implications counseling, and states that only trained counsellors can provide implications counseling. It is mandatory to offer counseling to parents but it is not obligatory on their part to accept it. BICA (British Infertility counseling association) is of the view that counsellors should not be part of screening and assessment other than being supportive.

### **What Counseling Services are Required ?**

- Patient counseling
  - Counseling to assist with decision-making regarding the choice of treatment
  - Ending treatment or exit counseling
- Implications counseling
  - Donor counseling,
  - Recipient counseling
  - Combined donor and recipient counseling
  - Long-term follow-up counseling for donors, recipients, offspring.
- Ethical counseling;
- Counseling related to stress or anxiety and coping/management, grief counseling
  - Relaxation training, crisis intervention
  - Therapy related to depression.
- Marital counseling and sexual counseling
- Adoption and resources counseling
- Counseling related to selective reduction
- Posthumous counseling
- Sperm banking counseling

- Counseling for surrogates
- Counseling for minors
- Counseling for people who have longer term psychological issues that require more intensive psychotherapy
- Genetics counseling
- Psychosocial counseling.

### **PATIENT CENTERD CARE AND COUNSELING**

Infertility involves suffering and being childlessness is a psychological trauma and it is this perceived undesirability that prompts patients and couples to seek professional help. However infertile people do not go to a psychologist or psychotherapist to resolve this trauma but to a physician or an infertility clinic because infertility requires medical diagnosis and medical diagnosis is generally a matter for physicians. Treatment of infertility is also a medical matter.

While the physician will deal primarily with this medical focus his/her relationship with the couple means that his/her work will also frequently involve dealing with psychological issues.

This would be expected given a patient-centered approach to infertility care; it may also extend, depending on qualifications, to professional counseling. The issues which confront the physician may also be experienced by the entire team involved in the care of the infertile patient and couple. The medical side is made up of physicians, biologists, embryologists, nurses and lab technicians whereas the psychological side is composed of counsellors, nurses, psychologists, psychotherapists and psychiatrists.

Patient centered care can be in the following way—

- IVF- group discussion by staff
- Team meetings should not only cover the discussion of organizational matters but also concern themselves with the “culture within the team”
- Third-party reproduction-for both donors and recipients private counsellor sessions
- Therapeutic counseling, crisis counseling, assessment and follow-up can be off-site.

A typical patient is able to absorb a maximum of three major points in one consultation. Booklets, videos and other materials can help to ensure information will be retained. Additional psychosocial services can be in the form of:

- Written psychosocial information, pamphlets, cards, CDS
  - Telephone counseling
  - Self-help groups, Professionally facilitated group work
- So in India and other SAFOG countries if we are in the process of formulating laws for IVF and ART centers we can make amendment or add to ART LAWS which are being made to add role of counseling and counselors—
- To make arrangements for the counselor training.
  - In the long-term, medical training needs to be changed so that training in counseling is an integral part of every physician's preparation for his professional task.

## Special Situations

### *Counseling of Commissioning Couples*

- With patient counselor should review of alternative treatment options and if not available implication of not having children in future.
- Possibility of adoption instead of surrogacy because of cost and other factors.
- Possibility to find their own host where they might find Potential practical difficulties of treatment by gestational surrogacy.
- Potential medical and psychological impact of surrogacy on the surrogate mother.
- Potential psychological risks, short and long-term, to a child born of surrogacy.
- Risks that the child may be born with a handicap and both the host and commissioning couple may refuse to accept the child.
- Host may wish to retain the child after birth as this happens more with altruistic than with paid surrogate.

### *Counseling of Surrogate Mother*

- Surrogate mothers should be told in details about the physical and psychological implications involved in the treatment of IVF surrogacy.
- The possibility that her family and friends may not support her decision and may go against her.
- The possibility of multiple pregnancy and the problems associated with it.
- Medical risks like hypertension and diabetes associated with pregnancy and the possibility of delivering by cesarean section.
- Feeling of guilt on both sides if the surrogate mother spontaneously aborts the pregnancy.
- Feeling the sense of bereavement when the surrogate mother hands over the child to genetic parent.
- The potential effect on her own children while she is acting as a surrogate for others.

### *Counseling for Sexual Dysfunction*

- About one third of all couples report sexual dysfunction during the diagnostic investigation and treatment.
- Couples have difficulties discussing matters of sexuality.
- Proper atmosphere needed to make it easier for couples to talk about such intimate matters.
- Address problems of sexuality both in diagnosis (e.g., post-coital test, masturbation for semen sample) and in treatment (e.g., time-scheduled sex, masturbation for insemination/IVF).

### *Counseling in HIV Discordant Couples*

These discordant couples one of whom is HIV positive need counseling regarding how to prevent transmission to their child.

ART helps to decrease the risk of HIV sexual Transmission

#### **HIV Positive Woman**

- Self insemination
- ART.

#### **HIV Positive Men**

It is supposed that sperms are not infected by HIV virus. Most recent studies show that sperm lack the CD4 and CCR5 receptors on their surface that allow the virus to bind with and enter the cell. HIV is probably found in highest concentration in the white cells present in the semen. Some may occur free in the liquid but none should be inside the sperm. But to prevent transmission to fetus of HIV negative mother following technologies can be used.

- ART with donor semen
- IUI with washed semen sample
- IVF.

### *Future Targets*

- All centers operating to quality standard counseling targeted to reduce risk of mental health problems
- Relevant counseling for the long-term implications of donor treatments
- 'Referrals' including overseas referrals
- Improved patient satisfaction results
- Further research on therapeutic outcomes of psychological therapies.

## **CONCLUSION**

- Counseling, aims to address the extraordinary needs of some patients.
- The basic aim of any counseling (whether patient-centered or professional) is to ensure that patients understand the implications of their treatment choice,
- Receive sufficient emotional support and can cope in a healthy way with the consequences of the infertility experience.
- A more holistic approach to patient care is believed to improve health outcomes, increase patient and team satisfaction, reduce negative psychosocial reactions and help patients better come to terms with their experiences.
- Women in whom treatment fails should be helped to cope with challenges to their sense of self and the meaning of their lives.

Only by including the psychosocial dimension into the infertility consultation, we will be able to make biological reproduction, the human reproduction (Johannes Bitzer).

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